

What Variables Should Be Included in A Burn Scar Outcome Measure?

Perceptions of Burn Therapists and Burn Survivors

By

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A Thesis submitted to the Faculty of Graduate Studies of

The University of Manitoba

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MASTER OF SCIENCE

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ABSTRACT

Comprehensive burn rehabilitation requires the use of an appropriate burn scar outcome measure (BSOM). The literature reports many BSOMs; however, an objective, standardized, practical, inexpensive, valid, reliable, and responsive instrument eludes us. A problem in the development of such a measure is disagreement in which burn scar properties to include. The objective of this study was to determine the burn scar variables that burn therapists and survivors believed should be included in a BSOM.

This mixed-methods study included an internet survey of burn occupational and physical therapists. The survey was developed based on a literature review of scar properties, was critiqued by 3 topic experts and piloted by 5 members of the target population. Survey administration followed the 5-contact Dillman strategy, including pre-notice and reminder emails. The study also included a focus group of burn survivors, and common themes were identified.

The response rate for the Internet survey was 38.6% (105 surveys). Almost every burn therapist surveyed indicated that pliability, vascularity and height should be included in a BSOM. The majority also stated that appearance, skin breakdown, itch, surface texture, pigmentation, and pain should be included as well. Respondents appeared to be undecided whether the variables of length, volume, temperature, transepidermal water loss and transcutaneous oxygen tension should be included in a BSOM; they indicated that these variables require highly technical measurement methods, and respondents report the desire for a clinically practical BSOM.

Surprisingly, less than half of respondents reported using a BSOM, but almost all indicated that using one is important. The Vancouver Scar Scale (VSS) was the most commonly used BSOM. Participants in the focus group of burn survivors reported the most important scar characteristics to be colour, surface irregularity, itch, skin quality, and sensory function.

This study suggests that using a BSOM is important despite its inconsistent use, and more education in the area of BSOMs may be valuable. The top 3 agreed-upon properties for inclusion by burn therapists are already incorporated into the most commonly used BSOM - the VSS, and have also been identified as important by burn survivors, suggesting that modifications to the VSS may be reasonable. A universally adopted BSOM could result in more meaningful research reports on scar treatments.

Table of Contents

Abstract	ii
Table of Contents	iv
Dedication	vii
Acknowledgments	viii
List of Tables	ix
Chapter 1 – Introduction	1
Statement of the Problem	1
Rationale for the Study	3
Chapter 2 – Literature Review	
Theory of Burn Scar Formation	5
Anatomy of Normal Skin	5
Burn Depth	7
Wound Healing and Normal Scar Formation	8
Hypertrophic Scar Formation and Maturation	10
Properties of Hypertrophic Scar	11
Burn Scar Outcome Measures	15
Low-Technology Burn Scar Outcome Measures	16
High-Technology Burn Scar Outcome Measures	20
Additional Issues in Scar Assessment	21
Conclusion of the Literature Review	22
Research Questions	23
Chapter 3 – Methodology	24
Research Design	24
Internet Survey	24
Participants	25
Internet Survey Development	26
Internet Survey Administration	27
Data Collection	29
Data Analysis	30
Focus Group	31
Participants	31
Questioning Route	32
Focus Group Implementation	32
Data Collection and Analysis	34
Delimitations	35

Chapter 4 – Results	36
Internet Survey	36
Response Rate	36
Respondent Demographics	37
Outcome Measure Use	40
Characteristics of an Outcome Measure	41
Additional Issues in Burn Scar Assessment	46
Relationships Between Variables	47
Focus Group	48
Participant Demographics	48
Themes	48
Chapter 5 – Discussion	54
Research Question #1	54
The Top Three Variables Burn Therapists Choose for Inclusion in a BSOM	54
Additional Variables Burn Therapists Chose for Inclusion in BSOM	55
Variables that Burn Therapists Indicated Were Important to Burn Survivors	57
Variables that Require Highly Technical Methods to Measure are Not Practical for Inclusion in a BSOM	57
Importance of using a BSOM and Barriers to Using One	58
Research Question #2	59
The Relationship Between Research Question #1 and #2	61
Limitations of the Study	62
Suggestions for Further Research	64
Chapter 6 – Conclusions	66
References	69
Appendices	82
Appendix A: Highly Technological Scar Assessments	
Appendix B: Internet Survey Procedures	
Appendix C: Ethics Letter of Approval for Study	
Appendix D: Internet Survey Questionnaire	
Appendix E: Potential Respondent Prenotice Email	
Appendix F: Potential Respondent Main Survey Email	
Appendix G: Potential Respondent Clarification Email	
Appendix H: Potential Respondent Reminder Email	
Appendix I: Focus Group Procedures	
Appendix J: Focus Group Potential Participant Letter	
Appendix K: Informed Consent form for Focus Group	
Appendix L: Focus Group Questioning Route	

Appendix M: Focus Group Participant Confirmation Letter
Appendix N: Focus Group Participant Demographics
Appendix O: Scar Property Definitions
Appendix P: Scar Property Rating Form
Appendix Q: Letter to Participants Summarizing Focus Group Themes

DEDICATION

This thesis is dedicated to burn survivors I have known and will meet: your courage, spirit and determination is a constant source of inspiration to me.

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LIST OF TABLES

Table 1: Demographics of Pilot Group	27
Table 2: Survey Response Rate	37
Table 3: Survey Response Rate by Administration Phase	37
Table 4: Respondent Demographics	38
Table 5: Job Function	39
Table 6: Geographic Area of Respondents	39
Table 7: Reasons Respondents Do Not Use A BSOM	40
Table 8: Reasons Respondents Felt that Using a BSOM is Important	41
Table 9: Characteristics of a BSOM That Respondents Felt Are Important	41
Table 10: Scar Properties Therapists Believed Should be Included in a BSOM	42
Table 11 (a): Reasons Why the Property Should Be Included in a BSOM	44
Table 11 (b): Reasons Why the Property Should Not Be Included in a BSOM	44
Table 12: "Other" reasons properties should or should not be included in a BSOM	45
Table 13: Rank Order of Importance of Burn Scar Properties	46
Table 14: Scar Properties Respondents Felt Are Important To Burn Survivors	47
Table 15: Relationships Between Categorical Variables	48
Table 16: Focus Group Participant Demographics	48

CHAPTER 1 – INTRODUCTION

Statement of the problem

Burn injuries are devastating for both patients and their families, and hypertrophic scar formation is the likely result of deep burns (Deitch, Wheelahan, Rose, Clothier & Cotter, 1983). The scar is a clinical challenge to members of the burn team (Bombaro et al., 2003) and is the most common factor influencing the degree of post-burn disability (Carr-Collins, 1992). Hypertrophic scars can be itchy, painful, and cause serious functional and cosmetic disability for many burn survivors (Bombaro et al.; Cheng et al., 1984).

As more people survive severe burn injuries due to advances in medical treatment, care of the burn patient must be concerned not only with survival, but also with cosmetic and functional rehabilitation (Powers, Sarkar, Goldgof, Cruse & Tsap, 1999). To achieve good outcomes in these areas, the effects of hypertrophic scarring must be controlled. Pressure therapy is the most widely accepted method used to help minimize this type of scarring, and involves the use of devices such as pre-fabricated or custom made garments (pressure garments), to apply pressure to a healing burn scar (Bombaro et al., 2003; Carr-Collins, 1992; Leung & Ng, 1980; Serghiou et al., 2007; Williams, Knapp & Wallen, 1998). These garments are commonly prescribed by occupational therapists (OTs) and physical therapists (PTs).

The exact mechanism of pressure therapy is unknown, but the theory is that pressure on a healing burn scar increases the maturation rate of the scar, decreases the

vascularization, controls local edema, promotes the alignment of collagen fibres, and minimizes the overgrowth of the area by limiting the supply of oxygen, thereby providing a flatter and paler scar, which leads to a more acceptable cosmetic and functional outcome (Baur, Larson, Stacey, Barrat & Dobrkovsky, 1976; Hambleton, Shakespeare & Pratt, 1992; Kischer, Shetlar & Shetlar, 1975; Leung & Ng, 1980). Additionally, patients report that wearing pressure garments results in greater comfort, mobility, and decreased itchiness (Hambleton et al.; Leung & Ng).

Pressure garments need to be applied early, and must be worn 23 hours a day until scar maturation, which can take up to 2 years (Carr-Collins, 1992; Cheng et al., 1984; Garcia-Valasco, Ley, Mutch, Surkes & Williams, 1978; Leung & Ng, 1980). Disadvantages of pressure garments include discomfort, skin breakdown, functional limitations, emotional distress and expense (Bombaro et al., 2003; Cheng et al.; Johnson, Greenspan, Gorga, Nagler & Goodwin, 1994; Williams et al., 1998).

Although pressure therapy has been used for decades, there is still disagreement regarding its efficacy (Bombaro et al., 2003; Mann, Yeong, Moore, Colescott & Engrav, 1997). Several studies have reported effectiveness of pressure garments by demonstrating an improvement in scar appearance (Berry et al., 1985; Clark, Cheng, Leung & Leung, 1987; Garcia-Velasco et al., 1978; Hambleton et al., 1992; Leung & Ng, 1980). One study reported no difference in the rate of scar maturation between a pressure garment group and a non pressure garment group (Chang et al., 1995). However, these studies have varying degrees of methodological limitations including lack of control groups, failing to discuss statistical procedures, small sample size, lack of power analysis, and lack of an appropriate outcome

measure to evaluate scar maturation.

A major problem in determining the effectiveness of scar management techniques is the inability to measure the properties of the hypertrophic scar and the changes in those properties over time, using an objective, clinically practical, inexpensive, valid, reliable, and standardized instrument that is sensitive to change (Masters, McMahon & Svens, 2005; McOwan, MacDermid & Wilton, 2001; Powers et al., 1999; Rodrigues & Roberto, 2006).

Rationale for the Study

Scar treatment techniques are expensive. For example, a burn survivor with a 60% Total Body Surface Area burn is provided with pressure garments that cost approximately \$7,200 over a period of eighteen months of treatment. Pressure garment therapy is sometimes prolonged unnecessarily due to differences in assessment of scar maturity. The high cost of the garments and the potential functional limitations resulting from wearing garments stress the point that an objective measure of scar maturity is needed to ensure pressure therapy is efficacious, and that it is not used beyond scar maturity (Berry et al., 1985; Johnson et al., 1994). To date, an objective burn scar assessment to determine scar maturation, monitor the effectiveness of pressure therapy, justify the use of pressure garments, and compare burn scar treatment methods does not exist (Draaijers, Tempelman, Botman, Tuinebreijer, et al., 2004; Fong, Hung & Cheng, 1997; Masters et al., 2005; Powers et al., 1999; Rodrigues & Roberto, 2006). The lack of an outcome measure that is

objective, clinically practical, inexpensive, valid, reliable and sensitive to change is an important issue for the burn team, burn patients, hospital administration, and insurance companies.

Many burn scar outcome measures have been reported in the literature, each with varying degrees of objectivity, reliability, validity and clinical practicality. The properties of burn scar that should be included in a burn scar outcome measure are not agreed upon by researchers or clinicians. The patient's perspective on his or her scar appearance has rarely been taken into account. It has been recommended that an overall evaluation of the scar by both the therapist and patient should be included in all scar evaluations (Martin, Umraw, Gomez & Cartotto, 2003; Powers et al., 1999).

A clinically useful burn scar outcome measure needs to be developed, and the first step in the development of such a measure is to identify the properties of burn scar that should be evaluated during scar assessment. Therefore, the overall objective of this study was to determine the variables of burn scar that burn therapists and burn survivors believe should be included in a burn scar outcome measure.

CHAPTER 2 – LITERATURE REVIEW

Theory of Burn Scar Formation

Anatomy of Normal Skin

Knowledge of normal skin anatomy is important as a basis for understanding burn wound healing and scar formation, and a brief review follows, summarizing the work of Falkel (1994), Rutan (1998) and Bessey (2007).

The skin consists of two layers, the outer epidermis and the inner dermis. The dermis is usually at least 10 times thicker than the epidermis. The epidermis ranges from 0.05 to 1 mm thick, is avascular, and is composed of 5 layers. The innermost basal layer of keratinocytes, the stratum germinativum, is bonded to the dermis. The fourth layer is the stratum spinosum, followed by the stratum granulosum (layer 3) where the cells begin to produce keratin. Next is the stratum lucidum (layer 2), where cells lose their nuclei and flatten, evolving into a dead layer called the stratum corneum (layer 1), composed of keratin and cellular debris, which eventually sloughs away. The process of epidermal maturation and turnover from the basal layer to shedding takes approximately 2 – 4 weeks. Cell types present in the epidermis include keratinocytes, which produce the protein keratin; melanocytes, which function to produce skin pigment; Langerhans cells which serve an immune function; and Merkel cell endings, which serve as mechanoreceptors for touch sensation. Cutaneous appendages such as hair, sebaceous glands and sweat glands, are epidermal in origin, extending from the epidermis downward and reside mostly in the dermis. Hair

follicles are composed primarily of epidermal tissue, therefore have a significant function in the re-epithelialization of the burn wound. Sebaceous glands secrete sebum to assist in keeping the skin moist and supple, and sweat glands have the important function of thermoregulation.

A basement membrane composed of a variety of connective tissues exists at the dermoepidermal junction. The basal epidermal layer consists of grooves which fit into projections from the dermis, resulting in structures called rete pegs. Rete pegs increase the surface area and resist shearing forces between the epidermis and dermis.

The dermis is strong and elastic, approximately 2 to 5 mm thick, and is comprised of fibroelastic connective tissue. The primary cell type of the dermis is the fibroblast, which produces collagen and elastin. Collagen provides tensile strength to the skin, and elastic fibers are interwoven into the network of collagen, providing resting tension to the skin. The ground substance of the dermis is nonfibrous, and provides a semifluid matrix that lubricates the cells and fibers.

The dermis is subdivided into a thin, superficial layer known as the papillary dermis, and a thicker, deep layer called the reticular dermis. A large plexus of blood vessels lies beneath the dermis, sending microvessels upward to form a plexus between the reticular and papillary dermis, and a small, superficial network of vessels lies beneath the basement membrane. The collagen bundles in the reticular dermis are primarily arranged parallel to the skin surface with some collagen fibres being arranged in a perpendicular orientation. In addition to fibroblasts, the dermis includes macrophages and mast cells which are both associated with immune protection. The dermis also includes important skin structures such as lymphatic vessels, nerve

endings and receptors such as Meissner's corpuscles, Pacinian corpuscles, Ruffini corpuscles and Krause end bulbs.

The functions of the skin are vital to the body, and include protection from harmful environmental objects and conditions; immunological protection by preventing entry of microorganisms and disposing of invasive bacteria; prevention of excessive loss of fluids, proteins, and electrolytes; thermoregulation by preventing heat loss and allowing for cooling; vitamin D production; processing and interpreting sensory information from the environment; and facilitating interpersonal reactions such as personal identity, attraction, and body image.

Burn Depth

Superficial burn injury involves damage to only the epidermis, and results in scarless healing within 7 days. Partial-thickness burns are categorized into superficial partial-thickness and deep partial-thickness burns. In superficial partial-thickness injuries, the epidermis and a portion of the papillary dermis is destroyed; healing will generally occur in 7 – 21 days with little scarring. In deep partial-thickness wounds, most of the dermis is destroyed, and will take 21 – 35 days or longer to heal if not skin grafted, with hypertrophic scarring resulting. Full-thickness burns involve the entire thickness of skin, and may include subdermal tissue such as muscle, tendon and bone. Skin grafting, and amputations in the case of subdermal burns, are required, and will likely produce severe hypertrophic scarring (Johnson, 1994).

Wound Healing and Normal Scar Formation

Wound healing can be categorized into three processes that are closely inter-related: re-epithelialization, scar formation, and contraction (Greenhalgh, 2007; Greenhalgh & Staley, 1994; Ward, 1998).

Superficial burns and superficial partial thickness burns heal through re-epithelialization. Superficial wounds heal through the basal cell layer of keratinocytes. Superficial partial thickness injury allows remaining skin appendages such as hair follicles, sweat and sebaceous glands, which contain epithelial cells, to regenerate the skin. The new epidermis temporarily lacks rete pegs for a period of time, and the skin is easily prone to blistering.

Scar formation is the process involved in repairing damaged connective tissue: for skin this means creating a new dermis. Scar formation involves the fabrication of new collagen, the most important protein for the strength of tissue repair. Scar formation involves three phases, which merge and overlap: the inflammatory phase, proliferative phase and remodeling phases.

The inflammatory phase, also known as the lag phase, occurs from the time of wounding and continues for 4 or 5 days. The main function of this phase is to prepare the wound for repair by initiating vascular and cellular responses responsible for clearing the wound of debris and starting the inflammatory reaction to help fight infection. The wound has very little strength during this stage. Clinical signs of this phase include redness, heat, swelling and pain.

The proliferative phase begins with the appearance of fibroblasts. The main functions of this stage are the restoration of collagen to increase the strength of the

wound, and the development of a blood supply, or angiogenesis. Granulation tissue is the precursor to scar tissue; it is red, moist and consists of newly organized collagen, proteins, ground substance, other cells of tissue repair and new capillaries. The strength of the wound improves during this phase, and is proportional to the production of collagen.

The remodeling, or maturation phase, begins after a few weeks, and may last years. During this stage, increasing wound strength occurs with no actual increase in collagen content, due to a dynamic balance between collagen synthesis and degradation. Collagen tends to increase along lines of stress, and to be broken down where it is not needed. More cross-linkages between collagen molecules are formed to increase the strength without increasing the quantity of collagen. The scar eventually becomes paler and flatter, reaching “maturity” when no further change in the scar occurs.

Contraction is the final type of healing, and is the migration of the wound edges toward the centre, reducing the wound size. Contraction parallels scar formation, beginning with a lag phase, followed by a phase of rapid wound shrinkage, followed by a slower contraction phase until wound closure occurs. Granulation tissue is necessary for contraction, and fibroblasts are responsible for wound contraction. Contraction is dependent on the looseness of the surrounding skin; for example, wounds on the buttocks will contract well, while wounds over tight ankle skin will not. Contraction is usually completed in 2 to 3 weeks, and collagen synthesis frequently continues long after contraction has completed.

