

**An Exploration of Burn Survivors' Experiences of Pressure  
Garment Therapy at  
Tygerberg Academic Hospital**

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## **Abstract**

**Introduction:** Pressure garment therapy (PGT) forms a significant part of burn rehabilitation. It is most commonly used to treat hypertrophic scars but the benefits of this intervention remain questionable. Adherence with this intervention also presents several challenges for the patient and clinician.

**Aim of the study:** The aim of this study was to explore the experiences of adult burn survivors who participated in PGT during 2006 - 2010 at Tygerberg Academic Hospital (TAH).

**Methods:** A phenomenological study design using qualitative research methods was implemented. Semi-structured interviews were conducted with eight burn survivors. The participants were chosen using purposive sampling methods. Thematic analysis was conducted using pre-determined themes from the literature as a starting point. Data was coded and categorised according to themes that emerged during data analysis.

**Results:** The findings of the study revealed that several factors impacted on the participant's experiences of pressure garment therapy. Factors related to the consequences of the burn injury included the participant's loss of function, loss of participation, loss of self-confidence, financial dependence, emotional impact and impact on relationships. Factors related to pressure garment usage included physical effects, socio-emotional effects and the wearing schedule (which included maintenance and effort, adherence and time). Factors that contributed to adherence included support, inner strengths, knowledge, seeing a difference, seeing others, enablers to accessing the service and satisfaction with the service. Factors that contributed to non-adherence included lack of support, emotional turmoil and barriers to accessing the service. Participants made recommendations to improve the overall burn service at TAH.

**Conclusion:** The findings of the study show that participants experienced PGT as a beneficial intervention. There were several complex factors that impacted the participants' experiences of PGT. The most significant benefit as described by the participants was the improvements noted in scar appearance, whilst the main barrier was that the garments were cosmetically displeasing due to their colour.

**Recommendations:** To adopt a person-centred approach to burn management, recommendations made include improvements needed within the occupational therapy service such as changing the colour of the garment material, the standardisation of the PGT treatment protocols and improving staff attitudes. Other recommendations include establishing a network for counselling services as well as an information pack for patients admitted to the burns unit.

**Keywords:**

Adherence, burn survivor, experiences, hypertrophic scars, participation, person-centred approach, pressure garment therapy, pressure garments

## Opsomming

Drukklereterapie vorm 'n belangrike deel van die rehabilitasie van brandwonde. Dit is die mees algemene behandeling vir hipertrofiese littekens, maar daar bestaan steeds twyfel aangaande die voordele van hierdie intervensie. Daar bestaan heelwat uitdagings, vir beide die terapeut en die pasiënt, om die behandelingsriglyne na te volg.

**Doel van die studie:** Die doel van hierdie studie was om die ervarings van volwasse brandwond oorlewendes wat vanaf 2006 tot 2010 drukklereterapie by Tygerberg Akademiese Hospitaal ontvang het, te ondersoek.

**Metode:** 'n Fenomenologiese studie ontwerp is geïmplimenteer deur middel van kwalitatiewe navorsingsmetodes. Semi-gestruktureerde onderhoude is met agt brandwond oorlewendes gevoer. Die deelnemers is gekies deur doelgerigte steekproefneming metodes. Tematiese analise is uitgevoer met behulp van voorafbepaalde temas wat as beginpunt uit die literatuur geneem is. Data is gekodeer en gekategoriseer volgens temas wat na vore gekom het tydens data analise.

**Resultate:** Die bevindings van die studie het aangedui dat verskeie faktore die deelnemers se ervarings van drukklereterapie beïnvloed het. Faktore wat met die gevolge van die brand beserings verband hou het die volgende ingesluit: verlies aan funksie, verlies aan deelname, verlies aan selfvertroue, finansiële afhanklikheid, emosionele impak en die impak op verhoudings. Die volgende faktore het verband gehou met die gebruik van drukkler: fisiese faktore, sosio-emosionele faktore en die dra skedule (dit sluit in onderhoud van die drukkler, moeite, volg van die dra skedule en tyd). Faktore wat bygedra het tot die navolging van die skedule het die volgende ingesluit: ondersteuning, innerlike krag, kennis, die sien van 'n verskil, sien van ander, toegang tot die diens en tevredenheid met die diens. Die volgende faktore het bygedra tot nie-navolging: gebrek aan ondersteuning, emosionele verwarring en hindernisse tot toegang tot die diens. Deelnemers het aanbevelings gemaak om die brandwonde diens te verbeter.

**Slot:** Die bevindings van die studie dui daarop dat die deelnemers drukklereterapie as 'n voordelige intervensie ervaar het. Daar was verskeie komplekse faktore wat 'n

impak op drukkereterapie gehad het. Die grootste voordeel, soos beskryf deur deelnemers, was die verbetering in litteken voorkoms; terwyl die hoof hindernis was dat die drukklere kosmeties onaanvaarbaar was as gevolg van die kleur.

**Aanbevelings:** Die volgende aanbevelings is gemaak om 'n persoon-gesentreerde benadering tot brandwond behandeling te verseker: verbeterings benodig binne die arbeidsterapie diens, soos die verandering van die kleur van drukklere materiaal, die standaardisering van drukkereterapie protokolle en die verbetering van personeel houdings. Ander aanbevelings sluit in 'n netwerk vir beradingsdienste, sowel as 'n inligtingspakket vir pasiente wat tot die brandwondeenheid toegelaat word.

**Sleutelwoorde:**

Brandwond oorlewende, deelname, drukklere, drukkereterapie, ervarings, hipertrofiese littekens, navolging, persoon-gesentreerde benadering

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## Definition of Key Concepts

**Adherence:** “The extent to which a person’s behaviour – taking medication, following a diet, and/ or executing lifestyle changes, corresponds with agreed recommendations from a health care provider” (WHO, 2003, pg.3). Adherence differs from compliance in that adherence requires the patient’s agreement to the recommendations. However the two terms often get used interchangeably.

**Burn survivor:** A burn survivor is a person who sustained burn injuries and survived the ordeal. Preferred terminology uses this concept over burn victim.

**Experience:** “The observing, encountering or undergoing of things, generally as they occur in the course of time” (Dictionary.com).

**Hypertrophic scars:** Hypertrophic scars can be described as raised, rigid and red with maturation occurring within the boundaries of the wound (Demling & DeSanti, 2001a; Harte, Gordon, Shaw, Stinson & Porter-Armstrong, 2009). Scars result in significant functional and psychological impairments, and are commonly associated with pain (Téot, 2005).

**Participation:** Defined as the involvement in any life situation. Any difficulties experienced in the involvement of life situations are referred to as participation restrictions (WHO, 2002, pg. 10).

**Person-centred approach:** An approach that incorporates the person's whole life (not just illness), involves prevention, includes the broader health community (not only formal healthcare workers), addresses human behaviour, and understands that improving health incorporates various factors (e.g. financial, housing, education, food) (Christopherson, 2010).

**Pressure garment therapy:** Pressure garment therapy is the most commonly used therapy in the prevention and treatment of hypertrophic scars (Macintyre & Baird, 2004; Anzarut, Singh, Tredget, Rowe & Olson, 2005) and is often used by occupational therapists during scar management (Harte *et al.*, 2009).

**Pressure garments:** Pressure garments are elastic garments manufactured into items of clothing such as gloves, pants or masks which are used to apply pressure to

areas of hypertrophic scars, almost like a second skin. It can be commercially bought, such as Jobst or Second Skin (Williams, Knapp & Wallen, 1998), or custom-made as is the case at Tygerberg Hospital.

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## List of Acronyms

<b>ADLs</b>	Activities of daily living
<b>DG</b>	Disability grant
<b>HAPA</b>	Health action process approach model
<b>ICF</b>	International classification of function
<b>ICU</b>	Intensive care unit
<b>MDT</b>	Multi-disciplinary team
<b>OT</b>	Occupational therapy or occupational therapist
<b>OTA</b>	Occupational therapy assistant
<b>PCE</b>	Patient-centred experience
<b>PEO</b>	Person-environment-occupation model
<b>PG</b>	Pressure garment
<b>PGT</b>	Pressure garment therapy
<b>RCT</b>	Randomised controlled trial
<b>ROM</b>	Range of movement
<b>SAHRC</b>	South African Human Rights Commission
<b>TAH</b>	Tygerberg Academic Hospital
<b>TBSA</b>	Total body surface area
<b>VSS</b>	Vancouver scar assessment scale
<b>WFOT</b>	World Federation of Occupational Therapy
<b>WHO</b>	World Health Organization

## Chapter 1 Introduction

### 1.1 Introduction

According to the World Health Organization (WHO), an estimated 195 000 deaths annually are caused by burns globally, with the highest incidence occurring in low- and middle-income countries (WHO, 2012). Stander & Wallis (2011, pg. 32) estimate that 3, 2% of South Africa's population will be burnt annually. According to the National Injury Mortality Surveillance System report of 2008, burns-related deaths accounted for 19% of the 31 177 non-natural deaths in South Africa. In addition to mortality caused by burns, burn injuries are one of the most painful injuries and are associated with serious long-term physical and psychological morbidity (Park, Choi, Jang & Oh, 2008). Survivors are left with impairments such as disfigurements which are often associated with rejection and stigma which might lead them to experience disability if one considers the International classification of function (ICF) definition of disability (WHO, 2002).

However, a lack of reliable national statistics has largely hidden the impact of burn injuries on health, financial and other resources (Norman, Matzopoulos, Groenewald & Bradshaw, 2007; Stander & Wallis, 2011). In South Africa an estimated US\$26 million is spent annually on burns sustained from paraffin stove incidents. Factors that contribute to indirect costs include rehabilitation (prolonged care for deformities), lost income, emotional trauma and commitment of family resources (WHO, 2012).

Tygerberg Academic Hospital (TAH) hosts the specialist adult burns unit in the Western Cape Province. Burn rehabilitation therefore forms a considerable part of the occupational therapy intervention at the hospital. It is an intensive and dynamic process, involving a multi-disciplinary approach that begins from the time of injury, and includes the acute, in-patient hospital phase, the out-patient phase and reintegration of the individual into the community. Occupational therapy (OT) treatment modalities are employed during the acute, post-operative and rehabilitative phases of burn rehabilitation at TAH. Modalities include positioning, splinting, compression bandaging and scar management; pressure garment therapy

comprises a large component of scar management. This study will focus on pressure garment therapy (PGT).

PGT has been the mainstay and most commonly used therapy in the prevention and treatment of hypertrophic scars (Macintyre & Baird, 2004; Anzarut, Olson, Singh, Rowe & Tredget, 2009) and is often used by occupational therapists (Harte *et al.*, 2009) during scar management. One of the main factors that influence the success of PGT is patient adherence (Ripper, Renneberg, Landmann, Weigel & Germann, 2009) which is influenced by garment comfort and cosmesis, effort in wearing and caring for the garment, pain and other psychosocial factors.

Studies have not been conclusive in their findings regarding the efficacy of pressure garments (Anzarut *et al.* 2009) and only a small number of studies have evaluated the experience of burn survivors through qualitative research (Tengvall, Wickman & Wengström, 2010).

## **1.2 Motivation and Significance of Study**

PGT is used as the basic treatment modality for scar management at TAH. It is an expensive and time consuming treatment modality, is labour intensive and relies on relative skill and experience of staff to produce optimal outcomes. An average of 600 metres of pressure garment (PG) material is bought annually, at a cost of R225 per meter. This amounts to approximately R135 000/year and represents a significant part of the TAH occupational therapy budget.

However, consultants of the burns unit and plastic surgery departments at TAH highly recommend this treatment modality. My own experience of PGT also favours using it as long as it is used in conjunction with other treatment modalities. Currently, the subjective benefits of PGT, as perceived by health professionals, outweigh the non-use of PGT.

Yet, as described in the literature review, its effectiveness is scientifically not well established. Most systematic reviews on the subject are quantitative studies and had shown that “pressure garments are not definitive in altering global scar scores but do

appear to improve scar height, although the difference is small and of questionable clinical importance” (Anzarut *et al.*, 2009, pg. 78).

I also want to point out the ethical dilemmas which arise during randomised controlled trials (RCTs), such as deciding which patient will get a PG only and no other alternate treatment, despite knowing that the skin must be moisturized and therefore scar massage is indicated. Thus, the feasibility of conducting a quantitative study to determine the physical effects of PGs on hypertrophic scarring is poor. Besides the ethical issues associated with RCTs mentioned, not having the proper tools to evaluate various scar characteristics adds to the challenge. The Vancouver Scar Assessment Scale (VSS), the most frequently used tool to assess scar characteristics, remains a subjective, inconsistent and unreliable evaluation tool (Draaijers, Tempelman, Botman, Tuinebreijer, Middelkoop, Kreis & van Zuilen, 2004).

Considering these concerns and, with the general trend to implement evidence-based practice, I have to interrogate the clinical significance of PGT and the benefits of this intervention. In addition, to providing an effective, efficient and enhanced pressure garment service, patients’ perceptions on whether PGT is beneficial to them must be gauged. Only a limited number of studies have evaluated the experience of PGT by burn survivors using non-quantitative methods, which is essential in generating a better understanding of how burn survivors themselves experience various interventions, including PGT, and life after injury (Tengvall *et al.*, 2010).

This highlights an opportunity to conduct qualitative research within burn rehabilitation to determine why patients wear or do not wear their garments. This study will attempt to understand the clients’ perception of the intervention and how they experienced it, to determine if PGT, in the view of the patient, is a valuable OT intervention at TAH.

With the information gained, the PG service can be evaluated and changes recommended and implemented accordingly. Participants’ active participation in the study will help inform management of future burn survivors who participate in PGT at TAH. This in turn should enhance overall clinical OT service delivery at TAH. Also,

the information gained could possibly be useful with regard to clients using pressure garments for other diagnoses.

The research will add much needed qualitative information to overall burn management and burn research, which according to Tengvall *et al.*, (2010) has been lacking. This information will be used to gain a better understanding of PGT from the perspective of the burn survivor thereby enhancing a person-centred approach, and may also be beneficial to OT colleagues in other hospitals providing similar services. They may also be able to implement changes, relevant to their setting, and enhance their clinical service.

### **1.3 Study Problem**

I have chosen to use a clinical intervention that has limited scientific basis and relies on my own and other's experience in the field of burn management. However, it remains to be answered whether PGT is perceived as beneficial or not by the patients who use it, and if it can be considered as a valuable OT intervention.

### **1.4 Study Aims and Objectives**

The aim of this study was to explore the experiences of adult burn survivors who participated in PGT during 2006-2010 at TAH.

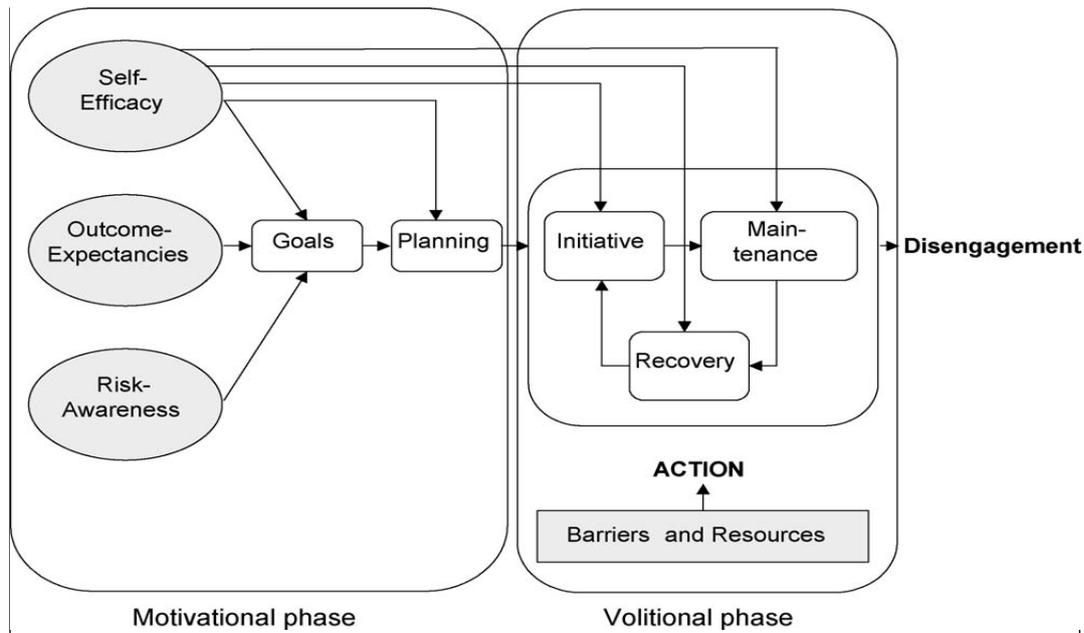
The following objectives were identified:

- To describe the demographic profile of the participants.
- To provide a qualitative, narrative description of participant's experience of the injury and its consequences which may impact PGT.
- To describe participants' perceptions on, and usage of, pressure garments.
- To describe factors that affect pressure garment therapy.
- To use the findings to make recommendations to enhance OT intervention at TAH and across similar services.

### **1.5 Study Framework**

The Health Action Process Approach (HAPA) model (as presented in Figure 1.1) was chosen as the framework for this study. The HAPA model suggests that a

change in health behaviour, such as complying with PGT, involves a process that consists of a volitional and a motivational phase (Ripper *et al.*, 2009, Schwarzer, 2011). The motivational phase is dependent on the patient's intent to initiate change in health behaviour whilst the volitional phase involves implementing this intent into action. This then can lead to action focussed on improvement or recovery as indicated in Figure 1.1.



**Figure 1.1 The Health Action Process Approach Model (Ripper *et al.*, 2009)**

In the motivational phase (intended behaviour) an 'intention to change' or consideration to wear the PGs is initiated, and is dependent in part on self-beliefs and what the person believes he/she is capable of doing (self-efficacy) (Schwarzer, 2011). It is in this phase that the pros and cons of wearing the garments are weighed up by the burn survivor; the study aims to determine factors that impact this.

In the volitional phase (actual wearing or not wearing the PGs) the change must be "planned, initiated, and maintained, and relapses must be managed" (Schwarzer, 2011, pg.4). The volitional process contains action and coping plans and is strongly influenced by perceived self-efficacy and by perceived situational barriers and support of the actual environment. According to the HAPA actions are not only a function of intentions and cognitive control, but are also influenced by the perceived and the actual environment (Schwarzer, 2011). Thus, variables in both phases can have a positive or negative impact on the experience of PGT and the use of PGs.