Hypertrophic Scar Formation and Maturation

A hypertrophic scar is the result of a disruption in the scar formation process, leading to abnormal healing (Tredget, Nedelec, Scott & Ghahary, 1997). A prolonged inflammatory phase causes excessive granulation tissue that consists of disorganized collagen, capillaries and other cells (Greenhalgh, 2007; Greenhalgh & Staley, 1994; Tredget et al.). The thickening of hypertrophic scars is likely the result of excessive collagen production (Ketchum, 1977). In contrast to regular scar tissue, the collagen is arranged in a whorl-like pattern, the tissue is more vascular and contains a greater number of fibroblasts (Larson et al., 1975; Tredget et al.). Hypertrophic scar has also been associated with increased water content (Tredget et al.).

Presently, the exact cause of hypertrophic scarring is not completely understood (Scott, Ghahary, Wang & Tredget, 2007). Length of healing time has been reported to be an important variable in determining which patients will develop hypertrophic scar development. Wounds healing in less than 10 days will likely not scar, a healing time of 14-21 days requires monitoring, and wounds healing in longer than 21 days are likely to form a hypertrophic scar (Deitch et al., 1983). Several additional factors have been reported such as ethnic background, age, and site of the wound (Greenhalgh & Staley, 1994; Ketchum, 1977; Tredget et al., 1997).

It is difficult to judge when a hypertrophic scar is actually mature. Scar maturation is unpredictable, a wide individual variation exists and most clinical judgments are subjective, depending largely on the experience of the clinician (Leung et al., 1984). Determination of scar maturation relies very much on the clinical observation of scar properties (Fong et al., 1997), and has generally been associated

with a progressively flatter, softer and paler scar. A more detailed discussion of scar properties associated with scar maturation is included below.

Properties of Hypertrophic Scar

Many properties of hypertrophic scar have been described in the literature, and have been classified by Fong et al. (1997) as either morphological, such as thickness, color, or elasticity; or physiological, such as transcutaneous oxygen tension. It is often difficult to record and measure scar properties (Fong et al.; Powers et al., 1999) and descriptive terminology has been inconsistent (McOwan et al., 2001). However, an attempt will be made to describe each scar property recorded in the literature.

Colour

The colour of a scar is influenced by both vascularity and pigmentation (McOwen et al., 2001; van Zuijlen, Angeles, Kreis, Bos & Middelkoop, 2002). Color variations within the scar are difficult to describe and quantify (Powers et al., 1999), therefore this is a complex property to study (McOwen et al.).

The degree of redness in a scar may correspond with the vascularity of a scar, as hypertrophic scars are associated with an increased microcirculatory blood flow (Davey, Sprod, Neild, 1999; Leung, Sher, Clark, Cheng & Leung, 1989; Oliveira et al., 2005) and have been found to be extensively vascularized with abnormally large vessels (Baur et al., 1976). Scar maturation has been associated with fewer and smaller capillaries and, as erythema diminishes, the scar becomes progressively paler (Hambleton et al, 1992; Baur et al.; Cheng et al., 2001; Leung et al.; Sullivan, Smith,

Kermode, McIver & Courtemanche, 1990). Fujimori, Hiramoto and Ofuji (1968) have noted that a scar without redness is not likely to develop further hypertrophy.

Changes in pigmentation are often seen after partial-thickness burn injuries (Grover & Morgan, 1996; Kahn, Cohen & Kaplan, 1991; Sullivan et al, 1990). Pigmentation reflects the presence of melanin, oxyhemoglobin, bile, and carotene in the scar (Tyack, Pegg & Ziviani, 1997). A scar with hypopigmentation may occasionally show a degree of improvement in colour with time, but more often remains permanently pale (Grover & Morgan; Kahn et al.), while highly variable patterns of pigmentation can occur in hypertrophic and non-hypertrophic scars (Oliveira et al., 2005). Cheng et al. (2001) found that pigmentation bore no relationship to the maturation of the wound. Several authors report that pigmentation is not a useful property to define or classify hypertrophic scars, or measure the progress of maturation (Deitch et al., 1983; Masters et al., 2005; Oliveira et al.).

Pliability

Pliability is related to contracture, elasticity, stiffness and extensibility of the scar (Clark et al., 1987; Leung et al., 1984; Sullivan et al., 1990). Powers et al. (1999) reported that pliability is one of the most important aspects of scars, but is also one of the most difficult to define and measure. Additionally, definitions of pliability are frequently not provided in research reports, making it difficult to determine whether researchers are discussing the same construct (McOwan et al., 2001). Several authors have reported elasticity to be an indicator of scar maturation (Bartell, Monafo & Mustoe, 1988; Clark et al.; Fong et al., 1997; Leung et al.). Additional scar properties described that are related to pliability are texture and surface irregularity (Beausang,

Floyd, Dunn, Orton & Ferguson, 1998; Crowe, Simpson, Johnson & Allen, 1998; Yeong et al., 1997).

Size

Various terms have been used to describe the size of scars: volume (Nedelec, Shankowsky & Tredget, 2000; Powers et al., 1999), width (Siana, Rex & Gottrup, 1992), length (Siana et al.), thickness (Fong et al., 1997; Katz, Frank, Leopold & Wachtel, 1983), depth (Hambleton et al., 1992), and height/elevation (Crowe et al., 1998; Sullivan et al., 1990; Sawada & Sone, 1992). Some authors distinguish between the aspects of size that they are measuring, while others measure size as a single entity, compounding the difficulty of comparing results (McOwan et al., 2001). Determination of the size of the scar is difficult because the margins of a scar are often irregular or may even be below the skin's surface, and the scar may be on a rounded surface such as the neck (McOwan et al.; Powers et al., 1999). Changes in the size of a scar may reflect the maturity of a scar, as scar tissue tends to go through a period of collagen overgrowth before maturing and becoming paler and flatter (Baur et al., 1976; Cheng et al., 2001; Fong et al.; Katz et al.; Tredget et al., 1997).

Transepidermal Water Loss

The relationship between transepidermal water loss (TWL) and scar maturity is not yet fully understood, but its potential as an indicator of wound healing has been investigated (Rodrigues & Roberto, 2006). TWL often increases with scarring due to the damaged stratum corneum and its role in barrier function (McOwan et al., 2001).

Transcutaneous Oxygen Tension

Berry et al. (1985) found that low levels of transcutaneous oxygen tension

(tcpO₂) in immature scars resulted from low oxygen diffusion through scar tissue. They reported that as maturation of the scar proceeded, thickened capillary walls began to thin, densely cemented masses of collagen fibres became less cohesive, and the tcpO₂ rose toward normal levels. This rise in oxygen tension correlated well with clinical observation of decreasing scar mass and with ultrasound measurements confirming reduction in scar thickness, supporting tcpO₂ as an indicator of scar maturity (Berry et al.).

Temperature

Scar temperature is dependent on the vascularity of the scar and the degree of metabolic activity occurring in it, and may provide information regarding the maturity of the scar (McOwan et al., 2001). However, Berry et al. (1985) found no change in relative scar temperature with increasing maturity.

Skin Breakdown

Skin breakdown with open areas is usually the result of blisters, a common and recurrent problem following wound closure. Scar epithelium is initially thin, fragile and intolerant of friction (Carr-Collins, 1992), and may affect scar treatment and maturity, as areas of healed partial-thickness burn with unstable scar epithelium and newly healed grafts will not tolerate the pressure or shear applied by most pressure appliances, therefore delaying pressure treatment (Carr-Collins; Johnson, 1984; Leung & Ng, 1980).

Subjective Factors

Important properties of a scar are the patient's opinions about it, and relate to sensory factors such as itching, pain, and appearance (Bombaro et al., 2003; McOwan

et al., 2001; Sullivan et al., 1990). Itching may be caused by the release of histamines by mast cells (Tredget et al., 1997). Oliveira et al. (2005) found that hypertrophic scars were associated with significantly more itching than non-hypertrophic scars, but no differences in pain were seen between the scar types, except in the case of acute scars, which were associated with increased pain. Cheng et al. (2001) found that itching did not correlate with the maturity of the scar, but was related to the type and depth of the skin injury. Subjective aspects of scars may be as or more important to the final scar outcome than the quantitative objective aspects of scars, as even patients with relatively minimal scarring may be unable to function (Powers et al., 1999). Subjective symptoms may be difficult to measure, as they can be influenced by anxiety and medications (Taal, Faber, van Loey et al, 1999).

Burn Scar Outcome Measures

An outcome measure is defined as a “measurement tool (instrument, questionnaire, rating form, etc.) used to document change in one or more patient characteristics over time” (Cole, Finch, Gowland, & Mayo, 1994, p. 22). An outcome measure should be reliable (measurement of the variable should be consistent), valid (should measure what it intends to measure) and responsive (sensitive to change) (Portney & Watkins, 2000). Additionally, it should measure an important outcome of the intervention and be easy to use and understand (Quinn & Wells, 1998). Several authors have suggested that a burn scar outcome measure should include both the objective and subjective aspects of scars, the functional limitations imposed by the

scar, capture the changes in the scar and its effects over time, allow early diagnosis of problems or complications arising from pressure therapy, be painless, non-invasive, inexpensive, portable, easy to obtain, and ideally be comparable to normal skin (Baryza & Baryza, 1995; Draaijers, Tempelman, Botman, Tuinebreijer, et al., 2004; Katz et al., 1983; Masters et al, 2005; Powers et al., 1999; Sullivan et al., 1990).

Several burn scar outcome measures are described in the literature, and can be categorized as low-technology or high-technology. Low-technology outcome measures generally consist of therapist and/or patient-judged rating scales.

Low-Technology Burn Scar Outcome Measures

The most widely used burn scar outcome measure is the Vancouver Scar Scale (VSS) (Sullivan et al., 1990). The VSS is administered subjectively by the therapist, and consists of four subscales which measure scar pigmentation, vascularity, pliability and height. The subscales use separate ordinal rating scales, deriving individual subscale scores. A total score is also derived by totalling the subscale scores. The authors reported statistically significant mean Kappa values for inter-rater agreement. They also found that inter-rater reliability (IRR) scores improved with time, which they attributed to increasing familiarity with the scale. Although the VSS is a clinically practical tool, its disadvantages are the subjectivity of the rating system (Powers et al., 1999) and the fact that the patient's opinion is not taken into account (Martin et al., 2003).

Several modifications to the VSS have been proposed. Baryza and Baryza (1995) developed a Plexiglas tool to ease administration of the pigmentation,

vascularity and height subtests. While the authors reported high IRR, the paper did not provide details of their methodology.

Nedelec et al. (2000) suggested scoring and wording adjustments to the VSS based on their study of IRR between three untrained multidisciplinary staff, and determination of construct validity by comparing the VSS with scar volume assessment. Fair IRR was found for total score, and poor to fair IRR was found for the subscales. Using multi-variate analysis, the authors found a judge effect for total score, pliability, height and pigmentation. When testing convergent validity of the VSS and scar volume, low correlation was reported for pigmentation, vascularity and pliability, and a minimal correlation for height was reported; correlation values were not provided. The authors proposed adjusting all subscales except vascularity. For example, they changed the height subscale to a four-point scale with equal increments, increasing sensitivity to change. They suggest that subscales not be totaled, as results may be misleading: the total score may be unchanged, even though there have been improvements in the quality of the scar. For example, the height of the scar may be decreasing yet the scar may become hyper pigmented (Nedelec et al.). Patient's subjective reports of itch and pain were also recorded, and itchiness was reported 61% of the time; discomfort 21% of the time.

Forbes-Duchart, Marshall, Cooper and Strock (2007) developed a pictorial color scale to aid with vascularity rating, and found significant correlations for IRR for all subtests except pigmentation. Powers et al. (1999) asserted that the use of a simple colour palette does not capture the color of the scar because it does not include the effect of texture. Forbes-Duchart et al. and Nedelec et al. (2000) both questioned the

inclusion of pigmentation in scar assessment, as it does not seem to provide useful information about scar treatment and maturity, a consideration also raised by Oliveira et al. (2005) and Tyack et al. (1997).

Several numeric scales have been proposed to assess scar parameters such as irregularity, pliability, disfigurement, thickness, height and colour from a photograph (Beausang et al., 1998; Smith, Tompkins, Bigelow & Antoon, 1988; Yeong et al., 1997; Crowe et al., 1998). A major limitation of these scales is the questionable validity of assessing three-dimensional components of scars (texture, height, and thickness) from a two-dimensional photograph. The quality and reproducibility of photographs for scar assessment are highly variable and costly (McOwan et al., 2001). Additionally, Richard (1997) has reported that rating scars by photograph after the patient has left the clinic is time-inefficient, particularly if decisions about scar treatment are to be made.

Masters et al. (2005) used a modification of the scale developed by Yeong et al. (1997), and developed a set of reference photographs for matching patients' scars during assessment of surface, border height, thickness and colour. Assessment is done on the patient; photographs are used for reference only. In addition, they added a patient self-rating of itch, pain and appearance. To ensure that the same scar sites were used for testing on each occasion, a digital photograph was taken of each scar with a small white plastic arrow placed at the chosen scar location. An anatomical landmark, such as an obvious joint, was included in the photograph to assist identification of the site at a later stage. The specific scar location was also marked on a body chart. The photograph was then printed in black and white and became an aid

to relocate the site chosen. The study consisted of two phases, first testing the IRR over a short time period, controlling for scar changes; and secondly, testing longer-term reliability which took into account anticipated scar changes. Phase two also incorporated the patients' self-rating. Localization of the chosen scar site by the rater was accurate in 96% of the 64 recordings in stage 1 and in 93% of the 282 recordings in stage 2. Good reliability was found for border height and thickness but poor correlation between therapist and patient ratings was found. A limitation of these two scales (Masters et al.; Yeong et al.) is the use of negative values for parameters which are in the opposite range of the hypertrophic score. For example, although hypopigmentation would be a poor cosmetic outcome, it is rated with a negative score, yielding an "improved" final score (Oliveira et al., 2005; Richard, 1997).

Martin et al. (2003) also examined the correlation between patients' subjective and therapists' objective evaluation of burn scar. They reported that agreement increased over time, but that the patient's impression of what others think of the scar continued to be poorly correlated to the VSS rating, suggesting that the patient experiences poor acceptance despite objective scar improvement.

Draaijers, Tempelman, Botman, Tuinebreijer, et al. (2004) developed the Patient and Observer Scar Assessment Scale (POSAS) which consists of two numeric scales for patient (pain, itch, colour, pliability, thickness, relief) and clinician (vascularity, pigmentation, pliability, thickness, relief) evaluation using a 10-point scale. The POSAS and the VSS were both tested for internal consistency and IRR. Additionally, agreement and concurrent validity of the observer scale were studied. Greater internal consistency was found on the POSAS, and the IRR of the POSAS'

Observer scale was higher than that of the VSS. The authors found a significant correlation between the POSAS Observer and VSS scales. The importance of scar characteristics for evaluation was determined by correlating overall opinions of the scar with individual scar characteristics. Significant clinician characteristics were relief, thickness, pigmentation and color; patient characteristics were itch and thickness.

High-Technology Burn Scar Outcome Measures

Many methods using highly technical equipment have been used for scar assessment with varying degrees of reliability and validity. Most of these assessments are costly, time-consuming, highly technological, inconvenient to use and often non-portable, making them clinically impractical (Masters et al, 2005; Yeong et al., 1997). Few have found their way from research applications into the clinical setting (McOwan et al., 2001). Due to the technological nature of these assessments, they will not be discussed in detail, but rather are summarized in Appendix A.

Van Zuijlen et al. (2002) reported that, in general, objective scar measurements such as the highly technical assessments described, are preferred over subjective scar assessment scales, but that subjective scar assessment scales have some important advantages: they are convenient, inexpensive, require little time to complete, and they give semi-quantitative information along several clinical parameters.

Additional Issues in Scar Assessment

An important aspect in scar assessment is scar relocation, or the ability to accurately relocate a scar for study over time (Masters et al, 2005; Richard, 2005). Relocation of the scar is important to determine results of different treatments and outcome, particularly because burn scar maturation takes 12 to 24 months. Reliability of a scar assessment tool is dependent on testing exactly the same area of scar each time (Cleary, Sanders & Nick, 2007; Masters et al.). Few scar assessment studies reviewed provided descriptions of how scars were relocated. Several authors (Cheng et al., 2001; Cleary et al; and Fong et al., 1997) marked scar sites to be tested and mapped them with translucent paper; Katz et al. (1983) took photographs of the test site; and Masters et al. used photography, but marked the tested area with a white plastic arrow and included an anatomical area, such as a joint, in the photograph.

Related to scar relocation is the difficult decision of what scar area to measure, as an area of burn injury is generally composed of varying burn depths (Richard, 2005). Richard reported that previous studies have focused on either specific changes in an entire area of scar, while others isolate an area of scar for serial evaluation, and recommended incorporating both strategies: isolating areas of scar for some characteristics and looking more globally at the scar for others.

Therapist-rating scales depend on the subjective assessments by the rater, and multiple factors may influence this assessment, including years of burn treatment experience. Powers et al. (1999) found that physicians with only a few months of burn experience drew a scar from a photograph of a patient with facial scars more accurately than a nurse with over 10 years of burn experience and concluded that

professionals with more years of burn experience may underestimate the extent of the scars. The authors theorized that staff members who work with injured or disfigured patients develop coping skills that may influence their judgment about the actual physical characteristics of scar (Powers et al.).

As previously stated, the patients' opinion in burn scar assessment is an important consideration. However, comparing the patient's and therapist's opinions may be difficult, especially if no correlation is found, as was the case in the two studies mentioned earlier (Martin et al., 2003; Masters et al., 2005). Masters et al. offered the explanation that a small test area used for therapist rating may not be suited to patient self-rating because it may be too difficult for patients to distinguish such a small segment of much larger burn areas when considering symptoms and appearance.

Conclusion of the Literature Review

Authors agree that an objective, clinically practical, inexpensive, valid, reliable and standardized instrument that is sensitive to change is important, but is not currently available. Several scar outcome measures have been reported in the literature, using both low and high technology. Varying degrees of reliability, validity and clinical practicality have been reported for these measures. The low-tech assessments appear to have more use in the clinical setting. Complicating the issue of scar assessment is that many scar properties have been described in the literature

using inconsistent definitions, and properties which are important indicators of the effectiveness of scar treatment and maturity do not seem to be agreed upon.

Research Questions

The following questions were addressed in this research study:

1. What are the variables of burn scar that burn occupational and physiotherapists believe should be included in a burn scar outcome measure?
2. What are the variables of burn scar that burn survivors believe should be included in a burn scar outcome measure?