Another framework that was considered for this study was the Person-Environment-Occupation (PEO) model of occupational performance (Law, Cooper, Strong, Stewart, Rigby & Letts, 1996). This model views the 'person' as a unique individual who assumes multiple roles and cannot be viewed in isolation of his/her contextual influences. The 'person' brings to the context a set of skills, attributes, experiences and knowledge (Law *et al.*, 1996). Law *et al.* (1996) defines the 'environment' as the context in which occupational performance takes place; it is further divided into socio-economic, institutional, social, cultural, and physical categories. The environment is unique to the 'person' and is considered from their perspective of themselves, their home, and community. 'Occupation' is defined as self-directed meaningful activities and tasks that the person engages in throughout their lifespan (Law *et al.*, 1996). The model identifies the areas of occupation as self-care, productivity and leisure. Optimal function or occupational performance results from a balance between the three components (P-E-O). A good balance relates to optimal occupational performance, whereas poor balance relates to minimum occupational performance, hence dysfunction.

The PEO model is a transactional approach which describes the interdependence between the person and the environment and is very similar to the HAPA model as described above. However, the HAPA model was chosen as the preferred framework to build on the findings of Ripper *et al.* (2009) who used this model as the framework in their work on PG adherence.

## **1.6 Chapter Summary**

Burn injuries are associated with physical and psychological morbidities (Park *et al.*, 2008) which results in disfigurement and possible disability. The TAH burns unit adopts a MDT approach to burn management which includes PGT as part of the OT intervention.

Pressure garment therapy, an expensive and labour intensive treatment modality, is the most popular intervention used in South Africa to prevent and treat hypertrophic scars although its efficacy is not well established. Hence the study aims to determine the significance of this intervention by exploring burn survivors' experiences of PGT through qualitative research methods. The HAPA model was chosen as the

preferred framework for the study. The findings and recommendations of the study will be used to review and enhance the PGT service at TAH as well as across similar services.

## **1.7 Study Outline**

The first chapter as presented above has given a brief introduction and provides clarity on the aims and objectives of the study. It also highlights the study problem as well as the motivation and significance of undertaking this research.

Chapter 2 provides a review of the relevant literature pertaining to the study while Chapter 3 describes and motivates methodological choices such as the qualitative design, purposive sampling and data collection by a third party. Themes identified from the findings are presented in Chapter 4 and discussed in Chapter 5. Chapter 6 concludes the study and provides recommendations from the study.

## Chapter 2 Literature Review

### 2.1 Introduction

This chapter presents literature relevant to the study. It provides detail on burn injuries and the rehabilitation of persons with burn injuries with a specific focus on the role of OT in scar management. Scar management is further explored, specifically detailing PGT with a focus on the controversy of PGT and factors influencing patient adherence.

### 2.2 Burn Injuries

A burn can be described as an injury to the skin or other organic tissue (WHO, 2012). Burns can be chemical, electrical or thermal in nature and may be caused by radiation, open flame, steam, hot liquids and hot surfaces (Pendleton & Schultz-Krohn, 2012). Respiratory damage resulting from smoke inhalation is also considered a burn injury (WHO, 2012).

#### 2.2.1 Classification of Burns

A burn can be classified according to the depth of the injury and the area of the body involved (percentage of Total Body Surface Area burnt or % TBSA) (Tor-wo, Lam, Burd & Ying, 2007 and Pendleton & Schultz-Krohn, 2012).

##### 2.2.1.1 Depth of the burn

The depth of the burn can be described as superficial, partial thickness or full thickness, depending on the layers of the skin or tissue involved (Table 2.1). This was previously described as first, second or third degree burns (Malick & Carr, 1982 and Pendleton & Schultz-Krohn, 2012). A superficial burn involves the epidermis only. A partial thickness burn, which is further classified as superficial partial-thickness and deep partial-thickness burns, involves the epidermis and some of the dermis (Pendleton & Schultz-Krohn, 2012). A full thickness burn extends down to the dermis. Burns involving the muscle and bone are sometimes referred to as deep dermal burns (Tor-wo *et al.*, 2007 and Pendleton & Schultz-Krohn, 2012) and are often seen in electrical burns. Electrical burns are sometimes referred to as fourth degree burns (Malick & Carr, 1982). However, "It is rare that a burn will present with a single depth" (Edgar & Katsu, 2007, pg. 29).

**Table 2.1 Description of Burn Injuries (Tor-wo *et al.*, 2007, pg.24)**

<b>Descriptive term</b>	<b>Features: Colour, blisters, capillary refill, sensation</b>	<b>Anatomical area involved</b>
Superficial		Epidermis only. Rapid healing with no scar
Superficial partial thickness	Pink May blister Capillary refill present. Painful	Epidermis and superficial dermis destroyed. Good potential for healing.
Deep partial thickness	Red/pale, may blister Poor refill, may have pain	Some dermal remnants spared from which re-epithelialisation can occur.
Full thickness	White/Charred No refill No sensation	Entire thickness of skin destroyed with no prospect of healing other than contraction.
Very deep		Deep structures such as muscle, tendon or bone

### **2.2.1.2 Percentage of total body surface area burnt**

The percentage TBSA or the extent of the burn is determined through the “Rule of Nines” or the Lund and Browder Chart (Pendleton & Schultz-Krohn, 2012). The adult body is divided into regions with each region representing 9% of the TBSA as indicated in Figure 2.1. The estimated TBSA is then calculated as the sum of the various percentages and excludes the donor area sites (Pendleton & Schultz-Krohn, 2012). This differs for children. More emphasis is placed on the head and neck of the infant/child (Figure 2.1).

The extent of smaller burns can be roughly estimated by using one’s hand, with fingers extended, to represent approximately 1% of the body surface (WHO, 2007 and Pendleton & Schultz-Krohn, 2012).

Patient Name and date of birth		Date completed	Type of burn
		Date and time of burn	

<p>Front</p>	<p>Back</p>	<p><b>Superficial</b> (pink, painful, moist)</p> <input type="text"/> %
		<p><b>+</b></p> <p><b>Indeterminate or deep</b> (White, mottled, dark red or black, leathery)</p> <input type="text"/> %
		<p><b>=</b></p> <p><b>Total % burn</b></p> <input type="text"/> %

<p><b>Paediatric adjustments</b></p> <ul style="list-style-type: none"> <li>• Weight approximated to <math>(8 + \text{age} \times 2)</math></li> <li>• &lt; 1 year - Head and neck are 18% and each leg 14% of RSA</li> <li>• &gt;1 year - For each of life             <ul style="list-style-type: none"> <li>• Head decreases by 1% of BSA</li> <li>• Leg increases by 0.5% of BSA</li> </ul> </li> </ul>	<p>Front &amp; Back</p>
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Figure 1. South African Burn Society Burn Assessment Form

Figure 2.1 Determining TBSA burnt (Stander & Wallis, 2011, pg.34)

### 2.2.1.3 Severity of burns

According to the WHO (2007) the severity of a burn injury is determined by the:

- **Depth of burn:** the deeper the more severe, “any full thickness burn is considered serious” (WHO, 2007, pg. 4).
- **% TBSA involved:** the greater the percentage, the more severe.
- Other factors:
  - **Source of the burn:** An electrical burn may be more serious than a flame burn as the extent of the injury may not be apparent and it may cause cardiac arrhythmias. Inhalation of smoke can double the mortality risk in relation to the size of the burn (Burn treatment and Triage, 2013)
  - **Body region burnt:** “The severity of an injury is greater if there is an inhalation injury or if deep partial- or full-thickness burns involve the hands, face or perineum” (Pendleton & Schultz-Krohn, 2012, pg. 1062). Facial burns may result in airway obstruction and/or damage to the

eyes. Circumferential burns are also considered as serious (WHO, 2007).

- **Age of the patient:** Small children and patients over 50 years of age react more severely to burn injuries. “Morbidity and mortality rises with increasing age so that even small burns may be fatal in elderly people”. (WHO, 2007, pg. 1).
- **Pre-existing physical or mental conditions:** any disease, such as diabetes mellitus, which may affect the healing process or conditions such as intellectual impairment which may impact patient adherence (WHO, 2007).

“Burns greater than 15% in an adult, greater than 10% in a child, or any burn occurring in the very young or elderly are serious” (WHO, 2007, pg. 3).

## 2.3 Consequences of Burns

Burn injuries result in many consequences, the worst being death. From my experience of working in a burn unit, those who survive may experience a variety of debilitating morbidities. For the purposes of this literature review, I further discuss these consequences according to the phases of burn management i.e. acute, sub-acute/ post-operative and rehabilitation phases (Pendleton & Schultz-Krohn, 2012).

### 2.3.1. Acute Phase

Also known as the inflammatory phase, patients are prone to infection (septicaemia) due to the loss of the protective qualities of skin that acts as:

- An environmental barrier that protects against chemical and bacterial contamination.
- Temperature regulator, with perspiration as a cooler and hair as an insulator.
- Moisture barrier, which prevents evaporation loss and moisture absorption.
- Sensory receptor, which assists the body in detecting infection and injury through tactile receptors (Pendleton & Schultz-Krohn, 2012).