CHAPTER 3 – METHODOLOGY

Research Design

A mixed-methods design using a concurrent triangulation strategy (Creswell, 2003) was used to collect data from two distinct populations. The quantitative phase was an Internet survey administered to burn occupational and physiotherapists. No literature could be found on the variables that burn therapists believe should be included in a burn scar outcome measure, and a survey was felt to be the most effective means to address this issue, as this method provides a quantitative description of trends, attitudes, values, opinions or feelings, levels of knowledge or experience, current practices, or characteristics of a population (Creswell; Portney & Watkins, 2000). The qualitative phase was a focus group of burn survivors; group discussion can be used with people from similar backgrounds to explore opinions, attitudes, feelings, beliefs, and experiences (Dawson, Manderson & Tallo, 1993; Krueger & Casey, 2000). The survey was considered to be the main focus of this research project; however, burn survivors' perspectives were sought to explore similarities and differences between burn therapists' and burn survivors' opinions on burn scar assessment.

Internet Survey

A summary of Internet survey procedures is found in Appendix B.

Participants

The study population for the Internet survey consisted of OTs and PTs in North America who are working in burn care (burn therapists), for any length of time, and in any capacity (direct patient care, teaching, research or administration). An email list generated by the Occupational/Physical Therapy Special Interest Group (OT/PT SIG) of the American Burn Association (ABA) was used as the sample frame. The OT/PT SIG is a meeting held each year within the annual meeting of the ABA, attended mainly by burn therapists. A contact list, including emails, is generated each year, and names were supplemented by representatives from each of 12 regions of the ABA (corresponding to regions of North America).

The sample frame originally contained 378 names. The list was reviewed, and names were removed from the list if the individuals were not OTs or PTs, if they were not from North America or if they did not have an email address listed. Attempts were made to contact individuals with no email address listed to obtain their email addresses. After removal of the researcher's own name, the final sample frame consisted of 344 potential respondents.

An Internet survey is felt to be a valid administration method for groups such as this population, who are members of a professional organization, as such individuals usually have Internet access, and complete sample frames can often be constructed (Dillman & Bowker, 2001; Schonlau, Fricker & Elliott, 2001). The entire sample frame, or a census, was used for this survey (Salant & Dillman, 1994).

This study was approved by the University of Manitoba Human Research Ethics Board (see Appendix C). Informed consent of burn therapists to participate in

the study was a possible ethical issue, as sending back an informed consent form is not practical in a web survey. A statement of consent was included at the start of the web survey, and therapists had to agree to participate in the survey before continuing. Additionally, Portney and Watkins (2000) assert that responding to a survey implies informed consent.

Internet Survey Development

The survey questionnaire items were developed based on burn literature and the principal investigator's clinical experience (see Appendix D for the survey questionnaire). A combination of question structures, including closed and open-ended questions was used. Question wording and survey construction were carried out using principles recommended to minimize measurement error, specifically those developed for web surveys (Dillman, 2000; Dillman & Bowker, 2001; Portney & Watkins, 2000; Salant & Dillman, 1994; Schonlau et al., 2001).

Pre-testing was carried out to establish content validity of the survey (Creswell, 2003; Portney & Watkins, 2000). The first stage of pre-testing was a review of the survey by three North American colleagues with extensive clinical burn experience, and who were knowledgeable in survey methodology and burn scar assessments. Revisions to the survey were made based on the experts' suggestions.

Next, a pilot study of the questionnaire and complete administration procedures was conducted on a sample of 5 burn therapists in North America (see table 1 for demographics of the pilot group). Based on the results, further revisions were carried out until an acceptable level of content validity was attained. Pre-testing

of different computer configurations is particularly important in a web survey (Schonlau et al., 2001), and was done to ensure that all computer platforms and Internet servers could have accessed the survey. Pilot members encountered several web-access difficulties and attempts were made to correct these for the actual study.

Table 1. Demographics of Pilot Group

Pilot Group Member	OT/PT	Years Working in Burns	Education	Client Age Group	Geographic Area
1	OT	8	Res Mas*	Both	Pennsylvania
2	OT	20	Bachelors	Adults	Winnipeg
3	OT	15	Bachelors	Pediatrics	Colorado
4	PT	12	Res Mas	Pediatrics	California
5	PT	11	Bachelors	Pediatrics	Ohio

*Res Mas = Research Master's

Internet Survey Administration

The Internet survey was delivered using SurveyMonkey.com, a commercial online survey website (SurveyMonkey, 2007). Potential respondents were contacted via email according to the 5-phase implementation system recommended by Dillman (2000). Initially, a prenotice email (Appendix E) was sent out which provided details about the survey. This contact was also used as a “test” to determine the accuracy of the email list, which is essential to avoid coverage error, the most recognized limitation of Internet surveys (Dillman). Participants were asked to respond to this email confirming their address and that they currently were an OT or PT working in burns. The email list was updated after this phase as detailed in the results section. The second contact contained the link to the questionnaire at the SurveyMonkey website (Appendix F). An unplanned third contact (Appendix G) was provided three

days later to clarify procedures; the investigator had received several email queries from respondents, for example: “Should more than one therapist at my facility complete the survey”, and “I am having trouble accessing the link, what should I do?” Two additional contacts followed (Appendix H), each 2 weeks after the previous contact, thanking those who responded and asking those who did not to reply. Contacting the respondent multiple times has been shown to increase the response rate to surveys (Dillman). All contacts went to all potential respondents whether they responded or not, as respondents were not identifiable.

Email contacts were staggered to avoid flooding the web server with respondents attempting to access the website at once (Schonlau et al., 2001). This was accomplished by entering the email list into 10 separate contact lists in the investigator’s Microsoft Outlook address book and sending the emails for each phase over a 3-day period. Using the appropriate list number in the contact line of the email facilitated the tracking of undeliverable emails. The investigator’s email was provided so that respondents could get assistance as needed. Due to the likelihood of respondents sharing computers, the survey collection procedure could not allow for respondents to suspend and reenter the survey. Unfortunately, this also meant that respondents could have potentially completed more than one survey. These issues were controlled for as much as possible in the email contacts. Respondents remained anonymous from the investigator, thereby protecting privacy. SurveyMonkey does not have the ability to track the identity of the respondents without disclosing to the investigator, therefore, partially completed surveys were not followed-up, and non-respondents could not be compared to the respondents.

The behavioural elements of the Social Exchange Theory were incorporated in an attempt to maximize survey response rate; these elements consist of rewards (what one expects to gain from a certain action), costs (what one expects to give up for the reward), and trust (the belief that the reward will outweigh the cost) (Dillman, 2000). Supporting values shared by a certain group can be a reward to individuals who identify with that group (Blau, 1964), as is responding to surveys of high importance (Heberlein & Baumgartner, 1978). Discussions at international conferences have shown that the topic of burn scar assessment is important to the burn therapy community, and was thought to increase the likelihood that burn therapists would respond to a burn scar assessment survey.

Strategies to decrease social costs were included such as designing the questionnaire to be short and easy (Dillman, Sinclair & Clark, 1993), decreasing the amount of physical or mental effort required (Thibaut & Kelley, 1959) and assuring confidentiality (Dillman, 2000). Several steps were taken to establish trust with the respondents and included professional-looking questionnaires from an authoritative source and a promise to share the results (Cialdini, 1984; Dillman).

Contacting potential respondents five times, whether they had responded to the survey or not was a concern; however, it was felt that the simplicity of deleting the email eased any potential respondent burden.

Data Collection

Survey data were gathered by SurveyMonkey and downloaded as an Excel file. One copy of the original file was made, and was not altered in any way. A

master Excel spreadsheet was then created, and data were cleaned by removing unnecessary information such as IP addresses, colour-coding each question, and converting data to the same format for inconsistently answered questions. For example, “Two years” was converted to “2”. Incomplete surveys were also removed; surveys were deemed usable only if respondents completed the survey until at least question 65, as this ensured that the respondent would provide data which sought to answer the research question. Sections of the master Excel spreadsheet were then copied for the analysis of each survey question. Individual sections were often further cleaned or organized, depending on the analysis technique. For example, quantitative variables such as number of years working were collapsed into categories for preparation of the Chi-Square analysis. Open-ended questions were organized into separate spreadsheets and were printed out for subsequent analysis.

Data Analysis

Open, closed and partially closed-ended questions were used within the survey. Data analysis consisted of descriptive statistics including calculation of averages for quantitative data and frequency of responses for categorical data (Portney & Watkins, 2000; Salant & Dillman, 1994). Relationships between variables were examined where appropriate by developing cross-tabulations and were analyzed using the Chi-square statistic (Hassard, 1991; Salant & Dillman). The Chi-square analysis was run in SPSS Version 14 for Windows. Statistical significance was set at a value of $p \leq 0.05$.

Open-ended responses were categorized and themed.

Focus Group

A summary of the focus group procedures is found in Appendix I.

Participants

Focus group participants were adult burn survivors. A purposive sample was used, whereby participants were selected to provide a full understanding of the phenomenon (Rice & Ezzy, 1999). Sampling in qualitative research seeks to describe the processes involved in a phenomenon, and the findings are not intended to be statistically generalized to the whole population (Rice & Ezzy).

Potential participants were clients of the Occupational Therapy burn program at the Winnipeg Health Sciences Centre. Clients who were on active treatment with the principal investigator were excluded. Maximum variation sampling was used to allow full exploration of the phenomenon (Rice & Ezzy, 1999); therefore participants differed in sex, age, and location and percentage of burn. Differences in compliance with pressure therapy was sought, however, this proved difficult, as the “compliant” burn survivors appeared more likely to participate in a focus group. It was felt that the common experience of surviving a burn allowed sufficient commonalities to encourage participants to speak openly (Dawson et al., 1993). Participants were recruited via a letter from the burn program, using a list of former Occupational Therapy clients (see Appendix J for potential participant letter). Potential participants were asked to contact the principal investigator if interested.

Confidentiality of the focus group discussion was a potential ethical concern, but as stated, focus group participants were asked to keep the dialogue confidential. Focus group participants signed an informed consent form (see Appendix K for Participant Consent Form).

Questioning Route

The questioning route was developed from research question #2 and from consulting with former burn clients; it followed recommendations for questioning route development (Dawson et al., 1993; Krueger & Casey, 2000) (See Appendix L for questioning route). The questioning route was pre-tested by one burn survivor to determine if the questions would obtain the required information, if they were confusing, if they flowed, and if the wording was appropriate (Krueger & Casey). Further modifications were made based on this feedback.

Focus Group Implementation

One focus group of six to eight burn survivors was planned. A letter was mailed approximately one week before the scheduled group to those who agreed to participate, with additional details about the session (see Appendix M), and participants were phoned the day of the focus group to confirm attendance (Krueger & Casey, 2000).

The focus group was held in the Physiotherapy Conference Room of the Winnipeg Health Sciences Centre, on a weekday evening in December 2007. Refreshments were offered upon participant arrival, and informal conversation was

encouraged. The principal investigator served as the moderator, with an assistant moderator available to operate the audio-recorder and take detailed written notes, including observations of body language.

Informed consent was obtained before the session began, followed by collection of demographic details of participants (see Appendix N). Next, an explanation of the purpose of the group, ground rules, presence of the assistant moderator and recording devices, and a reminder to keep group discussions confidential (Krueger & Casey, 2000) were given. After a brief introduction of group members, discussion followed the questioning route. Digression from the questioning route was allowed as long as discussion related to the research question. Participants were provided with a visual aid of scar characteristic definitions (Appendix O), and immediately following the discussion of scar characteristics, were asked to fill out a scar characteristic rating form (Appendix P). One participant arrived thirty minutes late, was briefly introduced to group members and subsequently joined in the discussion.

Participants were eager to share their experiences and thoughts, and it became evident that time would not allow for an adequate discussion of all planned questions, therefore, some questions were eliminated. The group lasted approximately 100 minutes. To conclude the group, the participants were thanked for their time, were invited to request the results of the study once completed, and any questions were answered.

Data Collection and Analysis

Field notes were made by the investigator immediately after the session to facilitate data analysis (Morgan, 1988), and assistant moderator notes were reviewed. The audio recording of the focus group was transcribed verbatim, with identifying information removed from the transcripts. The original transcripts will be stored in a locked drawer until thesis defense, after which they will be shredded and placed in confidential waste along with the focus group audiotapes.

Analysis began with several readings of the transcripts to gain a sense of the data as a whole. Codes were then developed inductively, that is, derived gradually from the data (Pope, Ziebland & Mays, 2000). A key of all codes and their explanations was kept and a logbook was developed to track responses (Dawson et al., 1993). Identification and interpretation of themes followed code development (Krueger & Casey, 2000). The scar characteristics rating form was not analyzed quantitatively, but rather was used to assist in interpretation of the verbal responses. Several strategies were used to ensure rigour, the term used for issues of reliability and validity in qualitative research (Mays & Pope, 1996; Rice & Ezzy, 1999). Accurate transcripts were maintained, and the analysis process was documented in detail. Substantial parts of text are included in the report of the findings to provide a believable and logical description of the results. Member checking was accomplished by mailing a summary of major themes to participants to check accuracy of the results (see Appendix Q). Field notes taken by the assistant moderator, the audiotaped transcripts, and the investigator's post-group notes were compared to achieve triangulation of the data (Rice & Ezzy).

Delimitations

The cellular and molecular biology of hypertrophic scars is complex (Tredget et al., 1997), therefore, the discussion of scar formation and theory of pressure therapy is limited to a burn therapists' knowledge base, and histological theories are not explored in detail.

Keloids and hypertrophic scars can both occur following burn injury, and have been called fibroproliferative disorders by Tredget et al. (1997). There are differences between the two types of scars, and the distinction between hypertrophic and keloid scars needs to be made during a discussion of scar formation and treatment. Hypertrophic scars develop within the margins of the original wound, develop in all ages, resolve at least partially over time, and respond to pressure therapy; keloids demonstrate the opposite clinical features (Fujimori et al., 1968; Tredget et al.). Furthermore, Fujimori et al. found that 95% of cases of excessive scar due to burns were hypertrophic scars. Since keloids do not seem to respond to pressure therapy, do not regress over time, and are infrequent sequelae of burn injury, this study will be limited to discussion of hypertrophic scars.

This thesis focuses on pressure therapy as the primary means for scar treatment, however, it is acknowledged that the successful treatment of the burn scar depends on many other modalities such as silicone gel (Ahn, Monafó & Mustoe, 1989), exercise, splinting, positioning, and massage (Serghiou et al., 2007).

CHAPTER 4 – RESULTS

Internet Survey

Response Rate

The first contact (prenotice email) was sent to 344 potential respondents. Eighty-four participants responded to the test emails confirming their address and that they currently were an OT or PT working in burns. After this test email, 19 responses were received stating the recipient or colleagues of the recipient no longer worked in burns, or were not an occupational or physical therapist. Four emails were received from burn therapists who were not on the list but wished to be part of the study. Undeliverable emails were tracked but were not removed in case the potential respondent simply had a full email in-box. Any known changes to emails were made. After revision, the potential respondent list contained 329 names. Upon calculation of the final response rate, consistently undeliverable emails were removed from the total, as well as 10 additional names that at some point in the remaining email contacts had been identified as no longer working in burns or who were not an OT or PT, leaving 272 potential respondents. One hundred and eighteen surveys were returned, and of those, 105 were useable. The final response rate was 38.6%. Table 2 summarizes the overall response rate and table 3 illustrates the response rate by administration phase. The majority of participants responded after the main survey contact phase.

Table 2. Survey Response Rate

Total Emails sent at Prenotice Phase	344
Total Emails sent during Survey Phase (4 contacts combined)	329
Actual Potential Respondents	272
Total Surveys Returned	118
Total Useable	105
FINAL RESPONSE RATE	38.6%

Table 3. Survey Response Rate by Administration Phase

Administration Phase	# of Responses	%
Main survey contact + clarification*	87	73.7%
Reminder 1	21	17.8%
Reminder 2	10	8.5%
TOTAL	118	100%

*The clarification email occurred only 3 days after the main survey email, therefore these 2 phases were calculated together

Respondent Demographics

Table 4 shows that slightly over half (57.1%) the survey respondents were occupational therapists. The majority of respondents (61.9%) hold a Bachelor's degree as their highest educational level. Most (79%) treat both in and outpatients, and treatment of both pediatric and adult patients was most common (41.9%). See table 4 for full details regarding respondents' practice.

Table 4. Respondent Demographics

Demographic Variable	Response Choices	# of Responses	%
OT or PT	OT	60	57.1%
	PT	44	41.9%
	No response	1	1.0%
Educational Level	Bachelor's	65	61.9%
	Entry Level Graduate Degree*	30	28.6%
	Research Graduate Degree**	10	9.5%
	No response	0	0%
Patient Age Group	Adults	32	30.5%
	Pediatrics	27	25.7%
	Both pediatrics and adults	44	41.9%
	No response	2	1.9%
In or outpatients	In patients only	14	13.3%
	Outpatients only	7	6.7%
	Both in and outpatients	83	79.0%
	No response	1	1.0%

N=105

*Entry Level Masters and Doctoral Degrees were combined for this category

**Research Masters and PhD degrees were combined for this category

The average years that respondents had practiced as an OT or PT was 14.1 (range 1 – 37) years, and average years working with burn patients was 9.7 (range 0.5 – 33) years. Respondents' facilities admitted an average of 299 (range 4 - 550) burn patients per year

With respect to job function, the majority of respondents (79%) do direct patient care over 50% of the time (see table 5), and the geographic areas most represented in the survey were California (11.4%), Texas (10.5%) and Manitoba (10.5%) (see table 6).