Oedema of affected body parts is common in this phase due to the leakage of protein-rich fluids and overloading of the lymphatic system resulting in increased risk for infection (Pendleton & Schultz-Krohn, 2012).

Circumferential full thickness burns with oedema may result in compartment syndrome resulting in increased pressure on blood vessels, tendons and nerves and therefore secondary complications such as loss of a limb (Pendleton & Schultz-Krohn, 2012). Escharotomies or fasciotomies (incisions through the burned tissue or muscle/fascia to release the pressure) are essential to prevent compartment syndrome and possible amputation.

To compensate for the skin loss/damage, surgical debridement (removal of dead/infected skin/tissue) and skin grafts (using healthy skin from donor areas to cover the burned area) may be necessary to improve the medical status of the patient. Daily dressings and non-surgical debridement on a “shower trolley” are also performed (Pendleton & Schultz-Krohn, 2012).

Pain and anxiety are often debilitating consequences of the above procedures (Malick & Carr, 1982). Adequate pain management is therefore essential. Some patients may also experience psychosocial problems such as sleep difficulties, depression, post-traumatic stress disorder and distress at reminders of the burn experience (Gilboa, 2001) and may be dealing with other losses such as the loss of loved ones in the accident, the loss of possessions or even a home and the ‘loss of their life’ pre-injury (Malick & Carr, 1982).

### **2.3.2 Sub-acute/Post-operative Phase**

This phase lasts until the wound heals. It involves “revascularization, re-epithelialisation and contraction of the burn wound” (Pendleton & Schultz-Krohn, 2012, pg. 1062). The development of scars becomes apparent with frequent bouts of skin breakdown due to the poor tensile strength of newly healed scars. Any delay in wound healing, such as infection, may increase the potential for scarring (Pendleton & Schultz-Krohn, 2012). Skin-related problems such as itching (pruritis) and dryness may lead to further skin/wound breakdown and possible infection.

Long-term hospitalisation, as is sometimes required, may be very traumatic for patients and interrupt their ‘normal’ life (Malick & Carr, 1982). Difficulties with interpersonal relationships and isolation from family and social arenas are highly probable. Inability or difficulty returning to work or previous levels of functioning can

also result in loss of income and other psychosocial stressors (Gilboa, 2001). This is over and above pre-existing stressors that the patient may have had prior to the injury (Malick & Carr, 1982).

### **2.3.3 Rehabilitation /Scar Maturation Phase**

This phase starts approximately by the third week, includes both in-patient and out-patient care, and may last up to two or more years (Pendleton & Schultz-Krohn, 2012). It should be noted that the time taken for scars to mature is significantly different amongst individuals. Healing time may be delayed by reconstructive surgery (Pendleton & Schultz-Krohn, 2012). Burn survivors therefore have to endure long-term rehabilitation.

It is during this phase that collagen remodelling takes place and the development of hypertrophic scars become apparent (Pendleton & Schultz-Krohn, 2012). "Upon discharge from the hospital the healed burn is usually flat and smooth. However, within the next three months dramatic changes may take place" (Malick & Carr, 1982, pg. 130). Hypertrophic scars can be described as raised and red with maturation occurring within the boundaries of the wound (Demling & DeSanti, 2001a; Harte *et al.*, 2009). Contractile properties of the scar tissue pull the boundaries of the wound together causing scar tightness. Collagen fibres tend to arrange in nodules or whorls giving the appearance of raised and rigid scars (Pendleton & Schultz-Krohn, 2012).

"Deeper burns that take longer than two weeks to heal have a greater potential to form hypertrophic scars." (Pendleton & Schultz-Krohn, 2012, pg. 1063) Scars result in significant functional and psychological impairments, and are commonly associated with pain (Téot, 2005). Scars may result in itching (pruritis), disfigurement, increased skin sensitivity, contractures of the joints and functional incapacity (Williams, Knapp & Wallen, 1998). Patients tend to remain in a position of comfort (flexed or curled up) to avoid pain and discomfort (Pendleton & Schultz-Krohn, 2012) and tend to become less active, which impacts overall function.

Many patients experience family conflict and social withdrawal (Ehde, Patterson, Weichman & Wilson, 2000; Park *et al.*, 2008). Social support has a significant impact

on satisfaction with life and self-esteem and highlights the need to establish a support network for burn survivors (Gilboa, 2001).

The implementation of PGT impacts body image and self-esteem as described later. Emotional rehabilitation must therefore occur in conjunction with the physical rehabilitation (Malick & Carr, 1982) to effectively assist a patient with a burn injury.

## **2.4 Burn Management**

“A multi-disciplinary approach to burn management is essential for optimal functional and cosmetic outcome” (Edgar & Katsu, 2007, pg. 14). It is also essential for effective discharge planning and appropriate follow-up of the patient.

With the advancement in burn injury management over the years, many people are now surviving burn injuries. With this decrease in burn injury mortality comes an increased need for effective burn management so that quality of life and participation in meaningful occupation is optimised (Pendleton & Schultz-Krohn, 2012).

### **2.4.1 Role of the Multi-Disciplinary Team in the Management of Burn Injuries**

According to the Australian and New Zealand Burn Association (Edgar & Katsu, 2007), specialist burns centres may include the following team members: anaesthetists / medical specialists, nurses, occupational therapists, physiotherapists, play therapists, dieticians, social workers, speech therapists, music therapists, oral health specialists, orthotists / prosthetists, parents / caregivers / family, pastoral carers, pharmacists, psychiatrists / psychologists, rehabilitation specialists, ward clerks / receptionists, cleaners, interpreters, researchers / research assistants, seamstress and pressure garment manufacturers, and, last but not least, the patient.

“All members of the burn care team interact throughout the recovery period from pre-hospital to admission to scar maturation and beyond to minimise the impact of the trauma long-term” (Edgar & Katsu, 2007, pg. 14). Multi-disciplinary team (MDT) members work together with the medical specialists and other team members to provide on-going patient care. This includes early assessment and clinical intervention (profession specific) and on-going education and support to the patient, family and staff during all phases of management (Edgar & Katsu, 2007).

The medical specialists / surgeons conduct the necessary surgical procedures. This often includes debridement, skin grafts, amputations of digits or limbs and other procedures as required by individual patients. The doctors also ensure that patients reach optimal medical stability and have sufficient pain relief. This includes adequate fluid resuscitation, prescribing medication and various wound dressings and regimes (Edgar & Katsu, 2007).

Nursing staff assist in theatre, perform dressings and non- surgical debridement, and ensure effective infection control in the unit. The nurses also play a vital role in monitoring the patient, dispensing prescribed medication and giving valuable feedback to the team members (Edgar & Katsu, 2007).

The physio- and occupational therapists (OTs) will both be involved in the physical, emotional and functional rehabilitation of the patients. Depending on the structure of the unit and the role that each professional undertakes, this may include positioning, splinting, mobilisation, respiratory / chest therapy, improving specific performance components such as range of movement (ROM), muscle strengthening, sensation, endurance, oedema, psychological components (concentration, attention, body image, depression, pain and anxiety), scar management and the prevention of secondary complications such as contractures. The focus on performance components should be integrated into activities of daily living (ADLs) and eventually reintegration in the home, work / school life of the patient. This may include remedial and compensatory approaches such as the provision of mobility and other assistive devices (Edgar & Katsu, 2007).

The social worker deals with the psychosocial aspects affected as a result of the burn injury. However, it should be noted that “the response to a burn injury may not be proportional to the severity of the burn injury” (Edgar & Katsu, 2007, pg. 131). As mentioned earlier, patients may also have pre-existing stressors prior to the injury (Malick & Carr, 1982) that may need to be addressed. Social work intervention may therefore include liaising with the family / caregivers, employers, teachers, community members as well as the MDT.

The dietician ensures that the patient obtains the necessary nutrition (type i.e. orally or tube feed and amount of feed) to reach optimal stability. “Patients who have

sustained 20% TBSA or more may have significant hyper-metabolism and require enteral feeds as they may be unable to meet their nutrition requirements orally” (Edgar & Katsu, 2007, pg.158). Patients with less severe burns may also have extra nutritional requirements and a high protein diet is often prescribed.

The speech therapist is generally involved with the assessment and management of swallowing (dysphagia) and communication disorders. Speech therapists are often involved with burn patients who have tracheostomies (Edgar & Katsu, 2007).

#### **2.4.2. Role of Occupational Therapy in the Management of Burn Injuries**

“Occupational therapy (OT) is a client-centred health profession concerned with promoting health and well-being through occupation. The primary goal of occupational therapy is to enable people to participate in the activities of everyday life” (*World Federation of Occupational Therapy, 2012*).

The role of the OT is to:

- Apply their specific knowledge to enable people (anyone who has an injury, illness, disability or psychological dysfunction) to engage in ADLs that have personal meaning and value.
- Develop, improve or restore functioning in the occupational domains of work, school, play, leisure, ADLs, rest and sleep.
- Address, by intervention, the person's capacity to perform the activity being performed, or the environment in which it is performed. This may include adaptations to the environment and modification of the activity.

Occupational therapy intervention in burn management therefore includes, but is not limited to (Malick & Carr, 1982 and Pendleton & Schultz-Krohn, 2012):

- **Assessment:** This involves obtaining a thorough medical history, occupational performance history, evaluating affected areas with regard to joint mobility or ROM, muscle strength, oedema, hand function, sensation, pain, endurance and functional ability.
- **Treatment of physical (as above) and psychosocial performance components** such as body image, depression and social interaction amongst others.

- Functional performance in ADLs (washing, eating, dressing, toileting, mobility), work, school, home management, leisure, sleep and rest.
- Education of the patient, family / caregivers and the team, as well as providing psychological support.
- Assessment and issue of assistive devices, splints, wheelchairs and compression bandages and education in the use thereof.
- Prevention of secondary complications.
- Scar management.

## **2.5. Scar Management**

“Scar management relates to the physical and aesthetic components as well as the emotional and psychosocial implications of scarring” (Edgar & Brereton, 2004, pg. 344). As described earlier, a common consequence of burn injuries is the development of hypertrophic scars. As hypertrophic scars mature, collagen bands start to relax and become softer and pliable, especially when treated with compression (Pendleton & Schultz-Krohn, 2012). “Mechanical pressure with a corresponding stretch applied to the scar will eventually remodel the hypertrophic scar” (Malick & Carr, 1982, pg. 132).

Hypertrophic scars cause disfigurement and therefore can impact negatively on body image and self-esteem, as skin plays a role in the development of body image and personal identity (Pendleton & Schultz-Krohn, 2012). According to Malick & Carr (1982) body image refers to individuals’ physical and emotional perception of themselves.

Scar management is challenging and often requires a combination of treatments which includes the use of corticosteroids, scar massage and/or physical therapy, silicone gel sheeting, splinting, PGT and surgical procedures (Téot, 2005).

Occupational therapy at TAH is primarily involved in PGT, silicone gel sheeting, splinting and scar massage.

## **2.6. Pressure Garment Therapy**

Pressure garments (PGs) have been the prescribed choice of hypertrophic scar treatment since the 1970s (Macintyre & Baird, 2004). Pressure garment therapy is

the best non-invasive and most common therapy used for the treatment and prevention of disfiguring (hypertrophic) scars after burn injury (Stewart, Bhagwangee, Mbakaza and Binase, 2000; Anzarut *et al.*, 2005).

Studies have shown that external pressure exerts a decongestive effect on the vascular nature of the hypertrophic scar, thereby facilitating scar maturation. It decreases collagen synthesis and alters the layout of collagen synthesis (Silfen, Amir, Hauben & Calderon, 2001), thereby improving cosmetic appearance. This describes the motivation for using pressure garment therapy.

Pressure garments are elastic garments manufactured into items of clothing such as gloves, pants or masks which are used to apply pressure to areas of hypertrophic scars, almost like a second skin. It can be commercially bought, such as Jobst or Second Skin (Williams, Knapp & Wallen, 1998), or custom-made as is the case at TAH.

Treatment recommendations for optimal outcomes for scar management with regard to pressure garments requires that the garments be worn 23 hours per day (only being removed for hygiene) to provide consistent and adequate pressure until scar maturation is attained. This is usually attained after 12-24 months (Malick & Carr, 1982; Pendleton & Schultz-Krohn, 2012). There is, however, consensus that subjective evaluation determines when the scar has reached maturity. The clinical experience of the therapist is thus important in making this assessment (William, Knapp & Wallen, 1998).

Currently the Vancouver Scar Assessment Scale (VSS) is most frequently used to document scar changes (Draaijers *et al.*, 2004). The VSS is used to measure height, vascularity, pigmentation and pliability of scars (Demling & DeSanti, 2001a; Téot, 2005) which are indicators of scar maturity. Whilst attempting to achieve objectivity, all objective markers rely on the therapist's perceptions and expertise, resulting in variations of assessment between therapists and decreased reliability (Demling & DeSanti, 2001a).

### **2.6.1 Other Advantages of Pressure Garment Therapy**

Some studies have shown that compression increases mast cell activity which is the likely reason for decreased itching with compression (Demling & Desanti, 2001a). Oral antihistamines, skin moisturisers and the addition of pressure garments decrease histamine release (Demling & Desanti, 2001b), thereby reducing itching.

Other advantages of PGs include the protective qualities (from dirt/sun) of the garment, and sometimes improved mobility, as described by patients (Ripper *et al.*, 2009). Hypopigmentation is a problematic, usually permanent, consequence following a burn injury, especially in races with darker races (Grover & Morgan, 1996). In my experience, patients have often stated that the PGs cover up their 'marks'.

Pressure garment therapy gives the therapist an opportunity to get to know the patient well, as scar maturation can take up to two years in some cases. This provides the therapist with opportunities to deal with physical and psychosocial sequelae of the burn injury. This may include poor ROM, referring to plastic surgery for contracture releases, determining if the patient would be able to return to the open labour market or not, identifying family problems, especially where alcohol and drug abuse is present, and referring to the social worker where necessary (Malick & Carr, 1982). At TAH, the social worker together with the OT arranges for financial assistance, post-discharge arrangements and other necessities as required.

### **2.6.2 Disadvantages of Pressure Garment Therapy**

Pressure garments are cosmetically displeasing and have been reported to cause pruritis, wound breakdown, overheating, abnormal bone growth (Anzarut *et al.*, 2005), and skeletal and dental deformities (Silfen *et al.*, 2001).

Pressure garment therapy is an expensive and time consuming treatment modality. Current prices of material are approximately R225/metre. It therefore requires relative skill and experience to avoid wastage of material. To achieve optimal outcomes for scar management, PGs are to be worn 23 hours per day and each patient is therefore supplied with two sets of garments allowing for one set to be worn and the other to be washed. Poor patient hygiene and excessive perspiration

increases the risk of skin maceration (Malick & Carr, 1982). Pressure garments also need to be replaced on a regular basis (Williams, Knapp & Wallen, 1998) as the elastic fabric wears out (Malick & Carr, 1982). The garments need to be laundered in a specific manner (hand wash only) and donned in a specific way to maintain their lifespan for as long as possible (Malick & Carr, 1982).

A case study found that pressure garments may result in or exacerbate obstructive sleep apnoea (Hubbard, Masters, Williams & Chand, 2000). This is an important factor to bear in mind when using PGs as many burn patients suffer inhalational injury with resulting respiratory complications. In my experience, patients sometimes complain of breathing difficulties when using their PG jackets or vests.

### **2.6.3 Controversy Surrounding Pressure Garment Therapy**

Despite their widespread use, only a few randomized controlled trials (RCTs) studying the efficacy of PGT have been undertaken to date. Williams, Knapp & Wallen (1998) found that a randomised study regarding the efficacy of PG's had shown that PGT does not influence scar maturation. Another RCT found no significant statistical difference among scar pigmentation, vascularity, and pliability (Groce *et al.* cited in Williams, Knapp & Wallen, 1998). However Anzarut *et al.* (2005) found that there was a significant statistical difference in scar height indicating improvement in this characteristic. A recent meta-analysis on the effectiveness of PGT concluded that the benefits of PGT on scarring remain unproven and further research is required (Anzarut *et al.*, 2009).

A possible reason for the uncertainty surrounding efficacy is that PGT is generally not used in isolation (Pillay, 2008). Scar massage and moisturisation are often performed even if not intended for therapeutic purposes. A study by Harte *et al.* (2009) showed no statistical difference in the VSS score between the participants who used PGs only and those who used PGs and silicone.

### **2.6.4 Factors Influencing Pressure Garment Therapy Adherence**

One of the main factors that influences PGT is patient compliance, or more currently referred to as adherence (Ripper *et al.*, 2009). A study by Johnson, Greenspan, Gorga, Nagler & Goodwin (1994) found that 50% of the burn survivors were non-

compliant with treatment. Patient non-adherence, although often described, is a poorly understood, complex phenomenon (Trick, 1993, cited in Ripper *et al.*, 2009).

Most research regarding non-adherence has been dominated by the perspective of the health professional with little attention being given to patients' perspectives (Stewart *et al.*, 2000). A tendency to attribute low adherence only to patients' behaviour exists (Ripper *et al.*, 2009), placing blame which denies patients an opportunity in decision making regarding their treatment and reinforces the maintenance of professional power and control (Stewart *et al.*, 2000). However, as indicated in the HAPA model, health behaviour, such as complying with PGT, has a motivational and volitional phase and is influenced by a variety of factors including physical, psychological and psychosocial factors as well as the efficacy of the PGs and of staff.

#### **2.6.4.1 Physical Factors**

Pressure garments can cause a number of physical symptoms and are uncomfortable to wear. This can lead to poor adherence (Ripper *et al.*, 2009). Various studies reported that common problems associated with wearing PGs included itching, rashes, necrosis, tenderness and blisters, increased sweating, pain and diminished physical functioning, such as reduced mobility, which influenced quality of life negatively (Stewart *et al.*, 2000; Pallau, Künsebeck & Noah, 2003; Ripper *et al.*, 2009). Patients also found that the garments were hot to wear, caused excessive skin friction and were sometimes not well constructed (Stewart *et al.*, 2000).

Pain after a burn injury is a significant problem and studies continue to show that pain remains under-treated (Tengvall *et al.*, 2010). In the study by Ripper *et al.* (2009) half the patients described pain as a problem whilst wearing PGs whilst the others reported 'numbness of the limbs' or 'unpleasant sensations'.