Table 5. Job Function

	50% of the time +	< 50% of the time	Do Not Perform	No Response
Direct Patient Care	83 (79.0%)	21 (20.0%)	1 (1.0%)	0 (0.0%)
Research	2 (1.9%)	53 (50.5%)	48 (45.7%)	2 (1.9%)
Program Development	9 (8.6%)	77 (73.3%)	18 (17.1%)	1 (1.0%)
University Instructor	1 (1.0%)	30 (28.6%)	64 (61.0%)	10 (9.5%)
Administration	12 (11.4%)	30 (28.6%)	58 (55.2%)	5 (4.8%)
Other	0 (0.0%)	5 (4.8%)	18 (17.1%)	82 (78.1%)

N=105

Table 6. Geographic Area of Respondents

Geographic Area	# of Responses	%
Alaska	1	1.0%
Arizona	1	1.0%
California	12	11.4%
Colorado	2	1.9%
Florida	1	1.0%
Illinois	8	7.6%
Indiana	2	1.9%
Kentucky	2	1.9%
Louisiana	1	1.0%
Maryland	1	1.0%
Massachusetts	2	1.9%
Michigan	1	1.0%
Minnesota	4	3.8%
Missouri	2	1.9%
Nebraska	1	1.0%
New York	5	4.8%
North Carolina	1	1.0%
Ohio	8	7.6%
Pennsylvania	1	1.0%
Tennessee	1	1.0%
Texas	11	10.5%
Utah	2	1.9%
Vermont	1	1.0%
Washington	1	1.0%
Alberta	4	3.8%
British Columbia	5	4.8%
Manitoba	11	10.5%
New Brunswick	1	1.0%
Newfoundland & Labrador	1	1.0%
Ontario	8	7.6%
Quebec	3	2.9%
No response	0	0%

N=105

Outcome Measure Use

Less than half (38.1%) of respondents reported using a burn scar outcome measure (BSOM). Of the therapists who use a BSOM, 75% use the Vancouver Scar Scale (VSS) or a modified version of the VSS. Only 26.7% of those using the VSS are fully satisfied with it as an outcome measure; the most common reason provided for lack of full satisfaction was that it is too subjective.

Table 7 presents the reasons respondents do not use a BSOM (61.9%). The most common reasons given were that they are not familiar with what is available (44.6%), they have not found one that is clinically practical (32.3%), and they believe they need more training to use existing outcome measures (27.7%). Most (83.1%) of the respondents who do not use a BSOM use written subjective descriptors of the scar as their method of burn scar assessment.

Table 7. Reasons Respondents Do Not Use A BSOM

Reasons	# of Responses	%
I am not familiar with what is available	29	44.6%
I have not found one that is clinically practical	21	32.3%
I believe that I need more training to use existing O.M's	18	27.7%
Other	15	23.1%
I have not found one with established reliability	13	20.0%
I have not found one with established validity	10	15.4%
I do not have time in my practice to use one	10	15.4%
I don't think that using an O.M. is necessary	3	4.6%

N=65

However, almost all (95.2%) of respondents felt that using a BSOM is important. The most common reasons reported (Table 8) were to measure the efficacy

of scar treatment (95%), make scar treatment decisions (87%) and assess burn scar maturity (83%).

Table 8. Reasons Respondents Felt that Using a BSOM is Important

Reasons	# of Responses	%
To measure the effectiveness of scar treatment	95	95%
To make a decision about scar treatment	87	87%
To assess burn scar maturity	83	83%
So the patient can see progress	77	77%
Formal research	63	63%
To assess joint function	40	40%
Other	9	9%
N=100		

Characteristics of an Outcome Measure

The following BSOM characteristics were reported as important by over 90% of respondents: has established reliability, has established validity, is quick to administer, is easy to use, and is non-invasive to the patient. Table 9 illustrates the characteristics of a BSOM that respondents felt are important.

Table 9. Characteristics of a BSOM That Respondents Felt Are Important

Characteristic	# of Responses	%
That the O.M.* has established reliability	100	95.2%
That the O.M. has established validity	100	95.2%
That the O.M. is quick to administer	98	93.3%
That the O.M. is non-invasive to the patient	96	91.4%
That the O.M. is easy to use	96	91.4%
That the O.M. is sensitive to change	91	86.7%
That the O.M. is inexpensive to purchase	87	82.9%
That the O.M. is portable	86	81.9%
Other	7	6.7%

N=105

*O.M. = Outcome Measure

When asked whether certain burn scar properties should be included in a BSOM, respondents agreed that pliability (96.2%), vascularity (92.4%), and height (87.6%) should be included, followed by appearance (75.2%), skin breakdown (74.3%), itch (73.3%) and surface texture (70.5%). Table 10 provides additional details regarding the burn scar properties therapists believed should be included in a BSOM. The “maybe” response choice provided an opportunity for additional comments, and a common theme emerging from this question was that respondents were unfamiliar with, or did not know enough about temperature, transepidermal water loss, and transcutaneous oxygen tension to make a decision about whether or not these properties should be included in a BSOM.

Table 10. Scar Properties Therapists Believed Should be Included in a BSOM

	Yes	No	Maybe	No Response
Pliability	101 (96.2%)	2 (1.9%)	2 (1.9%)	0 (0.0%)
Vascularity	97 (92.4%)	5 (4.8%)	3 (2.9%)	0 (0.0%)
Height	92 (87.6%)	1 (1.0%)	12 (11.4%)	0 (0.0%)
Appearance	79 (75.2%)	19 (18.1%)	5 (4.8%)	2 (1.9%)
Skin Breakdown	78 (74.3%)	20 (19.0%)	5 (4.8%)	2 (1.9%)
Itch	77 (73.3%)	19 (18.1%)	6 (5.7%)	3 (2.9%)
Surface texture	74 (70.5%)	15 (14.3%)	15 (14.3%)	1 (1.0%)
Pigmentation	72 (68.6%)	23 (21.9%)	9 (8.6%)	1 (1.0%)
Pain	71 (67.6%)	21 (20.0%)	12 (11.4%)	1 (1.0%)
Length	43 (41.0%)	46 (43.8%)	15 (14.3%)	1 (1.0%)
Volume	30 (28.6%)	37 (35.2%)	36 (34.3%)	2 (1.9%)
Temperature	21 (20.0%)	60 (57.1%)	23 (21.9%)	1 (1.0%)
TWL*	17 (16.2%)	42 (40.0%)	45 (42.9%)	1 (1.0%)
TcpO ₂ **	9 (8.6%)	44 (41.9%)	51 (48.6%)	1 (1.0%)

N=105

*TWL=Transepidermal Water Loss

** TcpO₂ =Transcutaneous Oxygen Tension

Therapists were also asked why or why not they felt the property should be included in a BSOM. The majority of respondents who reported that the following scar properties should be included in a BSOM state that they are indicators of scar maturity: pliability (78.2%), vascularity (87.6%), itch (68.8%) and pigmentation (89%). The majority of respondents who reported that the following scar properties should be included in a BSOM state that they are affected by scar management: pliability (86.1%), vascularity (67%), height (92.4%), appearance (73.4%), skin breakdown (66.7%), itch (79.2%), surface texture (93.2%) and pain (87.3%). The majority of respondents who reported that length should not be included in a BSOM indicated that this property is not an indicator of scar maturity (78.3%) and is not affected by scar management (69.6%). Many respondents who choose not to include temperature in a BSOM indicated it was because this property is not an indicator of scar maturity (61.7%). These responses are summarized in Table 11 (a) and (b). Respondents were provided with the opportunity to add “other” reasons beyond the response choices given. Common themes emerging from these other reasons are summarized in table 12.

Table 11 (a). Reasons Why the Property Should Be Included in a BSOM

Property	N	If Yes, why?			
		<u>Indicator of</u>	<u>Affected by</u>	<u>Other</u>	<u>No Response</u>
		<u>Scar</u> <u>Maturity</u>	<u>Scar</u> <u>Management</u>		
Pliability	101	79 (78.2%)	87 (86.1%)	10 (9.9%)	1 (1.0%)
Vascularity	97	85 (87.6%)	65 (67%)	2 (2.1%)	1 (1%)
Height	92	44 (47.8%)	85 (92.4%)	13 (14.1%)	0 (0.0%)
Appearance	79	24 (30.4%)	58 (73.4%)	18 (22.8%)	3 (3.8%)
Skin Breakdown	78	35 (44.9%)	52 (66.7%)	21 (26.9%)	0 (0.0%)
Itch	77	53 (68.8%)	61 (79.2%)	13 (16.9%)	0 (0.0%)
Surface texture	74	39 (52.7%)	69 (93.2%)	5 (6.8%)	0 (0.0%)
Pigmentation	72	65 (89.0%)	25 (34.2%)	8 (11.0%)	1 (1.4%)
Pain	71	33 (46.5%)	62 (87.3%)	14 (19.7%)	0 (0.0%)
Length	43	11 (25.6%)	27 (62.8%)	8 (18.6%)	3 (7.0%)
Volume	30	16 (53.3%)	23 (76.7%)	3 (10.0%)	0 (0.0%)
Temperature	21	17 (81.0%)	10 (47.6%)	2 (9.5%)	0 (0.0%)
TWL*	17	8 (47.1%)	14 (82.4%)	1 (5.9%)	1 (5.9%)
TcpO ₂ **	9	6 (66.7%)	7 (77.8%)	1 (11.1%)	0 (0.0%)

*TWL=Transepidermal Water Loss

TcpO₂=Transcutaneous Oxygen TensionTable 11 (b). Reasons Why the Property Should Not Be Included in a BSOM**

Property	N	If No, why not?			
		<u>Not an</u>	<u>Not Affected</u>	<u>Other</u>	<u>No Response</u>
		<u>Indicator of</u> <u>Scar</u> <u>Maturity</u>	<u>by Scar</u> <u>Management</u>		
Pliability	2	1 (50%)	0 (0.0%)	1 (50%)	0 (0.0%)
Vascularity	5	0 (0.0%)	0 (0.0%)	0 (0.0%)	5 (100%)
Height	1	1 (100%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
Appearance	19	13 (68.4%)	3 (15.8%)	9 (47.4%)	0 (0.0%)
Skin Breakdown	20	14 (70.0%)	6 (30.0%)	4 (20.0%)	2 (10.0%)
Itch	19	13 (68.4%)	7 (36.8%)	5 (26.3%)	1 (5.3%)
Surface texture	15	10 (66.7%)	3 (20.0%)	6 (40.0%)	1 (6.7%)
Pigmentation	23	13 (59.1%)	17 (77.3%)	1 (4.5%)	0 (0.0%)
Pain	21	15 (71.4%)	11 (52.4%)	7 (33.3%)	0 (0.0%)
Length	46	36 (78.3%)	32 (69.6%)	9 (19.6%)	1 (2.2%)
Volume	37	16 (43.2%)	11 (29.7%)	14 (37.8%)	4 (10.8%)
Temperature	60	37 (61.7%)	26 (43.3%)	13 (21.7%)	2 (3.3%)
TWL*	42	15 (35.7%)	20 (47.6%)	13 (31.0%)	2 (4.8%)
TcpO ₂ **	44	14 (31.8%)	20 (45.5%)	17 (38.6%)	4 (9.1%)

*TWL=Transepidermal Water Loss

**TcpO₂=Transcutaneous Oxygen Tension

Table 12. "Other" reasons properties should or should not be included in a BSOM

Property	Theme	
	<u>Reason the Property Should be Included</u>	<u>Reason the Property Should Not be Included</u>
Pliability	Affects joint motion, therefore function	—
Length	Helps to document the size and extent of the scar	—
Pain	Important to patients' quality of life	Too subjective
Itch	Important to patients' quality of life	Too subjective
Appearance	Important to patients' quality of life	Too subjective
Volume	—	Too time consuming/not practical
Surface Texture	—	Poor inter-rater reliability due to variability
Temperature	—	Hard to accurately measure - affected by too many variables
Transepidermal water loss	—	Not practical
Transcutaneous oxygen tension	—	Not practical

Therapists were then asked to rank the burn scar properties according to how important they felt it was that each should be included in a BSOM. Unfortunately, this question was poorly understood and answered; therefore several responses were unanswered or unusable. However, from the useable answers it was evident that pliability was ranked as the number one property for inclusion in a BSOM, followed closely by vascularity and height. Table 13 illustrates the rank order of importance of burn scar properties.

Table 13. Rank Order of Importance of Burn Scar Properties

Property	Rank Total	Final Rank Order
Pliability	223	1
Vascularity	319	2
Height	373	3
Surface Texture	592	4
Skin Breakdown	607	5
Appearance	620	6
Pain Rating	621	7
Pigmentation	677	8
Itch Rating	695	9
Volume	783	10
Length	798	11
Temperature	948	12
Transepidermal Water Loss	1049	13
Transcutaneous Oxygen Tension	1128	14

N=89

Additional Issues in Burn Scar Assessment

Almost half (44.8%) of respondents reported using a method of scar relocation during scar reassessment. Methods reported were photographs (74.5%), written descriptions (27.7%), diagrams (27.7%), skin markers (4.3%) and scar tracings (4.3%). Usually a combination of these methods was used.

The most common scar properties respondents reported as being important to burn survivors were appearance (89.5%), itch, (88.6%), pain (87.6%) and pigmentation (82.9%) (see table 14). When given the opportunity to add additional comments, the only theme that arose was that a small number of respondents felt that whether a scar was visible or not was important to burn survivors.

Table 14. Scar Properties Respondents Felt Are Important To Burn Survivors

Scar Property	# of Responses	%
Appearance	94	89.5%
Itch	93	88.6%
Pain	92	87.6%
Pigmentation	87	82.9%
Pliability	83	79.0%
Skin breakdown	82	78.1%
Height	80	76.2%
Surface texture	72	68.6%
Vascularity	65	61.9%
Length	32	30.5%
Volume	20	19.0%
Temperature	12	11.4%
Transepidermal water loss	6	5.7%
Transcutaneous oxygen tension	0	0.0%
No response	6	5.7%

N=105

When asked whether there was anything else they would like to add, the only common theme that emerged was that several respondents stressed that a BSOM should be quick and easy to administer.

Relationships Between Variables

Relationships between outcome measure use and the following variables were explored: experience level of burn therapists, education level of burn therapists, whether respondent was an OT or PT and number of burn patients admitted to respondent's facilities (see table 15). The only significant relationship found was between outcome measure use and number of burn patients admitted. Therapists working in facilities admitting higher numbers of burn patients were more likely to use a burn scar outcome measure.

Table 15. Relationships Between Categorical Variables

Relationship	Level of Significance
Experience Level vs. Outcome Measure Use	NS
Educational Level vs. Outcome Measure Use	NS
Therapist Type vs. Outcome Measure Use	NS
# of Burn Patients Admitted vs. Outcome Measure Use	0.002*

*Chi-square = 15.4 with 3 degrees of freedom

Focus Group

Participant Demographics

One focus group with six participants was carried out; there were an equal number of males and females. See table 16 for participant demographics.

Table 16. Focus Group Participant Demographics

Participant	Age	M/F	% Body Surface Burned	Years since burn	Level of compliance with Pressure Garment*
1	35	M	49%	3	Moderate
2	36	M	50%	1.5	Moderate
3	65	M	21%	3	High
4	26	F	60%	2.5	High
5	38	F	20%	6	Low
6	25	F	3%	4	High

*Compliance level defined as: Low = Less than 8 hours/day
 Moderate = 9 – 16 hours/day
 High = 17 – 24 hours/day

Themes

Several major themes emerged from the focus group discussion and are described below:

The Most Important Scar Characteristics are the Ones Most Visible

Participants all agreed that scar characteristics that were most visible and obvious to the public were the most important to them. Colour, specifically redness, was the scar characteristic that participants felt the strongest about. They talked about people noticing the dark red or purple colour immediately, and feeling uncomfortable with their appearance. Participants felt relieved as time passed and the colour started to fade. One participant related:

P1: "The redness for me in my first year after my injury was devastating, because it was so visible in the summer and I wanted to wear shorts and the redness was more of a thing for me but as time went on it got less and less so it was less of a thing for me."

Despite the scar definitions provided, participants seemed to use the terms height and surface irregularity interchangeably, and everyone agreed that these characteristics were very important to them as well. One participant shared her feelings about the height of her scar:

P2: "At the beginning before I had pressure garments or anything like that I always thought that my hand looked like a brain and that it really bothered me a lot to see it for the first time, like after they took the bandages off and stuff like that. It was really hard to deal with..."

Many shared feelings of wishing their skin was smooth and regular, and felt that the higher the scar was from the level of their skin, the more noticeable it was, as illustrated by this quote:

P1: "Initially it was important only because um, I wanted so much for it to um, feel normal, feel like the way it's supposed to, the way the rest of my skin felt."

Burn Scar Itch

Participants all agreed that burn scar itch was one of the biggest challenges in their recovery, and was an important scar characteristic. Most participants described their experiences with great emotion, as seen in these quotes:

P2: "I tried practically everything for my itching, it was so bad. I mean, especially when I'd get out of the bathroom, the shower, I'd be running around my mom's house, screaming. You know, not being able to do anything about it, just going absolutely crazy. Just all of a sudden, all my legs, my whole body, it was just...so she would just rub it, and oh my God, that was brutal."

P3: " If I stood up, it felt like my calves were going to explode, like rubbing you said, I know that one, rubbing with the towel, I wish I had four or five arms to kind of soothe it...Soon, you're sliding around the carpet. Literally, it was severe. Like I would take that for, probably out of it all, the most, for me, it was brutal like I said...Out of all of it, the biggest one for me was the itch."

Skin Quality

Participants raised the issue of skin quality at many points during the focus group discussion. They shared the frustration of small areas on their body taking months to heal, as described by this participant:

P4: “(The open areas) kind of scared me. I didn’t like it. I had two spots here and under my armpits. My armpit just healed up about two months ago. That’s a good thing...I was getting a little sick of it cause it’s a terrible place to get the dressing...no dressings held up there and uh you know so I’m glad it’s healing and I hope it stays that way.”

Participants all shared the experiences of scarred skin being more prone to blisters and skin breakdown, as this participant noted:

P5: “You don’t even notice that you get the scratch and then all of a sudden you look and the scar’s bleeding and it’s really weird.”

They all described having to be more cautious and taking extra special care of their skin. One participant discussed his strategy:

P3: “So this skin I’ve gotta guard more. I actually have it mapped out on my body when I am in an area where I have to use this hand I just know that psychologically from ‘oh that bled pretty easy.’”

Sensory Changes to the Burn Scar

Participants all described some type of sensory changes to their burn scars. Some experienced hypersensitivity as related by these participants:

P6: "It's interesting because... I had for about a year, year and a half, nerve pain, the scarring was more sensitive not, as, doesn't hurt as much as at the time of surgery but I'd feel the nerves start pulling and hurting and burning"

P5: "Like even now when I wear tight jeans like right now I know exactly, like I can feel it, like cause I had my donor site on my thigh. That took a really long time to heal and just like feel normal. Even now it still, I dunno, I think it's painful maybe I'm a wimp, but it was stabbing, tingly like pins, needles. It's been a long time, it's been like I don't even know, (X) years maybe. That's kind of weird."