#### **2.6.4.2 Psychological Factors**

As the scar appearance changes slowly and improvements are only noted by careful observation, PGT requires much patience and motivation on the part of the patient and therapist. High levels of patient frustration and expectations about minimal or no improvement of scar appearance also influenced adherence (Ripper *et al.* 2009).

According to Ripper *et al.* (2009) resources such as support, self-efficacy, and specific limitations resulting from PGT influences patients' adherence. Specific limitations include functional/physical impairments, deficiencies with regard to information, mental health issues (fear/anxiety), interpersonal problems and additional effort required to use the garments (Ripper *et al.*, 2009). Personal health management through behavioural/ coping strategies and information seeking behaviour also affects adherence (Ripper *et al.* 2009).

In the post-hospitalisation phase the cosmetic disfigurement is worse than the physical disability. In today's society, high value is placed on beauty and youth and judgement is passed on those less attractive (Gilboa, 2001). The greater the visible disfigurement (hands and face), the greater the need to support the patient therapeutically, to enhance self-image, self-esteem and assist social integration (Gilboa, 2001).

"Patients with clearly apparent scars appear less frequently in public and this is linked to limitations of social and occupational activity" (Pallau *et al.*, 2003, pg. 150). Feelings of embarrassment and shame about wearing visible garments were noted by Ripper *et al.* (2009). Material type and colour of the garments also affected adherence (Ripper *et al.*, 2009). Johnson *et al.* (1994) also noted that patients were less compliant with garments for the head, neck and hand.

#### **2.6.4.3 Psychosocial factors**

Psychosocial problems experienced by burn survivors might also impact PGT adherence. Park *et al.* (2008) in a study to identify risk factors that affect the psychosocial adjustment of burn survivors found that a lack of family support and the burden of medical and living expenses were all factors that impacted on rehabilitation. These could impact negatively on patient adherence.

Park *et al.*, 2008 described studies where patients with low incomes stopped therapy or had less therapy because of financial problems. They also reported that due to the loss of valuables in the fire, the problems of re-employment and low levels of social involvement, many patients became more financially strained. These stressors could have a significant effect on patient adherence with PGT as the little income that is available may be used for basic necessities such as providing food for the family.

Ripper *et al.* (2009) also noted that emotional and practical support by family and friends enhanced adherence with PGT. Pressure garment therapy places high demands on patients in terms of co-operation because it is recommended that the garments be worn almost 24 hours a day for a period of 12 months or until scar maturity is reached (Ripper *et al.*, 2009). Another factor that influenced patient adherence was the 'additional effort' such as the time taken to get dressed (donning) or washing the garments (Malick & Carr, 1982).

#### **2.6.4.4 Efficacy of pressure garments**

Efficacy of treatment, such as visible progress, the protective qualities (from dirt/sun) of the garment and sometimes improved mobility, was the main reason to continue with PGT (Ripper *et al.*, 2009). In my experience, patients often only realise the effects of the PG once they stop using it, believing that it has not done anything. Adherence often improves thereafter but usually to the detriment of the scar appearance. In Stewart *et al.* (2000), it was noted that a large percentage of both patients and clinicians were uncertain about whether the garments effectively reduced hypertrophic scarring.

#### **2.6.4.5 Efficacy of staff**

The competency of healthcare professionals and the provision of timely and appropriate health information may also affect burn survivors' rehabilitation experience. A good therapeutic relationship helps patients achieve optimal scar management outcomes because they rely on the knowledge and skill of the staff (Ripper *et al.*, 2009). Healthcare workers are often the ones that patients turn to for advice and support. A study by Riis, Andersen, Pedersen & Hall (1992) also found that support from relatives and staff and pre-morbid psychosocial integration, assists patients in attaining optimal long-term psychosocial adjustment. Patients who might struggle with adaptation need to be identified early and assisted as far as possible.

Stewart *et al.* (2000) reported that a majority of patients felt they received insufficient information despite clinicians' reports that patients were provided with a broad spectrum of garment instructions. Patients also noted treatment deficiencies due to the lack of adequate information regarding the purpose and intended effect of the garment, resulting in poor adherence (Stewart *et al.*, 2000). This may be further

exacerbated if the patient had difficulties in understanding the medical instructions (Ripper *et al.* 2009).

Another factor that affects patient adherence is choice of therapies and whether the patient was informed of alternate therapies (Ripper *et al.*, 2009).

A study to assess the perceived skill of nurses and health workers in providing physical rehabilitation and psychosocial advice found that respondents felt that they were better equipped to provide physical rehabilitation advice than psychosocial advice (Reeve, James & McNeill 2009).

## **2.7 Chapter Summary**

Basic concepts and terminology used in burn management is described. I explain how the severity of a burn is determined through depth and TBSA. This is followed by a description of the role of the MDT in general burn management and a brief outline of the functioning of the TAH Burns Unit.

The role of the OT is described in further detail with specific focus on scar management and pressure garment therapy. Literature focusing on the controversy that surrounds PGT is explored. Finally, the role of physical, psychological and socio-economic factors in adherence with PGT is explored. The review indicates the challenges that PGT poses to the patient with regard to comfort, maintenance requirements, the slow progress and hardly noticeable effects.

## **Chapter 3 Methodology**

### **3.1 Introduction**

This chapter outlines the study methodology. Key aspects highlighted include the study design, setting and population; sampling procedures; data instruments; pilot study; data collection; data analysis; ethical considerations; limitations and rigor.

### **3.2 Study Design**

A phenomenological, qualitative study design was implemented. "Qualitative research is a form of social inquiry that focuses on the way people interpret and make sense of their experiences and the world in which they live" (Holloway, 1997, p.2). In essence I wanted to explore burn survivors' individual and unique experiences with regard to PGT and any variables which may affect their experience. Thus, a phenomenological research design was chosen as "it 'gives voice' to the person being studied and requires that the researcher present the subjects' view of his or her world" (Domholdt, 2005, pg. 170).

The qualitative paradigm is based on three assumptions namely: there are different versions of reality; that the researcher and participant may undergo changes during the research process; and that the research is specific to a particular person in a particular context and time (Domholdt, 2005). This is of particular importance because although burn survivors share similar experiences within the same setting i.e. TAH Burns Unit, no two persons will experience it identically. In addition in trying to understand the underlying meaning of PGT to the participants, inevitably I broadened my view of the intervention and how it can best be delivered.

I felt that this design was most suitable as "it gives a broad description and understanding of phenomena without manipulation" of treatment (Domholdt, 2005, pg. 55). As mentioned in the motivation of the study only a limited number of studies have evaluated the experience of burn survivors using non-quantitative methods; hence the need to explore participants' experiences and perceptions of pressure garment usage by using semi-structured personal interviews.

### 3.3 Study Setting

The study was based at the occupational therapy department of TAH where the PGT service is delivered. Although the study was based primarily in the out-patient burns service at the OT department, it is important to have an understanding of the burns unit itself.

#### 3.3.1 Tygerberg Academic Hospital Burns Unit

The TAH Burns Unit delivers services to the metro health district but also accepts referrals from outside this catchment area to include the greater Western Cape Province. The burns unit can accommodate 22 patients, six of whom can be treated in the specialist in-house ICU as required. On average the unit admits 339 patients annually and treats approximately 400 patients annually in the out-patient clinic (Van der Merwe, 2008). Although referred to as an adult burns unit, patients from the age of 11 are admitted using set criteria based on the severity of the burn.

Van der Merwe (2008), head of the unit in 2008, described the profile of patient admissions (Table 3.1). The cause of injury in 37% of persons admitted to the unit was assaults. She noted that “alcohol abuse is often involved and the victim will know the perpetrator” (Van der Merwe, 2008, pg. 429). Domestic incidents such as: clothes catching alight, candles falling over, having an epileptic fit, falling asleep near the fire or using highly flammable liquid to ignite a fire, accounted for a further 30% of admissions. “Once again intoxication and substance abuse contribute to the accidents” (Van der Merwe, 2008, pg. 429). The remaining 10% (other) consisted of other causes including substance abuse, motor vehicle accidents, smoking and eating.

**Table 3.1 Causes of burn injury in patients admitted to Tygerberg Academic Hospital Burns Unit for nine year period (1997-2005) (Van der Merwe, 2008, pg. 429)**

Assaults	37%	Industrial accidents	8%
Suicide attempts	3%	Electrical accidents	3%
Domestic accidents	30%	Other	10%
Flame stoves	9%		

### **3.3.2 Tygerberg Academic Hospital Burns Unit Multi-Disciplinary Team**

This information is based on my experience as OT in the burn unit. At TAH the MDT consists of a surgeon, 2-3 medical officers, specialised burn nurses, an occupational therapist, a physiotherapist, a social worker, dietician, auxiliary staff and various professional students who rotate through the unit. Ward rounds occur on Monday and Friday mornings and are attended by all MDT members. This allows for effective discussion and management of all patients in the unit as well as providing opportunities for learning and teaching (TAH being an academic hospital).

The surgeon manages the unit and provides the relevant experience, skills and training to the medical officers and nurses. Together they manage the overall medical status of the patient and perform the necessary surgical procedures. "Wound care is the most important activity in a burn unit" (Van der Merwe, 2008). Due to this, the nurses spend the largest amount of time with the patients. In addition, nurses are often the first to make contact with the patients' families as they are on duty during visiting hours at night.

The physiotherapist is primarily involved with chest physiotherapy (especially in the intensive care unit (ICU), maintaining ROM, mobility and the provision of gait-assistive devices where necessary. The dietician provides the relevant nutritional prescription as described above.

The social worker in the unit is generally involved in counselling of the patient and involved parties (related to domestic violence and substance abuse), liaising with employers, family members and/or carers, completion of temporary or permanent disability grant- applications (DGs) in consultation with the MDT and sometimes seeking alternative housing as many patients are left homeless by the fire. The social worker, together with the occupational therapist, conducts socio-emotional groups with the patients.

There is no designated psychologist and referrals to psychology often have unsatisfactory outcomes due to the limited service coverage provided within the hospital. All other services are requested on a referral basis as required e.g. speech

therapy or specialist medical services (ear, nose and throat, cardiology, psychiatry, etc.)

The burns unit has a designated OT with a treatment area outside the ward. An occupational therapy assistant (OTA) is also available to assist with in-patient service but is mostly involved with out-patient rehabilitation. Occupational therapy student placements occur throughout the academic year. The OT service will be discussed in further detail.

### **3.3.2 Occupational Therapy Pressure Garment Service**

All in-patients are given an out-patient follow-up appointment for PGT on discharge from the burns unit. In addition, new referrals (patients who were never in the burns unit) are referred for PGT from the out-patient burns clinic. Pressure garment therapy referrals are also received from community health centres, general practitioners and self-referral of patients.

The service comprised of an occupational therapist (OT), and occupational therapy assistant (OTA), with 10 and 30 years' experience respectively, who manufactured custom-made PGs in-house. In conjunction with PGT, overall scar management intervention is implemented as described in the literature review (it includes silicone gel sheeting, taping, splinting, massage, exercising, education and psychosocial support).

The PGT service also serves patients with other diagnoses but for the purpose of this study only patients with burn injuries will be included.

### **3.4 Study Population**

During the five years of the study (2006 – 2010) a total of 826 burn patients were referred to the out-patient OT service. Of these, 461 patients did not require pressure garments and could be treated with other scar management methods, and 186 patients required PGT but did not return for treatment after having been measured or having the first set of garments issued. This left 179 patients who participated in PGT over the five year period and included patients who defaulted during later stages of therapy. It was this group that formed the study population as indicated in Table 3.2.

**Table 3.2 Deriving the Study Population**

Total number of patients referred to out-patient burns OT service	826 (100%)
Total number of patients who received other scar management treatment	461 (55, 8%)
Total number of patients who defaulted after measurement or 1 <sup>st</sup> PG issued	186 (22, 5%)
<b>Total number of patients who received PGT &amp; may have defaulted later</b>	
<b>Study population</b>	<b>179 (21, 7%)</b>

These numbers were sourced from PGT records as well as patient medical folders.

### 3.4.1 Inclusion Criteria

- Burn survivors 18 years or older residing in the metro health district of the Western Cape who received PGT at the TAH OT department between 2006 and 2010. This time period was selected since it was the period during which I was the OT that provided the PGT service at TAH.

### 3.4.2 Exclusion Criteria

- Patients with intellectual/cognitive impairment.
- Patients who received other forms of pressure therapy (elasticated tubular bandage, compression bandages) but not pressure garments.
- Patients who received PGT for reasons other than burn injuries.
- Patients who did not return for treatment after being measured or having the first set issued.
- Those who died.
- Those who refused to participate.

### 3.5 Sampling Procedure

Purposive sampling was used to identify study participants. Purposive sampling is generally the most highly regarded sampling method in qualitative research (Domholdt, 2005; Cohen & Crabtree, 2006). “The logic and power of purposeful sampling lie in selecting information-rich cases from which one can learn a great deal about issues of central importance to the purpose of the inquiry” (Domholdt, 2005, pg. 113).

I specifically wanted to draw information related to patients' experiences of PGT and as many aspects related to this as possible. I felt the following categories would maximise the participant diversity relevant to the research question:

- Those who completed their PGT (long- and short-term);
- Those who did not complete their therapy;
- Male and female informants;
- Varying ages from 18 to old age;
- Varying socio-economic status;
- Varying % TBSA and burn depth and
- Varying garments received.

Fifteen informants were purposively selected from the study population. Each of these fell into at least one of the above categories thus ensuring maximum variation (Domholdt, 2005). In addition I used my personal knowledge of the patients to purposively sample those patients whom I thought would be able to provide rich information. Data saturation was reached after the eighth interview and therefore only eight informants were used.

### **3.6 Instruments Used To Collect Data**

#### **3.6.1 Interview Schedule**

I developed basic guidelines (pre-developed questions) for use during the semi-structured interviews to ensure that the interviewer was able to gather rich and relevant information. I used my clinical experience as well as information drawn from the literature to develop the interview schedule (Pallau *et al.* (2003), Domholdt, (2005), Anzarut *et al.* (2005 & 2009), Stewart *et al.* (2000) and Ripper *et al.* (2009).

The interview schedule comprised a list of pre-developed questions that needed to be covered during the conversation, in no particular order (Domholdt, 2005). As I was not conducting the interviews myself, the interview schedule had to be given some structure in terms of other questions that the interviewer could ask to explore the patients' experiences further. This clear guide (Appendix 5) for the interviewer allowed for reliable and comparable qualitative data collection (Cohen & Crabtree, 2006).

Open-ended questions were preferred so as not to lead the participant. The interviewer followed the guide, but could diverge and follow 'leads' in the conversation when she felt this was appropriate (Cohen & Crabtree, 2006). The interviewer translated the interview schedule directly into Afrikaans when she conducted the Afrikaans interview.

### **3.6.2 Recording instruments**

A voice recorder was used to record the interview. In addition the interviewer made notes or comments on the interview schedule for her to refer back to or probe on during the interview. This information, although useful for the interview process, was irrelevant to the study and therefore not included as part of the data.

### **3.6.3 Demographic Profile of Participants**

I compiled a demographic data schedule. This was completed from information obtained in the medical and pressure garment folders of the participants (Appendix 6). This included information on the sex, age, race, % TBSA, degree of burn, cause of burn, other complications, type of PGs received, number of PGs received, body part burnt, work status at time of injury and whether therapy was completed or not at the time of interview.

### **3.7 Pilot Study**

The aim of the pilot study was to determine if the interview schedule yielded results necessary to answer the aim and objectives of the study. I conducted semi-structured pilot interviews with two burn survivors, who were not included in the main study. The study setting was also TAH.

The interviews lasted forty and fifty-five minutes respectively. The interview schedule was therefore adapted according to findings by adding or removing phrases. I identified leading questions and rephrased them.

### **3.8 Data Collection**

Whilst aware that "the in-depth face-to-face interview has become the paradigmatic method" (Gordon, 2009, pg. 326), I decided not to perform data collection personally

in this study. My direct involvement with providing PGT might have caused biased responses from participants. For instance they might have wanted to please me or felt bad to be honest about their experiences if these were negative. “In qualitative interviewing, there is much greater interest in the interviewee’s point of view” (Gordon, 2009, pg. 313), highlighting the need to avoid such instances of bias. To prevent this, an OT with relevant skills performed the interviews. The OT has experience in conducting qualitative research, performing in-depth interviews and was familiar with the OT burns service as she managed the OT service at TAH. She also has several years of experience in the field of psychiatry.

According to Gordon (2009) the OT interviewer met several of Kvale’s (1996) qualification criteria for interviewers namely: she is “knowledgeable”, “empathetic in dealing with the interviewee”, “is open and is flexible” and “interprets and clarifies meanings of interviewees’ statements but without imposing meaning on them” (pg. 318).

I explained the interview guide to the interviewer and provided clarification regarding the purpose of the study. The interviewer was given opportunities before and after each interview to clarify any questions or issues pertaining to burn management that she may have been questioning or needed to clarify.

Once permission had been obtained from TAH (Appendix 4) management to perform the study I accessed medical records and pressure garment folders, from 2006 - 2010, to identify potential participants. Fifteen participants were purposively sampled in the event that some refused to participate or could not be contacted or that data saturation could not be obtained with fewer participants. I contacted the participants telephonically or when they attended their out-patient appointment and explained the study to them. During this explanation they were told the purpose of the study and that data would be collected by another OT. Once they gave provisional verbal consent a date and venue for the interview was set. This initial contact further gave me an opportunity to determine the language preference of the participant and to give appointment options that suited the participant and the availability of the interviewer. The participant had the opportunity to ask questions and gain clarity on any issues. It was made explicit that participation was completely voluntary and that the participant had the right to withdraw at any point during the study.

Venue options included the OT department or the participants' home.

Prior to the interview I reminded the participants of the purpose of the study and asked for formal written consent (Appendix 1 and 2). This included consent for the interviewer to use a voice recorder and make notes where necessary. I introduced the participants to the interviewer. I explained to the participants that the interviewer did not have access to their folders and did not have any knowledge of the participant's background or situation other than that they had sustained burn injuries and were treated by me. It was also explained that the interviewer was hearing impaired and that participants needed to speak clearly and may be requested to repeat themselves. Participants were agreeable to this. I further explained that I would be listening to the recording and using that information for the study.