Numbness to some of their scarred areas was a common experience as well, and is summed up by participant, "P4" who stated that on *"either side of that scar, there's nothing."*

Respectful Treatment During Burn Scar Assessment

Participants raised many issues with the common theme being that they valued respectful treatment during burn scar assessment. Participants felt the following factors were important: privacy, that their opinion was taken into account during scar treatment decisions, that therapists answered their questions, and spent appropriate amounts of time in the session, as noted by these participants:

P4: "Patient to therapist is excellent compared to doctor to patient. You get 15 minutes with your doctor. It's nice that the therapists have time to spend with you for different stuff you need."

P6: "I found it very comforting, there were no issues in terms of privacy, problems like that, it was very good, there's no question about that. The therapists are the people obviously who are involved in most, 99%, of your healing process. Something catastrophic - you're relying on that person."

CHAPTER 5 - DISCUSSION

Research Question #1: What are the variables of burn scar that burn occupational and physiotherapists believe should be included in a burn scar outcome measure?

The Top Three Variables Burn Therapists Choose for Inclusion in a BSOM

Overwhelmingly, burn therapists believed that pliability (96.2%), vascularity (92.4%) and height (87.6%) should be included in a BSOM. These results correspond directly to the top three variables identified in the rank order question. The literature also reports these variables to be important, and they will be discussed individually below. It is interesting to note how well these results parallel the results reported in the literature, but it is not known if respondents answered the survey based on their readings of the literature, or on clinical observation.

Powers et al. (1999) agreed that pliability is one of the most important aspects of scars. Most of the respondents who indicated that pliability should be included in a BSOM considered this variable to be an indicator of scar maturity (78.2%); this is in agreement with the observations of Clark et al. (1987), Clark, Cheng, and Leung (1996), Fong et al. (1997), and Leung et al. (1984). These respondents also felt that scar management techniques affect pliability (86.1%), and this finding is supported by the literature (Clark et al., 1996; Kisher, Shetlar & Shetlar, 1975). A common theme that arose in the open-ended responses was that pliability affects joint motion

and therefore relates to function, a concept supported by the findings of McOwan et al. (2001) and Sullivan et al. (1990).

The majority of respondents who believed that vascularity should be included in a BSOM, did so because they consider that it is an indicator of scar maturity (87.6%) and that it is affected by scar management (67%). This finding is congruent with the observations of Baur et al. (1976), Cheng et al. (2001), Hambleton et al. (1992), Leung, Sher, Clark et al. (1989), and Sullivan et al. (1990) that vascularity is an indicator of scar maturity and of Baur et al., Hambleton et al., Johnson (1984), Kischer et al. (1975), Larson et al. (1975), and Parks, Burke Evans and Larson (1978) that it is affected by scar management.

Respondents who believed that height should be included in a BSOM appeared to agree that it is because it is affected by scar management (92.4%). Several authors (Cheng et al., 2001; Hambleton et al., 1992; Katz et al., 1983; Kischer et al., 1975) have reported similar findings. Less than half (47.8%) of the respondents who indicated that height should be included did so because they consider height to be an indicator of scar maturity; however, many authors state that it is (Cheng et al.; Fong et al., 1997; Hambleton et al.; Katz et al.).

Additional Variables Burn Therapists Chose for Inclusion in BSOM

In addition to the variables of pliability, vascularity and height, the majority of respondents stated that appearance (75.2%), skin breakdown (74.3%), itch (73.3%), surface texture (70.5%), pigmentation (68.6%), and pain (67.6) should be included in a BSOM. Most of these respondents (79.2%) consider itch to be affected by scar

management, a finding congruent with that of Leung and Ng (1980), who reported that itching may be relieved by the application of pressure. Almost all (93.2%) of the respondents consider surface texture to be affected by scar management; however, evidence that scar management techniques affect surface texture as a single variable was not found in the literature. Pigmentation was reported to be an indicator of scar maturity by 89% of the respondents; however this is in contrast with the opinions of Cheng et al. (2001), Deitch et al. (1983), Masters et al. (2005), and Oliveira et al. (2005). Most of the respondents (87.3%) indicated that pain was affected by scar management techniques, agreeing with the findings of Leung and Ng. Skin breakdown was reported to be affected by scar management techniques by 66.7% of the respondents, and open-ended comments explained that scar treatment decisions would be affected by open areas i.e. implementation of pressure therapy may be delayed or the choice of pressure therapy may be affected by the presence of open areas. These points are consistent with the observations of Carr-Collins (1992), Johnson (1984), and Leung and Ng. Appearance was reported to be affected by scar management techniques by 73.4% of respondents; there are numerous reports in the literature of the value of pressure garments in improving the appearance of burn scars (Parks et al., 1978; Leung & Ng; Larson, Abston, Evans, Debrkovsky & Linares, 1971; Serghiou et al., 2007).

A major theme arose from the responses to the open-ended questions regarding the patient-reported variables of pain, itch and appearance. Those who indicated that these variables should be included in a BSOM stated that they were important to the patient's quality of life. Those who indicated that these variables

should not be included in a BSOM stated that they were too subjective to be included in an objective measure.

Variables that Burn Therapists Indicated Were Important to Burn Survivors

It is interesting to note that when asked what properties are important to burn survivors, almost all respondents chose appearance (89.5%), itch (88.6%), pain (87.6%) and pigmentation (82.9%). Many respondents also chose pliability (79%), skin breakdown (78.1%) and height (76.2%). Overall, the top 3 variables that burn therapists choose to be clinically important for inclusion in a BSOM are different from those they believe are the top 3 variables important to burn survivors. Appearance, itch and pain are “subjective” properties of burn scar, so it is not surprising that these 3 variables were chosen as important to burn survivors. Perhaps burn therapists are more comfortable with “objective” measures that can be palpated and visualized, but it appears that they still acknowledge the importance of subjective reports.

Variables that Require Highly Technical Methods to Measure are Not Practical for Inclusion in a BSOM

Respondents were undecided whether the variables of length, volume, temperature, transepidermal water loss (TWL) and transcutaneous oxygen tension (T_{cpO₂}) should be included in a BSOM. Comments related to volume, TWL and T_{cpO₂} were that these variables are too time consuming to measure and therefore not

practical to include. Authors have described temperature (McOwan et al., 2001), TWL (Rodrigues & Roberto, 2006; McOwan et al.) and TcpO₂ (Berry et al., 1985) as promising indicators of scar maturity; however, measuring these variables requires highly technological assessment methods, making them clinically impractical, and better suited to a research setting (Masters et al, 2005; McOwan et al.; Yeong et al., 1997). Respondents echoed this sentiment, commenting that a BSOM should be quick and easy to administer.

In fact, the desire for a clinically practical outcome measure is a major finding of this study, further evidenced when respondents were asked what characteristics of a BSOM they felt were important. Most respondents answered that it should be quick to administer (93.3%), non-invasive to the patient (91.4%), easy to use (91.4%), inexpensive (82.9%) and portable (81.9%). Also of major importance to respondents was that a BSOM have established reliability (95.2%) and validity (95.2%), and be sensitive to change (86.7%).

Importance of using a BSOM and Barriers to Using One

Interestingly, almost all (95.2%) respondents reported that using a BSOM is important, and they appeared to agree on why outcome measure use is important (to measure the efficacy of scar treatment, to make scar treatment decisions and to assess burn scar maturity). Perhaps, however, the barriers to using a BSOM (not familiar with what is available, have not found one that is clinically practical, need more training to use existing outcome measures) cannot be overcome, as less than half (38.1%) of respondents actually use a BSOM.

In summary, almost every burn therapist surveyed indicated that pliability, vascularity and height should be included in a BSOM. The majority also stated that appearance, skin breakdown, itch, surface texture, pigmentation, and pain should be included as well. It is interesting to note that the top 3 variables that respondents indicated they believed were important to burn survivors were appearance, itch and pain. Respondents appeared to be undecided whether the variables of length, volume, temperature, TWL and TcpO₂ should be included in a BSOM; they indicated that these variables require highly technical measurement methods, and respondents report the desire for a clinically practical BSOM. Surprisingly, less than half of respondents reported using a BSOM, but almost all indicated that using one is important.

Research Question #2: What are the variables of burn scar that burn survivors believe should be included in a burn scar outcome measure?

The finding that focus group participants believed the most important scar characteristics are the ones that are most visible is not surprising. Differences in colour and height/surface irregularity affect the appearance of a scar a great deal. The only scar assessment found in the literature that evaluates colour and height/surface irregularity from the patients' perspective is the Patient and Observer Scar Assessment Scale (Draaijers, Tempelman, Botman, Tuinebreijer, et al., 2004).

Burn survivors felt strongly about the scar characteristic of itch; despite being a common clinical issue for all burn therapists, itch has only been included in three

published burn scar scales (Draaijers, Tempelman, Botman, Tuinebreijer, et al., 2004; Masters et al., 2005, Nedelec et al., 2000).

A major theme arising from the focus group was that sensory changes to the burn scar were very important to burn survivors. Participants discussed true sensory issues such as hyper and hypo sensitivity. Interestingly, an assessment of sensory function is commonly recommended as part of comprehensive burn therapy evaluation (Howell, 1994; Ward, Saffle, Schnebly, Hayes-Lundy & Reddy, 1989), but has not been included in any known published burn scar outcome measure. Pain has been included in some published BSOM's (Draaijers, Tempelman, Botman, Tuinebreijer, et al., 2004; Masters et al., 2005, Nedelec et al., 2000), but has not been described as sensory dysfunction.

Focus group members frequently discussed skin quality as an important issue for them, especially as it relates to skin breakdown. Carr-Collins (1992) explained that open areas are a common and recurrent problem following wound closure due to thin and fragile epithelium. Skin breakdown has not been included in any known published BSOM's.

Appearance has been included in two BSOM's (Martin et al., 2003; Masters et al., 2005), but interestingly, overall appearance was not a scar characteristic that focus group participants discussed in great detail. When the concept was raised during focus group discussion, participants usually referred to individual scar characteristics such as colour and height/irregularity; they did not discuss the scar as a whole. Three participants also related that, when put in a greater context of almost having lost life or limb, they would choose to have an altered appearance.

The Relationship Between Research Question #1 and #2

It is not possible to directly compare the results of the quantitative (Internet survey of burn therapists) and qualitative (focus group of burn survivors) phases of this research study, however, some general observations are offered.

The characteristics of vascularity (redness) and height/surface irregularity are clearly important to both burn survivors and burn therapists, although apparently for different reasons. Burn therapists appear to be assessing these characteristics (vascularity and height) to make treatment decisions and burn survivors seem to be more concerned with visibility of their scar.

Burn therapists and burn survivors appear to be in agreement about the scar characteristics of itch and skin breakdown as well, although these characteristics are further down burn therapists' lists.

The issue of sensory changes is an interesting one, as it appears that burn therapists and burn survivors are not discussing exactly the same characteristic. Burn survivors appear to find the experience of actual sensory changes such as hyper and hypo sensitivity to be very important, whereas it is unclear whether burn therapists view pain as a sensory dysfunction.

The top characteristics of scar that burn therapists feel are important to burn survivors appear to loosely parallel the actual characteristics discussed by focus group participants. Itch, pain (? hypersensitivity), pigmentation (colour), skin breakdown and height are thought to be important to burn survivors by at least 75% of burn therapists surveyed. Only appearance is clearly out of place – it is the top

characteristic that burn therapists believed is important to burn survivors, but as discussed in the above section, does not seem to be as important to burn survivors as individual scar characteristics.

Pliability, vascularity and height are already included in the Vancouver Scar Scale (Sullivan et al., 1990), which is, according to respondents, the most commonly used BSOM. Pliability was identified as the most important variable by burn therapists, and vascularity (colour) and height are important to both burn therapists and burn survivors. These findings suggest that further modifications to the VSS may be warranted, perhaps with the inclusion of itch. It is acknowledged that skin breakdown, pain and sensory changes are important variables for both the burn therapist and burn survivor, but these variables do not provide useful information on the maturity of the burn scar or on scar treatment effectiveness.

Limitations of the Study

The main limitation to this study was the low survey response rate (38.6%). This response rate is comparable to that of two recent Internet surveys of burn care practices, each reporting a 30% response rate (Hermans, 2007; Reimel, Klein, Nathens, Heimbach, & Gibran, 2005). The literature recognizes the low response rate for Internet surveys, ranging from 7 to 44% (Schonlau et al., 2001), however, Kemalyan (2007), in a critique of Hermans' article, states that "the 30% response rate is remarkable, insofar as surveys are fortunate to achieve 20% response on average" (p. 849). The low response rate may have been related to another recognized

limitation of Internet surveys; the potential for coverage error, as a result of which all members of the population do not have an equal chance of being sampled (Dillman, 2000). Despite diligence in constructing an accurate email list to use a sample frame, the unstable nature of email addresses is unavoidable. It is almost certain that the list included some inaccurate email addresses, and is missing some burn therapists. Kemalyan, in reference to Hermans' article, stated that challenges both in collecting accurate email addresses and successfully sending the survey may have contributed to the limited responses rather than lack of interest of the potential respondents.

Respondents of the survey could not be compared to non-respondents, as SurveyMonkey does not have the ability to track the identity of the respondents without disclosing this to the investigator. Therefore, non-response error, or the result of those responding to the survey being different from those who did respond (Dillman, 2000) could not be estimated.

Several Internet survey questions allowed respondents to choose many responses within a single question, making chi-square analysis of these questions impossible, as respondents would be represented in more than one category. For example, whether a therapist used an outcome measure or not could not be compared to job function, as respondents were allowed to choose more than one job function. This would have been corrected by simply asking the respondent to choose one main job function.

Many of the planned questions during the focus group had to be deleted or were rushed due to the length of time spent discussing the scar characteristics, therefore it is reasonable to assume some relevant information may be missing from

these data. However, it is felt that the questions prioritized for inclusion generated the data needed to answer research question #2. Also, the fact that the facilitator had treated each of the focus group members in the past made some of the questions awkward to ask, which was a reason to delete them. For example, a negative response to the question “Do you think that your opinion was taken into consideration when your scars were evaluated?” would likely have been difficult for the participants.

A limitation of focus group methodology is the small number of participants and the non-random sampling method, preventing the results from being generalized to the larger population. Additionally, the open-ended questions and large amount of data make interpretation of results difficult (Dawson et al., 1993; Morgan, 1988). In qualitative research, the investigator makes an interpretation of the data, filtering the information through his or her personal viewpoint, thereby creating the potential for several different interpretations (Creswell, 2003). The strategies described for rigorous qualitative research sought to minimize these limitations.

Suggestions For Further Research

Determining the variables that burn surgeons believe should be included in a BSOM would likely be a worthwhile follow-up to this study. Based on clinical experience and during the course of a previous study (Forbes-Duchart et al., 2007), it has been observed that physicians and therapists view scars differently. Typically, burn therapists are responsible for carrying out the conservative scar management techniques, while surgeons are presumably assessing burn scars to determine the need

for further surgery. It would be interesting to establish the similarities and differences between these two disciplines' viewpoints.

Due to the small number of participants, focus group results are not generalizable to the general population. For this reason, it would be useful to conduct a quantitative study with a larger number of participants to determine the burn scar variables that burn survivors feel are important to them.

The focus group discussion went beyond the scope of the research question, into topics such as respectful medical treatment, how to best manage itch, and dealing with staring related to disfigurement. In the interest of time, these topics were re-directed by the moderator, but these subjects would be interesting to pursue in additional studies.

It is clear that a BSOM that is objective, clinically practical, inexpensive, valid, reliable and sensitive to change is needed. As noted above, further modifications to the VSS may be warranted, based on the findings of this study. Modifications made to the VSS would need to be followed by further research into the reliability, validity and responsiveness of the tool. It is imperative that a BSOM be sensitive to small changes in burn scar, as scars mature slowly over time. A research study evaluating the effectiveness of a scar treatment technique using a BSOM that is not sensitive to change may reach the conclusion that the treatment is not effective, when in fact the improvement was not detected due to low sensitivity of the measure.

CHAPTER 6 – CONCLUSIONS

Clearly burn therapists agree that the scar characteristics of pliability, vascularity and height should be included in a BSOM, with the majority also believing that appearance, skin breakdown, itch, surface texture, pigmentation and pain should be included. This finding closely parallels burn survivors' beliefs that redness, height/surface irregularity, itch, skin breakdown and sensory changes are important characteristics.

The body of literature on highly technological burn scar assessments is growing and these devices may hold promise as objective tools; however it is evident that burn therapists desire a BSOM that is quick, easy, non-invasive, inexpensive and portable.

As previously discussed, pliability, vascularity and height are already included in the most commonly used BSOM, the Vancouver Scar Scale (Sullivan et al., 1990). These variables have been identified by both burn therapists and burn survivors as important, suggesting that modifications to the VSS may be reasonable. Based on the findings of this study, the literature, and clinical experience, the following variables are proposed for inclusion: pliability, vascularity, height, and itch. The inclusion of pigmentation is not recommended based on the findings of several authors (Cheng et al., 2001; Deitch et al., 1983; Forbes-Duchart et al., 2007; Masters et al., 2005; Nedelec et al., 2000; Oliveira et al., 2005; & Tyack et al., 1997). It is acknowledged that skin breakdown, pain and sensory changes are important clinical variables for the burn therapist and survivor, but do not provide useful information on the maturity of

the burn scar or on scar treatment effectiveness. Further research into the reliability, validity and responsiveness of the modified VSS would be necessary.

Overall appearance appears to be too complex of a construct to include in a BSOM, and was not identified by the burn survivors in this study to be an important variable. Additionally, Powers et al. (1999) and Martin et al. (2003) have found that perceptions of burn survivors' scars and those of their therapists did not correspond. Subjective feelings of appearance are related to many factors including body image, pre-injury psychiatric status and defense mechanisms such as denial (Powers et al.).

Despite burn therapists' and burn survivors' agreement on the importance of individual scar variables, the complex nature of appearance and how a burn survivor feels about their burn scars makes it unlikely that therapists and survivors will always agree on a "good outcome". A therapist may perceive a good outcome based on a particular variable, yet the survivor may perceive a poor outcome because they value a different variable. These two perspectives may never be aligned; however, the therapist can educate the client on how each variable relates to scar maturity and may be affected by scar treatments. If the therapist takes the time to understand which variables are important to her/his client, then treatment decisions can be made using a client-centered approach, potentially leading to increased compliance. Difficulties that remain for the survivor regarding the outcome of the scar may be dealt with by offering psychosocial support programs such as support group meetings (Cooper & Burnside, 1996), Image Enhancement Program and positive communication techniques (Kammerer-Quayle, 2001).

The study suggests that using a BSOM is important despite the fact that less than half of the burn therapists reported using one. Barriers to using a BSOM included unfamiliarity with available BSOMs and that more training to use existing outcome measures is necessary. This finding suggests that more education in the area of BSOMs may be valuable. Education in the area of BSOMs could perhaps be accomplished at an OT/PT SIG at an American Burn Association meeting.

This study has helped to identify the scar properties that burn therapists and burn survivors believe should be included in a burn scar outcome measure. It is anticipated that the information collected in this study could be used as a first step in the development or modification of a much needed burn scar outcome measure to evaluate scar progress and treatment effectiveness. Perhaps the burn therapy community can universally adopt such a BSOM that incorporates scar variables that are important to the majority of burn therapists, resulting in more meaningful research reports on scar treatments.

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Appendix A

Highly Technological Scar Assessments

Assessment	Characteristic of Scar Measured	Reference
Photography	Colour	Oliveira et al., 2005
Ultrasound	Thickness	Cheng et al., 2001; Fong et al., 1997; Lau, Li-Tsang & Zheng, 2005; Van den Kerckhove et al., 2005
Elastometer	Pliability	Ahn et al., 1989
Extensometer	Pliability	Clark et al., 1987; Spann, Mileski, Atilas, Purdue & Hunt, 1996
Tonometer	Pliability	Katz et al., 1983; Lye, Edgar, Wood & Carroll, 2006.
Pneumatonometer	Pliability	Oliveira et al., 2005; Spann et al., 1996
Durameter/Durometer	Pliability	Oliveira et al., 2005 Cleary et al, 2007
Cutometer	Pliability	Fong et al., 1997; Rennekampff, Rabbels, Reinhard, Becker & Schaller, 2006); van Zuijlen et al., 2001
Laser Doppler	Vascularity	Oliveira et al., 2005; Rodrigues & Roberto, 2006
Biopsy	Thickness, vascularity, histological characteristics	Hambleton et al, 1992; Oliveira et al., 2005
Three-Dimensional Mould	Volume	Nedelec et al., 2000
Dermaspectrometer	Colour (vascularity and pigmentation)	Draaijers, Tempelman, Botman, Kreis, et al., 2004; Oliveira et al., 2005
Chromameter	Colour (vascularity and pigmentation)	Draaijers, Tempelman, Botman, Kreis et al., 2004; Van den Kerckhove et al., 2005; Oliveira et al., 2005
Spectrocolorimeter	Colour (vascularity and pigmentation)	Li-Tsang, Lau & Lui, 2003
Infra-red Camera	Temperature (for vascularity and metabolic activity)	Berry et al., 1985
Three-dimensional Imaging	Colour, texture, volume, shape, size and pliability	Powers et al., 1999; Zhang, Goldgof, Sarkar & Tsap, 2004
Oximetry	Transcutaneous oxygen tension	Berry et al., 1985
Planimetry (using photography, tracing or imaging)	Surface area	Oliveira et al., 2005

Appendix B

Internet Survey Procedures

PARTICIPANT RECRUITMENT

Study population: North American occupational therapists and physiotherapists working in burn care (burn therapists)

- For any length of time
 - In any capacity (direct patient care, teaching, research or administration)
1. Generate sample frame: email list from the Occupational/Physical Therapy Special Interest Group of the American Burn Association
 2. The entire sample frame will be used for the survey (census)

SURVEY DEVELOPMENT (see survey tool Appendix D)

1. Create first draft of survey
2. Place on SurveyMonkey.com website
3. Further revisions with thesis advisor
4. Pre-testing:
 - a. Review by colleagues knowledgeable in survey methodology and burn scar assessment
 - b. Make revisions based on the feedback
 - c. Conduct pilot study on a sample of 5 burn therapists across North America, who use a variety of computer configurations
 - d. Further revisions

IMPLEMENTATION

1. Potential respondents receive a prenotice email from the principal investigator (see Respondent Prenotice Letter).
 - a. Follow-up undeliverable emails via telephone (where possible) to confirm email and/or they are currently working in burns
 - b. Revise email list
2. One week later, potential respondents receive an email with a link to the survey at SurveyMonkey.com (see Main Respondent Letter).

3. Two days later, potential respondents receive a third email answering questions and concerns (see Respondent Clarification Letter).
4. Two weeks later, potential respondents receive a fourth email with a link to the questionnaire thanking those who responded and asking those who did not to reply (see Respondent Reminder Letter).
5. Two weeks later, potential respondents receive a fifth email with a link to the questionnaire thanking those who responded and asking those who did not to reply (see Respondent Reminder Letter).

*Email contacts will be staggered to avoid flooding the web server with respondents attempting to access the website at once

DATA ANALYSIS

1. Survey data are gathered by SurveyMonkey.com and is retrieved by way of a downloaded Excel file.
2. Data are exported into SPSS for Windows
3. Data analysis is conducted

PROCEDURES TO ENSURE ANONYMITY AND CONFIDENTIALITY

1. Respondents complete the questionnaire on the SurveyMonkey website, and are completely anonymous to the investigator.
2. The spreadsheet downloaded by the investigator from SurveyMonkey contains IP addresses, but no names. IP addresses are removed from the spreadsheet upon first cleaning, which will contain numbers only.
3. Data reporting will ensure that data is collapsed sufficiently to avoid any individuals or groups of individuals being identified.
4. Individual surveys will not be printed in hard copy. Raw data in the form of spreadsheets or tables do not in any way identify individuals. Data analysis may be utilized in the future for further inquiry and will be retained for such purposes in a secure cabinet on a data storage device.

Appendix C



UNIVERSITY
OF MANITOBA

BANNATYNE CAMPUS
Research Ethics Boards

P126-770 Bannatyne Avenue
Winnipeg, Manitoba
Canada R3E 0W3
Tel: (204) 789-3255
Fax: (204) 789-3414

APPROVAL FORM

Principal Investigator: Ms. L. Forbes Duchart
Supervisor: Dr. J. Cooper

Protocol Reference Number: H2005:264
Date of Approval: March 16, 2007
Date of Expiry: December 12, 2007

Protocol Title: "What Variables Should Be Included in A Burn Scar Outcome Measure?
Perceptions of Burn Therapists"

The following is/are approved for use:

- Annual Approval
- Research Participant Information and Consent Form, Version dated January 25, 2006

The above was approved by Dr. John Arnett, Ph.D., C. Psych., Chair, Health Research Ethics Board, Bannatyne Campus, University of Manitoba on behalf of the committee per your letter dated March 15, 2007. The Research Ethics Board is organized and operates according to Health Canada/ICH Good Clinical Practices, Tri-Council Policy Statement, and the applicable laws and regulations of Manitoba. The membership of this Research Ethics Board complies with the membership requirements for Research Ethics Boards defined in Division 5 of the *Food and Drug Regulations*.

This approval is valid until the expiry date only. A study status report must be submitted annually and must accompany your request for re-approval. Any significant changes of the protocol and informed consent form should be reported to the Chair for consideration in advance of implementation of such changes. The REB must be notified regarding discontinuation or study closure.

This approval is for the ethics of human use only. For the logistics of performing the study, approval must be sought from the relevant institution, if required.

Sincerely yours,

John Arnett, Ph.D., C. Psych.
Chair, Health Research Ethics Board
Bannatyne Campus

Please quote the above protocol reference number on all correspondence.

Inquiries should be directed to the REB Secretary Telephone: (204) 789-3255 / Fax: (204) 789-3414



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BANNATYNE CAMPUS
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APPROVAL FORM

Principal Investigator: Lisa Forbes Duchart
Supervisor: Dr. Juliette Cooper

Protocol Reference Number: H2005:264
Date of REB Meeting: December 12, 2005
Date of Approval: January 30, 2006
Date of Expiry: December 12, 2006

Protocol Title: "What Variables Should Be Included in A Burn Scar Outcome Measure? Perceptions of Burn Therapists"

The following is/are approved for use:

- Internet Survey Protocol dated 22/11/05
- Survey Draft dated 22/11/05
- Respondent Pre-notice Letter dated 22/11/05
- Focus Group Protocol dated 25/01/06
- Research Participant Information and Consent Form dated 25/01/06
- Potential Participant letter dated 25/01/06
- Focus Group Questions Route dated 08/11/05

The above was approved by Dr. Laine Torgrud, PhD, Acting Chair, Health Research Ethics Board, Bannatyne Campus, University of Manitoba on behalf of the committee per your letter dated January 22, 2006. The Research Ethics Board is organized and operates according to Health Canada/ICH Good Clinical Practices, Tri-Council Policy Statement, and the applicable laws and regulations of Manitoba. The membership of this Research Ethics Board complies with the membership requirements for Research Ethics Boards defined in Division 5 of the *Food and Drug Regulations*.

This approval is valid for one year from the date of the REB meeting at which the study was reviewed. A study status report must be submitted annually and must accompany your request for re-approval. Any significant changes of the protocol and informed consent form should be reported to the Chair for consideration in advance of implementation of such changes. The REB must be notified regarding discontinuation or study closure.

This approval is for the ethics of human use only. For the logistics of performing the study, approval should be sought from the relevant institution, if required.

Sincerely yours,


Laine Torgrud, Ph.D., C. Psych.
Acting Chair, Health Research Ethics Board
Bannatyne Campus

Please quote the above protocol reference number on all correspondence.
Inquiries should be directed to the REB Secretary Telephone: (204) 789-3255 / Fax: (204) 789-3414

Appendix D

What Variables Should be Included in a Burn Scar Outcome Measure?

Welcome

Thank-you for your decision to participate in this research study. The purpose of this study is to determine the variables of burn scar that burn therapists believe should be included in a burn scar outcome measure.

Your decision to take part in this study is voluntary. By completing this survey and answering "yes" to the question at the bottom of this page, you are consenting to participate in this study.

Your responses are anonymous and cannot be traced back to your email address. All documents will include only your assigned study number, and I will not know your identity. This study has been approved by the University of Manitoba Research Ethics Board.

This survey should take approximately 15 minutes to complete. Please maximize your screen to prevent having to scroll side to side. Please note that the survey will automatically skip some questions depending on your answers, causing some questions to appear incorrectly numbered.

Due to the possibility of therapists sharing computers, this survey has been set up to allow multiple respondents to enter the survey from the same computer. Unfortunately, this means that you will need to complete the survey in one session. I apologize for the inconvenience. If you need to leave the survey, please do so by clicking the link at the top of each page. You may start the survey again at a later date, but your previous answers will not have been saved. As well, please submit only one completed survey.

Please complete this survey within 2 weeks. Your responses are extremely valuable to me - every therapist's answer counts! Please contact me if you have any questions about this study or experience any difficulties in completing this survey.

email: lforbes-duchart@hsc.mb.ca

phone: 204-787-3164

Thank-you and best regards,

Lisa Forbes Duchart
Occupational Therapist
Clinical Specialist in Burn Care
Master of Science in Rehabilitation Candidate

* 1. I agree to participate in this research study.

- ☐ Yes
☐ No

Demographic Information

2. Are you an Occupational or Physical Therapist?

- ☐ Occupational Therapist
☐ Physical Therapist

3. What is your professional entry level qualification? eg) BSc (OT)

- ☐ Diploma
☐ Bachelors degree
☐ Entry level masters degree
☐ Entry level doctoral degree
☐ Other (please specify)

What Variables Should be Included in a Burn Scar Outcome Measure?

4. Please list any additional degrees you might have.

- ☐ Thesis-based research masters degree
- ☐ PhD
- ☐ Other (please specify)
-

5. In what province or state do you practice? (Please scroll down to the bottom of the list for Canadian Provinces)

6. How many years have you been practicing as an OT or PT?

7. How many years have you worked with burn patients/clients?

8. For your current job, please indicate how much time is spent performing each function below:

	I do not perform this task	50% or less	Greater than 50%
Direct patient care	☐	☐	☐
Research	☐	☐	☐
Program development/evaluation	☐	☐	☐
University instructor/professor	☐	☐	☐
Administration	☐	☐	☐
Other	☐	☐	☐

9. If you answered "other" above, what is the function?

10. On average, how many burn patients/clients does your center admit in a year?

11. What is the age group of the burn patients you treat?

- ☐ Adults (18+ years)
- ☐ Pediatrics (under 18 years)
- ☐ Both Pediatric and Adults
- ☐ I do not directly treat burn patients

12. Do you treat inpatient burns, outpatient burns or both?

- ☐ Inpatient burns
- ☐ Outpatient burns
- ☐ Both in and outpatient burns

Outcome Measure Use

What Variables Should be Included in a Burn Scar Outcome Measure?

13. Do you currently use a burn scar outcome measure (O.M)?

(An outcome measure is defined as a measurement tool used to document change in one or more patient characteristics over time.)

- ☐ Yes
☐ No

Yes

14. If yes, which O.M.(s) do you use?

15. If yes, are you satisfied with the O.M.(s) you use (please answer separately for each O.M.):

16. If you are not satisfied with any of the O.M.(s) you are using, what are the reasons you are not satisfied? (please answer separately for each O.M.)

17. In addition to the O.M.(s) described above, do you use any other method of assessing scars? If yes, please describe.

No

18. If no, why don't you use an outcome measure?

(Please check all that apply)

- ☐ I have not found one that is clinically practical
☐ I do not have time in my practice to use one
☐ I am not familiar with what is available
☐ I believe that I need more training to use existing O.M's
☐ I have not found one with established reliability (The degree of consistency with which an instrument or rater measures a variable)
☐ I have not found one with established validity (The degree to which an instrument measures what it is intended to measure)
☐ I don't think that using an O.M. is necessary
☐ Other (please specify)

What Variables Should be Included in a Burn Scar Outcome Measure?

19. Please feel free to expand upon your answers provided above:

20. If you are not using an O.M., what method(s) do you use to assess burn scars?

Importance of Outcome Measure Usage

Please answer the following questions WHETHER OR NOT you are using a burn scar O.M.

21. Do you think that it is important to use a burn scar O.M.?

- ☐ Yes
☐ No

Yes

22. If you answered yes, why do you think that it is important to use a burn scar O.M?

(Please check all that apply)

- ☐ To assess joint function
☐ To assess burn scar maturity
☐ To measure the effectiveness of burn scar treatment
☐ To make a decision about scar treatment (e.g. discontinuing pressure garments)
☐ So the patient can see progress
☐ Formal research
☐ Other (please specify)

Characteristics of an Outcome Measure

23. What characteristics do you think are important in a burn scar O.M.?

(Please check all that apply)

- ☐ That the O.M. is easy to use
☐ That the O.M. is quick to administer
☐ That the O.M. is portable
☐ That the O.M. is inexpensive to purchase
☐ That the O.M. is non-invasive to the patient
☐ That the O.M. has established reliability (The degree of consistency with which an instrument or rater measures a variable)
☐ That the O.M. has established validity (The degree to which an instrument measures what it is intended to measure)
☐ That the O.M. is sensitive to change
☐ Other (please specify)

Properties of Burn Scar

What Variables Should be Included in a Burn Scar Outcome Measure?

The following questions include properties of burn scar that have been described in the literature. For each property, please indicate whether or not that property should be included in a burn scar outcome measure.

Vascularity

24. Should vascularity be included in a burn scar outcome measure (vascularity is defined as the amount of redness in a scar, caused by increased blood supply)

- ☐ Yes
☐ No
☐ Maybe (please expand)

Yes

25. If yes, why? (Please check all that apply)

- ☐ I believe vascularity is an indicator of scar maturity
☐ I believe that scar management techniques affect vascularity
☐ Other (please specify)

No

26. If no, why not? (Please check all that apply)

- ☐ I do not believe vascularity is an indicator of scar maturity
☐ I do not believe that scar management techniques affect vascularity
☐ Other (please specify)

Pliability

27. Should pliability be included in a burn scar outcome measure (pliability is defined as the suppleness and elasticity of the scar)

- ☐ Yes
☐ No
☐ Maybe (please expand)

What Variables Should be Included in a Burn Scar Outcome Measure?

yes

28. If yes, why? (Please check all that apply)

☐

I believe pliability is an indicator of scar maturity

☐

I believe that scar management techniques affect pliability

☐

Other (please specify)

No

29. If no, why not? (Please check all that apply)

☐

I do not believe pliability is an indicator of scar maturity

☐

I do not believe that scar management techniques affect pliability

☐

Other (please specify)

Height

30. Should height be included in a burn scar outcome measure (height is defined as the amount of vertical elevation of the scar, measured from unburned skin to the highest point of the scar)

☐

Yes

☐

No

☐

Maybe (please expand)

yes

31. If yes, why? (Please check all that apply)

☐

I believe height is an indicator of scar maturity

☐

I believe that scar management techniques affect height

☐

Other (please specify)

no

What Variables Should be Included in a Burn Scar Outcome Measure?

32. If no, why not? (Please check all that apply)

- ☐ I do not believe height is an indicator of scar maturity
- ☐ I do not believe that scar management techniques affect height
- ☐ Other (please specify)

Length

33. Should length be included in a burn scar outcome measure (length is defined as the linear measurement of the scar)

- ☐ Yes
- ☐ No
- ☐ Maybe (please expand)

yes

34. If yes, why? (Please check all that apply)

- ☐ I believe length is an indicator of scar maturity
- ☐ I believe that scar management techniques affect length
- ☐ Other (please specify)

no

35. If no, why not? (Please check all that apply)

- ☐ I do not believe length is an indicator of scar maturity
- ☐ I do not believe that scar management techniques affect length
- ☐ Other (please specify)

Volume

What Variables Should be Included in a Burn Scar Outcome Measure?

36. Should volume be included in a burn scar outcome measure (volume is defined as the "quantity" of scar, as measured by weight of a scar impression)

- ☐ Yes
☐ No
☐ Maybe (please expand)

yes

37. If yes, why? (Please check all that apply)

- ☐ I believe volume is an indicator of scar maturity
☐ I believe that scar management techniques affect volume
☐ Other (please specify)

no

38. If no, why not? (Please check all that apply)

- ☐ I do not believe volume is an indicator of scar maturity
☐ I do not believe that scar management techniques affect volume
☐ Other (please specify)

Surface Texture

39. Should surface texture be included in a burn scar outcome measure (surface texture is defined as the extent to which surface irregularities are present)

- ☐ Yes
☐ No
☐ Maybe (please expand)

yes

What Variables Should be Included in a Burn Scar Outcome Measure?

40. If yes, why? (Please check all that apply)

- ☐ I believe surface texture is an indicator of scar maturity
- ☐ I believe that scar management techniques affect surface texture
- ☐ Other (please specify)

no

41. If no, why not? (Please check all that apply)

- ☐ I do not believe surface texture is an indicator of scar maturity
- ☐ I do not believe that scar management techniques affect surface texture
- ☐ Other (please specify)

Pigmentation

42. Should pigmentation be included in a burn scar outcome measure (pigmentation is defined as the amount of brownness in the scar, determined by the amount of melanin, bile and carotene pigments in the scar)

- ☐ Yes
- ☐ No
- ☐ Maybe (please expand)

yes

43. If yes, why? (Please check all that apply)

- ☐ I believe pigmentation is an indicator of scar maturity
- ☐ I believe that scar management techniques affect pigmentation
- ☐ Other (please specify)

no

What Variables Should be Included in a Burn Scar Outcome Measure?

44. If no, why not? (Please check all that apply)

- ☐ I do not believe pigmentation is an indicator of scar maturity
- ☐ I do not believe that scar management techniques affect pigmentation
- ☐ Other (please specify)

Temperature

45. Should temperature be included in a burn scar outcome measure (temperature is defined as the degree of hotness or coldness in the scar)

- ☐ Yes
- ☐ No
- ☐ Maybe (please expand)

yes

46. If yes, why? (Please check all that apply)

- ☐ I believe temperature is an indicator of scar maturity
- ☐ I believe that scar management techniques affect temperature
- ☐ Other (please specify)

no

47. If no, why not? (Please check all that apply)

- ☐ I do not believe temperature is an indicator of scar maturity
- ☐ I do not believe that scar management techniques affect temperature
- ☐ Other (please specify)

Transepidermal Water Loss

What Variables Should be Included in a Burn Scar Outcome Measure?

48. Should transepidermal water loss be included in a burn scar outcome measure (transepidermal water loss is defined as the level of skin hydration in the stratum corneum)

- ☐ Yes
☐ No
☐ Maybe (please expand)

yes

49. If yes, why? (Please check all that apply)

- ☐ I believe transepidermal water loss is an indicator of scar maturity
☐ I believe that scar management techniques affect transepidermal water loss
☐ Other (please specify)

no

50. If no, why not? (Please check all that apply)

- ☐ I do not believe transepidermal water loss is an indicator of scar maturity
☐ I do not believe that scar management techniques affect transepidermal water loss
☐ Other (please specify)

Transcutaneous Oxygen Tension

51. Should transcutaneous oxygen tension be included in a burn scar outcome measure (transcutaneous oxygen tension is defined as the rate of oxygen diffusion)

- ☐ Yes
☐ No
☐ Maybe (please expand)

yes

What Variables Should be Included in a Burn Scar Outcome Measure?

52. If yes, why? (Please check all that apply)

- ☐ I believe transcutaneous oxygen tension is an indicator of scar maturity
- ☐ I believe that scar management techniques affect transcutaneous oxygen tension
- ☐ Other (please specify)

no

53. If no, why not? (Please check all that apply)

- ☐ I do not believe transcutaneous oxygen tension is an indicator of scar maturity
- ☐ I do not believe that scar management techniques affect transcutaneous oxygen tension
- ☐ Other (please specify)

Skin Breakdown

54. Should skin breakdown be included in a burn scar outcome measure (skin breakdown is defined as open areas present in the scar)

- ☐ Yes
- ☐ No
- ☐ Maybe (please expand)

yes

55. If yes, why? (Please check all that apply)

- ☐ I believe skin breakdown is an indicator of scar maturity
- ☐ I believe that scar management techniques affect skin breakdown
- ☐ Other (please specify)

no

What Variables Should be Included in a Burn Scar Outcome Measure?

56. If no, why not? (Please check all that apply)

- ☐ I do not believe skin breakdown is an indicator of scar maturity
- ☐ I do not believe that scar management techniques affect skin breakdown
- ☐ Other (please specify)

Patient Pain Rating

57. Should pain rating by the patient be included in a burn scar outcome measure (pain rating by the patient is defined as the level of pain experienced subjectively by the patient)

- ☐ Yes
- ☐ No
- ☐ Maybe (please expand)

yes

58. If yes, why? (Please check all that apply)

- ☐ I believe pain rating by the patient is an indicator of scar maturity
- ☐ I believe that scar management techniques affect pain rating by the patient
- ☐ Other (please specify)

no

59. If no, why not? (Please check all that apply)

- ☐ I do not believe pain rating by the patient is an indicator of scar maturity
- ☐ I do not believe that scar management techniques affect pain rating by the patient
- ☐ Other (please specify)

Patient Itch Rating

What Variables Should be Included in a Burn Scar Outcome Measure?

60. Should itch rating by the patient be included in a burn scar outcome measure (itch rating by the patient is defined as the level of itch experienced subjectively by the patient)

- ☐ Yes
☐ No
☐ Maybe (please expand)

yes

61. If yes, why? (Please check all that apply)

- ☐ I believe itch rating by the patient is an indicator of scar maturity
☐ I believe that scar management techniques affect itch rating by the patient
☐ Other (please specify)

no

62. If no, why not? (Please check all that apply)

- ☐ I do not believe itch rating by the patient is an indicator of scar maturity
☐ I do not believe that scar management techniques affect itch rating by the patient
☐ Other (please specify)

Patient Appearance Rating

63. Should appearance rating by the patient be included in a burn scar outcome measure (appearance rating by the patient is defined as how satisfied the patient is with his or her appearance, expressed subjectively by the patient)

- ☐ Yes
☐ No
☐ Maybe (please expand)

yes

What Variables Should be Included in a Burn Scar Outcome Measure?

64. If yes, why? (Please check all that apply)

☐

I believe appearance rating by the patient is an indicator of scar maturity

☐

I believe that scar management techniques affect appearance rating by the patient

☐

Other (please specify)

no

65. If no, why not? (Please check all that apply)

☐

I do not believe appearance rating by the patient is an indicator of scar maturity

☐

I do not believe that scar management techniques affect appearance rating by the patient

☐

Other (please specify)

Importance ranking of properties

66. How important do you feel each scar property is for inclusion in a burn scar outcome measure?

Please **RANK** the scar properties according to how important you feel it is that each should be included in a burn scar outcome measure.

Your ranking will extend from 1 (most important) to 14 (least important). Please use each number only once, even if you feel several properties are of equal importance. A way to approach this question is to think about being in a busy clinic with limited time: which scar properties would be most important to measure?

Vascularity (Defined as the amount of redness in a scar, caused by increased blood supply)

Pliability (Defined as the suppleness and elasticity of the scar)

Height (Defined as amount of vertical elevation of the scar, measured from unburned skin to the highest point of the scar)

Length (Defined as the linear measurement of the scar)

What Variables Should be Included in a Burn Scar Outcome Measure?

Volume (Defined as the "quantity" of scar, as measured by weight of a scar impression)

Surface texture (Defined as the extent to which surface irregularities are present)

Pigmentation (Defined as the amount of brownness in the scar, determined by the amount of melanin, bile and carotene pigments in the scar)

Temperature (Defined as the degree of hotness or coldness in the scar)

Transepidermal water loss (defined as the level of skin hydration in the stratum corneum)

Transcutaneous Oxygen Tension (defined as the rate of oxygen diffusion)

Skin Breakdown (defined as open areas present in the scar)

Pain rating by the patient (defined as the level of pain experienced subjectively by the patient)

Itch rating by the patient (defined as the level of itch experienced subjectively by the patient)

Appearance rating by the patient (defined as how satisfied the patient is with his or her appearance, expressed subjectively by the patient)

Scar Relocation

67. Do you use a method of relocating the scar each time you reassess a burn scar? i.e. do you have a method (such as photography) of ensuring that the same area of scar is remeasured during each assessement period?

- ☐ Yes
☐ No

What Variables Should be Included in a Burn Scar Outcome Measure?

Yes

68. If yes, what method do you use?

Perceptions of Burn Survivors

The following question asks your opinion of what might be important to BURN SURVIVORS in regards to scar assessment.

69. What properties of burn scar do you think are important to BURN SURVIVORS?

- ☐ Vascularity (Defined as the amount of redness in a scar, caused by increased blood supply)
- ☐ Pliability (Defined as the suppleness and elasticity of the scar)
- ☐ Height (Defined as amount of vertical elevation of the scar, measured from unburned skin to the highest point of the scar)
- ☐ Length (Defined as the linear measurement of the scar)
- ☐ Volume (Defined as the "quantity" of scar, as measured by weight of a scar impression)
- ☐ Surface texture (Defined as the extent to which surface irregularities are present)
- ☐ Pigmentation (Defined as the amount of brownness in the scar, determined by the amount of melanin, bile and carotene pigments in the scar)
- ☐ Temperature (Defined as the degree of hotness or coldness in the scar)
- ☐ Transepidermal water loss (defined as the level of skin hydration in the stratum corneum)
- ☐ Transcutaneous Oxygen Tension (defined as the rate of oxygen diffusion)
- ☐ Skin Breakdown (defined as open areas present in the scar)
- ☐ Pain rating by the patient (defined as the level of pain experienced subjectively by the patient)
- ☐ Itch rating by the patient (defined as the level of itch experienced subjectively by the patient)
- ☐ Appearance rating by the patient (defined as how satisfied the patient is with his or her appearance, expressed subjectively by the patient)
- ☐ Other (please specify)

70. Please feel free to expand upon your answers provided above:

Additional Information

71. Is there anything else you'd like to add about scar assessment that was not asked in this survey?

What Variables Should be Included in a Burn Scar Outcome Measure?

72. Please provide any feedback you have on the burn scar properties and/or definitions.

eg) a property was missed in your opinion, you have read other definitions, etc

Thank-you

Thank-you for your valuable time.

If you would like the results of this study, please email me at: lforbes-duchart@hsc.mb.ca and I will forward a summary of the results to you when they are completed.

Appendix E

Potential Respondent Pre-notice Email

Dear Valued Colleague,

I am writing to ask you to participate in a research study to determine which variables of burn scar assessment that burn therapists believe should be included in a burn scar outcome measure. You may be aware that a clinically practical, comprehensive burn scar outcome measure is not currently available. It is anticipated that the information collected in this study could then be used as a first step in the development of a much needed burn scar outcome measure to evaluate scar progress and treatment effectiveness.

Your name was obtained from an email list generated by the Occupational/Physical Therapy Special Interest Group of the American Burn Association. Your participation in this study involves responding to a short Internet survey. In less than two weeks, you will receive an email from me that will include a link to a reputable survey website called “**SurveyMonkey**”, along with more information about the study.

Your decision to take part in this study is voluntary. However, my goal is for this survey to be as representative of North American Burn Therapists as possible, and I value the input of each of you! I also would like to ensure that my email list is as accurate as possible, and I am using this initial contact email to test my list. **If you could assist me by sending a quick reply to this email it would be greatly appreciated.** If you are not an occupational or physical therapist practicing in any aspect of burn care (clinical, research, administrative, teaching, etc), please indicate this information in a reply email so that I can remove you from the list.

Please do not hesitate to email me at ! _____ if you have any questions about this study. Thank-you in advance for helping with this important research study!

Sincerely,

Lisa Forbes Duchart
Occupational Therapist, Clinical Specialist in Burn Care
Masters of Science in Rehabilitation Candidate

Appendix F

Potential Respondent Main Survey Email

Dear Valued Colleague,

Approximately two weeks ago, you received an email asking you to participate in a research study to determine which variables of burn scar assessment that burn therapists believe should be included in a burn scar outcome measure. You may be aware that a clinically practical, comprehensive burn scar outcome measure is not currently available. One problem in developing such an outcome measure is that relevant scar characteristics are not agreed upon by researchers or clinicians. It is anticipated that the results of this study could then be used a first step in the development of a much needed burn scar outcome measure to evaluate scar progress and treatment effectiveness.

Your participation in this study involves responding to a short Internet survey on a reputable survey website called “SurveyMonkey”.

- The study should take approximately 15 minutes to complete
- Due to the possibility of therapists sharing computers, this survey has been set up to allow multiple respondents to enter the survey from the same computer. Unfortunately, this means that you will need to complete the survey in one session. I apologize for the inconvenience.
- To maximize the response rate of this survey, I will be sending 2 reminder emails. You will receive these reminder emails whether or not you have responded to the survey, as I will not know the identity of the respondents. If you have already completed the survey, please simply delete these emails.
- Please submit only one completed survey.
- Please complete this survey **within 2 weeks**; my goal is for this study to be as representative of North American Burn Therapists as possible, and I value the input of every burn therapist!
- If you wish to decline participation in this study, please click on the link below, and follow the instructions on the first page.

To begin the survey, please click on this link:

<http://www.surveymonkey.com/s.asp?u=882032293583>

***If you are unable to access the survey by clicking on this link, please cut and paste the above link into your server's address bar.**

Please email me at ' if you have any questions about this study.
If you would like the results, please email me and I will forward you a summary when they are completed. Thank-you in advance for helping with this important research study!

Sincerely,

Lisa Forbes Duchart
Occupational Therapist, Clinical Specialist in Burn Care
Masters of Science in Rehabilitation Candidate

Appendix G

Potential Respondent Clarification Email

Dear Valued Colleague,

Recently, you received an email asking you to participate in a research study to determine which variables of burn scar assessment that burn therapists believe should be included in a burn scar outcome measure.

If you have completed the survey, THANK-YOU, and please disregard this email.

I have received some emails from people who have experienced difficulties completing the survey. This message is to hopefully solve some issues and make the survey more accessible.

1. I contacted SurveyMonkey, and they have given me a different link to try that is compatible with more servers (if you were successful with the old link, don't worry, your survey has been recorded):

http://www.surveymonkey.com/s.aspx?sm=u6bZwdpmEbcM3y52swTgjQ_3d_3d

You can try and click on this link directly, or if that doesn't work, highlight the whole address, right click "copy", open your internet, then in the address bar of your internet page, right click "paste", and then hit return.

2. If you have started the survey and had to leave it incomplete for some reason, PLEASE consider logging on again. You will likely have to start the survey from the beginning.

3. If you receive a "security alert", you can choose to disregard this and complete the survey anyways (if you are comfortable with this). SurveyMonkey is a reputable and safe website.

****If you have ANY difficulties completing the survey, please contact me by email or phone, and I will be happy to assist you. I value the responses of each burn therapist, and would like the survey to be as representative of North American Burn Therapists as possible!**

Thank-you for your valuable time!

Best regards,

Lisa Forbes Duchart
Occupational Therapist, Clinical Specialist in Burn Care
Masters of Science in Rehabilitation Candidate

Appendix H

Potential Respondent Reminder Email

Dear Valued Colleague,

A few weeks ago, you received an email asking you to participate in a research study to determine which variables of burn scar assessment that burn therapists believe should be included in a burn scar outcome measure. Many of you have responded to the survey, and I **THANK-YOU**. You are receiving this email again because the survey is anonymous, and I have no way to track the identity of the respondents. **Please simply delete this email.**

***If you have not responded to the survey, please consider doing so.**

*I have been asked if I only want one survey from each facility. Since this is a survey based on professional individual opinions, **I would like each therapist to answer their own survey.**

***If you have started the survey and had to leave it incomplete** for some reason, PLEASE consider logging on again. You will have to start the survey from the beginning.

***SurveyMonkey is a reputable and safe website.** If you receive a “security alert” when you log on to the website, you can choose to disregard this and complete the survey anyways (if you are comfortable with that).

***Your participation in this study involves responding to a short Internet survey on a reputable survey website called “SurveyMonkey”.**

- The study should take approximately 15 minutes to complete
- Due to the possibility of therapists sharing computers, this survey has been set up to allow multiple respondents to enter the survey from the same computer. Unfortunately, this means that you will need to complete the survey in one session. I apologize for the inconvenience.
- Please submit only one completed survey.
- Please complete this survey **within 2 weeks**; my goal is for this study to be as representative of North American Burn Therapists as possible, and I value the input of every burn therapist!
- If you wish to decline participation in this study, please click on the link below, and follow the instructions on the first page.

To begin the survey, please click on this link:

http://www.surveymonkey.com/s.aspx?sm=u6bZwdpmEbcM3y52swTgjQ_3d_3d

*You can try and click on this link directly, or if that doesn't work, highlight the whole address, right click “copy”, open your internet, then in the address bar of your internet page, right click “paste”, and then hit return.

***If you have ANY difficulties completing the survey**, please contact me by email _____ or phone _____ and I will be happy to assist you. If you would like the results, please email me and I will forward you a summary when they are completed. Thank-you in advance for helping with this important research study!

Sincerely,

Lisa Forbes Duchart
Occupational Therapist, Clinical Specialist in Burn Care
Masters of Science in Rehabilitation Candidate

Appendix I

Focus Group Procedures

PARTICIPANT RECRUITMENT

Study population: A purposive sample of adult burn survivors

- Current or former clients of the Occupational Therapy burn program at the Health Sciences Centre, excluding clients on active treatment with the principal investigator
- Differences regarding sex, age when burned, location and percentage of burn, and compliance with scar treatments

Send recruitment letter to potential participants (see Potential Participant Letter Appendix J)

QUESTIONING ROUTE DEVELOPMENT

1. Create first draft of questioning route (see Questioning Route Appendix L).
2. Further revisions with thesis advisor
3. Pre-testing:
 - a. Review by burn client
 - b. Further modifications

IMPLEMENTATION

1. Send letter to participants who have agreed to participate approximately one week before the focus group, providing details about the session (see Participant Confirmation Letter Appendix M).
2. Phone participants the day before the focus group to confirm attendance
3. Prepare for focus group
 - b. Arrange room (table and chairs, arranged in a circle)
 - c. Set-up audio-recording equipment
 - d. Set out refreshments
4. Carry out focus group
 - a. Assistant moderator obtains informed consent (see Research Participant Information and Consent Form Appendix K)

- b. The principal investigator serves as moderator
 - i. Introductions, purpose of group
 - ii. Definitions of terms used during focus group
 - iii. Rules (confidentiality, one person speaking at a time)
 - iv. Conclusion, including opportunity to add topics not addressed and invitation for results if desired
- c. Assistant moderator operates audio-recorder and takes detailed written notes, including observations of body language.
- d. Make field notes immediately following the session
- e. All data is kept strictly anonymous and confidential

DATA ANALYSIS

1. Transcribe verbatim the audio-recording of focus group session, using only participant initial on transcript
2. Develop codes inductively, i.e. gradually as they emerge from the data
3. Keep a key of all codes and their explanations and a logbook to track responses
4. Identify and interpret themes from the transcribed material.
5. Bring findings back to the participants to check accuracy of results (member checking)
6. Destroy all identifying information as soon as is practical i.e. upon completion of data analysis (no longer than 1 year post focus group implementation)

Appendix J



Health Sciences Centre
Winnipeg

General Hospital
820 Sherbrook Street
Winnipeg, MB R3A 1R9

Ph # (204) 787-3164
Fax # (204) 787-1101

OCCUPATIONAL THERAPY - Burns/Plastics

September 26, 2007,

Dear

We are writing to ask you to consider participating in a research study being carried out by Lisa Forbes Duchart, an Occupational Therapist working in Burn Care. The purpose of the study is to explore how adult burn survivors feel or felt about their burn scars and the way that scar treatment decisions were made. Your name was obtained from lists kept in Occupational Therapy of patients treated in our department. Information is also being gathered from a survey of burn therapists. The researcher's hope is that the information gained in this study will be used to develop a tool that will help us better monitor and make decisions about burn scars.

The study involves participation in a focus group, lasting approximately 1½ hours. The focus group will be tape-recorded and brief notes will be taken to make sure what you say is recorded accurately. You will be asked questions regarding how you feel or felt about your burn scars and the way that scar treatment decisions were made. If necessary, you may also be contacted by phone to clarify or check information you provided. The researcher will reimburse parking costs while you are at the focus group.

Information gathered in this study will be kept strictly confidential. It may be published or presented in public forums; however your name and other identifying information will not be used or revealed. All documents will include only your assigned study number. Results of this study will be made available to you if you want.

Your decision to take part in this study is voluntary. You may withdraw from the study at any time. Your decision not to participate or to withdraw from the study will not affect your care at this center.

Please call **Lisa at** _____ (collect if out of town) if you would like more information about participating in this study. We are looking forward to hearing from you!

Sincerely,

The Occupational Therapy Burn Program

Appendix K



Health Sciences Centre
Winnipeg

General Hospital
820 Sherbrook Street
Winnipeg, MB R3A 1R9

Ph # (204) 787-3164

Fax # (204) 787-1101

OCCUPATIONAL THERAPY - Burns/Plastics

RESEARCH PARTICIPANT INFORMATION AND CONSENT FORM

Title of Study: What Variables Should Be Included in A Burn Scar Outcome Measure?
Perceptions of Burn Survivors.

Principal Investigator: Lisa Forbes Duchart

Co-Investigator: Dr. Juliette Cooper
R112-771 McDermot Ave.
Winnipeg, MB R3E OT6
204-789-3371

Sponsor: N/A

You are being asked to participate in a research study. Please take your time to review this consent form and discuss any questions you may have with the study staff. You may take your time to make your decision about participating in this study and you may discuss it with your friends, family or your doctor before you make your decision. This consent form may contain words that you do not understand. Please ask the study staff to explain any words or information that you do not clearly understand.

Purpose of Study

This research study is being conducted to explore how adult burn survivors feel or felt about their burn scars and the way that scar treatment decisions were made. It is part of a larger study in determining what should be looked at when evaluating burn scars.

It is estimated that 6 to 8 participants will participate in this phase of the study.

Study procedures

For this study, you will participate in one focus group consisting of 6 to 8 burn survivors. The focus group will take between 1 to 2 hours, and will be moderated by an occupational therapist experienced in treating burn patients. The focus group discussion will be tape recorded to ensure what you say is recorded accurately. An assistant moderator will be present to operate the recording equipment and take notes. You will be asked questions

regarding your experiences about having a burn injury and especially how you feel about different aspects of your scars (the colour, texture, etc). The interview will take place in a private room at the University of Manitoba, Bannatyne Campus.

Participation in only one focus group is required, but you may be contacted by phone to clarify or check information you provided. Participation in the study will continue until all the interviews are completed, and the information is analyzed (approximately 6 months).

You can stop participating at any time. However, if you decide to stop participating in the study, we encourage you to talk to the study staff first. There are no consequences if you stop participating in this study. Current or future therapy or involvement with Burn Survivor Programs will not be affected by your decision to stop participating.

Results of this study will be made available to you if desired.

Risks and Discomforts

There are no physical risks involved with participating in this study. You may experience some memories or feelings related to the burn injury or dealing with scars. Should this occur, please speak with study staff and a list of counselling services will be provided to you.

Benefits

There may or may not be direct benefit to you from participating in this study. We hope the information learned in this study will benefit other burn survivors in the future.

You will receive no payment for taking part in this study. Reimbursement of parking will be covered for you.

Costs

All the procedures, which will be performed as part of this study, are provided at no cost to you.

Confidentiality

Absolute confidentiality cannot be guaranteed in a focus group, however, we ask that all participants keep all that is said in the focus group session confidential and not repeat anything outside of the focus group.

Information gathered in this research study may be published or presented in public forums; however your name and other identifying information will not be used or revealed. Despite efforts to keep your personal information confidential, absolute confidentiality cannot be guaranteed. Your personal information may be disclosed if required by law. All study-related documents will bear only your assigned study number and/or initials.

Data will be entered into a computer to be analyzed, however, your name will not be attached to the data.

The University of Manitoba Health Research Ethics Board may review records related to the study for quality assurance purposes.

All records will be kept in a locked secure area and only those persons identified will have access to these records. If any of your medical/research records need to be copied to any of the above, your name and all identifying information will be removed. No information revealing any personal information such as your name, address or telephone number will leave the University of Manitoba.

Voluntary Participation/Withdrawal from the Study

Your decision to take part in this study is voluntary. You may refuse to participate or you may withdraw from the study at any time. Your decision not to participate or to withdraw from the study will not affect your care at this centre. If the study staff feel that it is in your best interest to withdraw you from the study, they will remove you without your consent.

We will tell you about any new information that may affect your health, welfare, or willingness to stay in this study.

You are not waiving any of your legal rights by signing this consent form nor releasing the investigator(s) or the sponsor(s) from their legal and professional responsibilities.

Questions

You are free to ask any questions that you may have about your treatment and your rights as a research participant. If any questions come up during or after the study or if you have a research-related injury, contact Lisa Forbes Duchart (787-3164).

For questions about your rights as a research participant, you may contact The University of Manitoba, Bannatyne Campus Research Ethics Board Office at (204) 789-3389.

Do not sign this consent form unless you have had a chance to ask questions and have received satisfactory answers to all of your questions.

Statement of Consent

I have read this consent form. I have had the opportunity to discuss this research study with Lisa Forbes Duchart. I have had my questions answered by her in language I understand. The risks and benefits have been explained to me. I believe that I have not been unduly influenced by any study team member to participate in the research study by any statements or implied statements. Any relationship I may have with the study team has not affected my decision to participate. I understand that I will be given a copy of this consent form after signing it. I understand that my participation in this study is voluntary and that I may choose to withdraw at any time. I freely agree to participate in this research study.

I understand that information regarding my personal identity will be kept confidential, but that confidentiality is not guaranteed. I authorize the

inspection of any of my records that relate to this study by The University of Manitoba Research Ethics Board for quality assurance purposes.

By signing this consent form, I have not waived any of the legal rights that I have as a participant in a research study.

I agree to be contacted for future follow-up in relation to this study,
Yes ____ No ____

Participant signature _____ **Date** _____
(day/month/year)

Participant printed name: _____

I, the undersigned, have fully explained the relevant details of this research study to the participant named above and believe that the participant has understood and has knowingly given their consent

Printed Name: _____ **Date** _____
(day/month/year)

Signature: _____

Role in the study: _____

Appendix L

What Variables Should Be Included in A Burn Scar Outcome Measure? Perceptions of Burn Survivors

Focus Group Questioning Route

1. How important are the following scar characteristics to you?
*Discuss individually and include definitions (see next page), then rate importance
 - a. Colour
 - b. Height
 - c. Length
 - d. Surface irregularity
 - e. Suppleness
 - f. Skin breakdown
 - g. Pain
 - h. Itchiness
 - i. Overall appearance
2. What scar characteristics are most important to you for the final outcome of your scar?
3. Were there any characteristics that you believe received too little attention? Too much attention?
4. Do you think that your opinion was taken into consideration when your scars were evaluated?
5. Was it important to you that your therapist involved you in decisions about whether your scar was mature or not? (include definition of scar maturity)
6. Was it important to you that your therapist involved you in decisions about whether or not to stop scar treatments such as pressure garments?
7. Do you think that your level of satisfaction with the outcome of your scars corresponded to that of your occupational therapist and the other members of the burn team?
8. What factors were important to you when your therapist was evaluating your scar (comfort/discomfort caused by the assessment, length of time to complete the assessment, privacy)?
9. Do you believe that your scars were adequately/accurately monitored? If so was this information then used to support treatment decisions?

10. Overall, what was most important to you when your therapist was making decisions about your scar treatment?

11. Have we missed anything in this discussion?

Definition of terms:

Scar characteristics (compared to nearby, unburned skin):

Colour – amount of redness and brownness present in the scar

Height – amount of vertical elevation of the scar

Length – linear measurement of the scar

Surface irregularity – the extent to which surface irregularities are present in the scar

Suppleness – how the scar feels i.e. soft, firm, tight

Skin breakdown – open areas present in the scar

Pain – the level of pain experienced by the burn survivor

Itchiness – the level of itch experienced by the burn survivor

Overall appearance – The burn survivor's satisfaction with overall appearance

Scar maturity – the point at which the scar no longer changes in colour, texture and height

Appendix M



Health Sciences Centre
Winnipeg

General Hospital
820 Sherbrook Street
Winnipeg, MB R3A 1R9

Ph # (204) 787-3164
Fax # (204) 787-1101

OCCUPATIONAL THERAPY - Burns/Plastics

November 26, 2007,

Dear

I am writing to confirm your attendance in a research study to explore how adult burn survivors feel or felt about their burn scars and the way that scar treatment decisions were made. Information was also gathered from a survey of burn therapists. My hope is that the information gained in this study will be used to develop a tool that will help us better monitor and make decisions about burn scars.

The study involves participation in a focus group, lasting approximately 2 hours. The focus group will be tape-recorded and brief notes will be taken to make sure what you say is recorded accurately. You will be asked questions regarding how you feel or felt about your burn scars and the way that scar treatment decisions were made.

The focus group will be held **Thursday, December 6, 2007 at 6:30 p.m. in the physiotherapy conference room GG 549** (This is the same location where the burn support group meetings have been held recently. It is just down the hall from the burn unit – see map enclosed). Please submit your parking receipt to me and I will reimburse your parking costs.

Information gathered in this study will be kept strictly confidential. It may be published or presented in public forums; however your name and other identifying information will not be used or revealed. All documents will include only your assigned study number. Results of this study will be made available to you if you want.

Your decision to take part in this study is voluntary. You may withdraw from the study at any time. Your decision not to participate or to withdraw from the study will not affect your care at this center.

Please call **Lisa at** if you have any questions about this study. I am looking forward to seeing you and appreciate your help!

Sincerely,

Lisa Forbes Duchart
Occupational Therapist

Appendix N

Focus Group Participant Demographics

Name: _____

How many years ago were you burned? _____ years

Percentage of body area burned: _____ %

Is your burn visible to others? Yes _____ No _____

On average, how much did you/do you wear your pressure garments in a 24 hour day? (Please circle one choice below)

Less than 8 hours/day

9 – 16 hours/day

17 – 24 hours/day

Appendix O

Scar Property Definitions

Colour – amount of redness and brownness present in the scar

Height – amount of vertical elevation of the scar

Length – linear measurement of the scar

Surface irregularity – the extent to which surface irregularities are present in the scar

Suppleness – how the scar feels i.e. soft, firm, tight

Skin breakdown – open areas present in the scar

Pain – the level of pain experienced by the burn survivor

Itchiness – the level of itch experienced by the burn survivor

Overall appearance – The burn survivor's satisfaction with overall appearance

Scar maturity – the point at which the scar no longer changes in colour, texture and height

Appendix P

Scar Property Rating Form**Colour**

Not important 1-----2-----3-----4-----5 Very important

Height

Not important 1-----2-----3-----4-----5 Very important

Length

Not important 1-----2-----3-----4-----5 Very important

Surface irregularity

Not important 1-----2-----3-----4-----5 Very important

Suppleness

Not important 1-----2-----3-----4-----5 Very important

Skin breakdown

Not important 1-----2-----3-----4-----5 Very important

Pain

Not important 1-----2-----3-----4-----5 Very important

Itchiness

Not important 1-----2-----3-----4-----5 Very important

Overall appearance

Not important 1-----2-----3-----4-----5 Very important

Appendix Q



Health Sciences Centre
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820 Sherbrook Street
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Ph # (204) 787-3164
Fax # (204) 787-1101

OCCUPATIONAL THERAPY - Burns/Plastics

December 17, 2007,

Dear

Thank-you so much for your recent participation in my research study to explore how adult burn survivors feel or felt about their burn scars and the way that scar treatment decisions were made. As explained during the focus group, I want to make sure that I have captured your thoughts and beliefs correctly. This letter includes a summary of the focus group results. Please read it and let me know if I have interpreted the groups' statements correctly. If I do not hear from you by January 11, 2008, I will assume that you agree with the summary. If you would like to clarify or comment on anything to do with this study, please contact me at the number below.

Again, information gathered in this study will be kept strictly confidential. It may be published or presented in public forums; however your name and other identifying information will not be used or revealed. All documents will include only your assigned study number.

Please call **Lisa at** if you have any questions about this study. I am looking forward to seeing you and appreciate your help!

Sincerely,

Lisa Forbes Duchart
Occupational Therapist

Focus Group Results

Several major themes emerged from the focus group discussion and are described below:

The Most Important Scar Characteristics are the Ones Most Visible

Participants all agreed that scar characteristics that were most visible and obvious to the public were the most important to them. Colour, specifically redness, was the scar characteristic that participants felt the strongest about. They talked about people noticing the dark red or purple colour immediately, and feeling uncomfortable with their appearance. Participants felt relieved as time passed and the colour started to fade. One participant related:

P1: "The redness for me in my first year after my injury was devastating, because it was so visible in the summer and I wanted to wear shorts and the redness was more of a thing for me but as time went on it got less and less so it was less of a thing for me."

Despite the scar definitions provided, participants seemed to use the terms height and surface irregularity interchangeably, and everyone agreed that these characteristics were very important to them as well. One participant shared her feelings about the height of her scar:

P2: "At the beginning before I had pressure garments or anything like that I always thought that my hand looked like a brain and that it really bothered me a lot to see it for the first time, like after they took the bandages off and stuff like that. It was really hard to deal with..."

Many shared feelings of wishing their skin was smooth and regular, and felt that the higher the scar was off of their skin, the more noticeable it was, as illustrated by this quote:

P1: "Initially it was important only because um, I wanted so much for it to um, feel normal, feel like the way it's supposed to, the way the rest of my skin felt."

Burn Scar Itch

Participants all agreed that burn scar itch was one of the biggest challenges in their recovery, and was an important scar characteristic. Most participants described their experiences with great emotion, as seen in these quotes:

P2: "I tried practically everything for my itching, it was so bad. I mean, especially when I'd get out of the bathroom, the shower, I'd be running around my mom's house, screaming. You know, not being able to do anything"

about it, just going absolutely crazy. Just all of a sudden, all my legs, my whole body, it was just...so she would just rub it, and oh my God, that was brutal."

P3: "If I stood up, it felt like my calves were going to explode, like rubbing you said, I know that one, rubbing with the towel, I wish I had four or five arms to kind of soothe it...Soon, you're sliding around the carpet. Literally, it was severe. Like I would take that for, probably out of it all, the most, for me, it was brutal like I said...Out of all of it, the biggest one for me was the itch."

Skin Quality

Participants raised the issue of skin quality at many points during the focus group discussion. They shared the frustration of small areas on their body taking months to heal, as described by this participant:

P4: "(The open areas) kind of scared me. I didn't like it. I had two spots here and under my armpits. My armpit just healed up about two months ago. That's a good thing...I was getting a little sick of it cause it's a terrible place to get the dressing...no dressings held up there and uh you know so I'm glad it's healing and I hope it stays that way."

Participants all shared the experiences of scarred skin being more prone to blisters and skin breakdown, as this participant noted:

P5: "You don't even notice that you get the scratch and then all of a sudden you look and the scar's bleeding and it's really weird."

They all described having to be more cautious and taking extra special care of their skin. One participant discussed his strategy:

P3: "So this skin I've gotta guard more. I actually have it mapped out on my body when I am in an area where I have to use this hand I just know that psychologically from 'oh that bled pretty easy.'"

Sensory Changes to the Burn Scar

Participants all described some type of sensory changes to their burn scars. Some experienced hypersensitivity as related by these participants:

P6: "It's interesting because... I had for about a year, year and a half, nerve pain, the scarring was more sensitive not, as, doesn't hurt as much as at the time of surgery but I'd feel the nerves start pulling and hurting and burning"

P5: "Like even now when I wear tight jeans like right now I know exactly, like I can feel it, like cause I had my donor site on my thigh. That took a really long time to heal and just like feel normal. Even now it still, I dunno, I think it's painful maybe I'm a wimp, but it was stabbing, tingly like pins, needles. It's been a long time, it's been like I don't even know, five years maybe. That's kind of wierd."

Numbness to some of their scarred areas was a common experience as well, and is summed up by participant, "4" who stated that on *"either side of that scar, there's nothing."*

Respectful Treatment During Burn Scar Assessment

Participants raised many issues with the common theme that they valued respectful treatment during burn scar assessment. Participants felt the following factors were important: privacy, that their opinion was taken into account during scar treatment decisions, that therapists answered their questions, and spent appropriate amounts of time in the session, as noted by these participants:

P4: "Patient to therapist is excellent compared to doctor to patient. You get 15 minutes with your doctor. It's nice that the therapists have time to spend with you for different stuff you need."

P6: "I found it very comforting, there were no issues in terms of privacy, problems like that, it was very good, there's no question about that. The therapists are the people obviously who are involved in most, 99%, of your healing process. Something catastrophic - you're relying on that person."