The interviewer conducted interviews with eight participants over a 10 month period. At the beginning of the each interview, the interviewer reminded the participant of the use of a tape recorder and that notes could be made. Although most participants were isiXhosa-speaking, they opted to participate in the interviews in English. One participant was French-speaking but was also happy to participate in English. The use of a translator was therefore not required as participants opted for English or Afrikaans in which both the interviewer and I were fluent. After each interview I discussed the overall interview process with the interviewer and this gave the interviewer an opportunity to 'debrief'. I then transcribed the data to determine if the interviewer was extracting relevant information as well as provisionally analyse the data to evaluate for saturation. I felt that data saturation was obtained by the eighth interview.

During the write up of the results section, I made telephonic contact with four of the participants to check if my interpretation of their information was correct. This was also voice-recorded, with their permission, and transcribed accordingly. This data was also used in the study.

### **3.9 Data Analysis**

Once the interviews had been recorded, I transcribed all data independently to familiarize myself with the data. A translator was not required as there were no

isiXhosa interviews. I immersed myself in the data by repeatedly reading and re-reading the transcribed data and listening to the audiotapes.

To assist with the organisation of the data I used colour coding to determine from which interview a piece of data originally came. Each transcribed interview was underlined in a colour allocated to a specific participant. Participants' names were not used and each was assigned a pseudonym to maintain confidentiality.

I conducted in-depth analysis by coding and reducing the raw data. Codes are typically words or phrases for identifying categories and themes (Miles & Huberman, 1994). After reading and re-reading the interviews, codes that recurred formed categories and these emerged into themes that were related to the study objectives. I used two broad themes i.e. 'PG usage' and 'factors affecting PG usage' as a starting point. These were identified through the literature review. Sub-themes under 'PG usage' included direct effects of wearing PGs and wearing schedules. Sub-themes under 'factors affecting PG usage' focussed on adherence and non-adherence. Another broad theme that emerged was related to the burn injury itself, namely 'consequences of the burn injury'. I continuously reflected on the objectives of the study so that relevant information could be used to generate meaningful patterns. This was done by going beyond what the participants said and trying to understand the meaning behind the literal words. By continuously stopping and reflecting I was able to generate meaningful themes and identify relationships among the themes (Domholdt, 2005).

Direct quotes are used to display data because it allows readers to examine the data I analysed and to understand the findings of the analysis (Cohen & Crabtree, 2006); in other words to illustrate the themes. This information in turn can be found in the data base. The data base also contains setting, dates and duration of interviews. Finally, for the purpose of this study, all Afrikaans data was translated to English.

### **3.10 Ethical Considerations**

The study as described in the methodology was seen as low risk research. As there were no clinical interventions, the risk of causing harm to the participants was

minimal (Domholdt, 2005). However, the researcher endeavoured to adhere to the highest possible ethical standards which included the following aspects:

### **3.10.1 Registration and Permission**

The study was registered with the Health Research Ethics Committee at Stellenbosch University (Ethics Reference Number: N10/11/376) in November 2010. In February 2011 permission was obtained from the Chief Executive Officer of TAH to conduct the study on TAH premises and to access patient folders (Appendix 4).

### **3.10.2 Informed Consent**

Participants were given adequate information on the study to make an educated decision about participating. Disclosure of information (using the information leaflet and consent form) was clear, simple and in a language that the participant could understand i.e. English and Afrikaans (Appendix 1 and 2).

Potential participants were contacted telephonically or in person for provisional consent and further explanation and clarification of the information leaflet was done face-to-face. The participant's comprehension and understanding of the information leaflet was further enhanced through explanations by me and the interviewer where needed. Participants were encouraged to ask questions, which were answered by me. They were also informed that a tape recorder would be used during the interviews. Once they indicated that they were happy to participate in the research they were asked to sign the consent form prior to the interview.

It was made explicit that participation was voluntary and since the process of informed consent was on-going and interactive, the right to withdraw at any time was permitted and withdrawal would not be held against that participant if they were still receiving treatment (i.e. participating in PGT).

Only participants who were legally able to give consent and who were cognitively competent to do so participated in the study (i.e. 18-years or older and no cognitive impairment). The information leaflet and consent form were read to those who were illiterate and with the help of a caregiver or witness they were able to give consent.

### **3.10.3 Confidentiality**

All information was kept confidential. No names of participants were used in the study. Pseudonyms were used to identify participants during the write up of the data.

All research data were stored on a computer that was password protected. The data was also backed up on an external hard drive and a universal serial bus (USB) flash drive. These, as well as the hard copies, were stored separately in locked drawers. Only I had access to the data.

### **3.10.4 Potential risks**

There were no direct physical risks to the participants. Social risks were avoided as confidentiality was maintained. There were no financial risks to the participants. Transport costs were remunerated to those participants who indicated that they required assistance.

There were some instances of traumatizing/painful moments where participants were recalling memories of their burn injury and the rehabilitation process. I was made aware of these psychological risks by the interviewer and offered the participants follow-up support sessions, which the interviewer offered to provide (being an OT herself). Options to be referred to the social worker were also provided. With the intensive interaction associated with qualitative research, I needed to ensure that closure was achieved and had follow-up feedback sessions with the participants either telephonically or personally.

### **3.10.5 Benefits of the study to the participants**

The anticipated benefit of the study was to develop new knowledge. There was no direct benefit for participants but rather for subsequent users of pressure garment therapy. This was explained to the participants beforehand.

## **3.11 Rigor**

To prevent bias I opted not to conduct the interviews personally and opted to use an occupational therapist colleague who was familiar with burn management, PGT and

qualitative research to conduct the interviews. This was due to the fact that I was the service provider and the participants might have felt pressured to answer favourably. The same occupational therapist conducted all eight interviews for consistency.

Maximum variation purposive sampling was used as described under 3.5 above. “With purposive sampling, researchers deliberately seek to include “outliers” conventionally discounted in quantitative approaches” (Barbour, 2001).

To ensure credibility and transferability, member checking, triangulation, independent data coding by more than one researcher and audit by an outside researcher is recommended (Domholdt, 2005).

For this study data saturation, as described under 3.8 above, was attained by the eighth interview. The interviewer verified the researcher’s transcriptions of the recorded interviews thus increasing the validity of each document. Telephonic contact was made with four of the participants to check if my interpretation of their information was correct. Attempts to contact two other participants telephonically failed. All data, transcriptions and recordings, were kept to allow for independent analysis and for review to verify the conclusions.

### **3.12 Chapter Summary**

A qualitative study design was used. Semi-structured interviews were performed with eight purposively-sampled participants who received PGT at TBH OT department from 2006 - 2010. Interviews were performed by an OT who was not involved in PGT service delivery during the study period, but who was knowledgeable about PGT. I adhered to the ethical principles of informed consent, voluntary participation and confidentiality. Rigor was achieved through data saturation and member checking.

The results of the study are presented in Chapter 4.

## Chapter 4 Results

### 4.1 Introduction

This chapter presents the findings of the semi-structured interviews conducted with the eight burn survivors. The results are presented using five core concepts, four of which were derived from the study objectives and the other from the findings itself.

The five core concepts are:

- Profile of participants
- Consequences of the burn injury
- Perception and usage of PGs
- Factors affecting PGT
- Participants recommendations to improve PGT service

Emerging themes were organised under the above core concepts (see Table 4.3).

### 4.2 Profile of Participants

#### 4.2.1 Demographic Profile of Participants

Table 4.1 provides information on the demographic status of the eight participants. Participant's ages at the time of injury ranged from 20 - 79 years. With regard to ethnicity the participants reflected the general distribution of patients admitted to the burns unit, namely a majority of Black Africans followed by Coloureds. Over half of the participants were involved in a relationship and did not receive an income.

**Table 4.1 Age, gender, ethnicity, language, marital and income status at time of injury**

<b>Age</b>	
20-29	5
30-39	1
40-49	1
70+	1
<b>Gender</b>	
Male	3
Female	5
<b>Ethnicity</b>	
African	4
Coloured	2
White	1
French (European)	1

<b>Language</b>	
English	2
Afrikaans	1
Xhosa	4
French	1
<b>Marital Status</b>	
Single	1
Boyfriend/girlfriend	3
Life Partner /Married	2
Divorced/separated	2
<b>Income Status</b>	
Unemployed	3
Student	2
Casual/contract work	2
Pensioner	1

#### 4.2.2 Burn Profile of Participants

All eight participants sustained partial thickness burns ranging from 5 – 30% TBSA (See Table 4.2). Four of the participants had sustained ‘visible’ burns (face, hands and arms). The cause of most injuries was household accidents whilst two were alcohol-related social accidents and one was due to a taxi accident.

The number of PGs received varied from 1 - 5 sets. Over 60% of participants received 2 - 3 sets of garments. PG pants were the most common type of garment, probably due to the fact that donor areas often included the thighs. Half of the participants completed their PGT whilst the other half was still participating in therapy at the time of the interviews.

Some participants had pre-existing conditions at the time of injury such as diabetes mellitus and hypertension (79-year-old). One of the female participants was pregnant and another was breastfeeding. Two of the participants developed complications following the burn injury, namely above knee amputation and lymphoedema of both lower limbs respectively.

**Table 4.2 Burn and PGT Status**

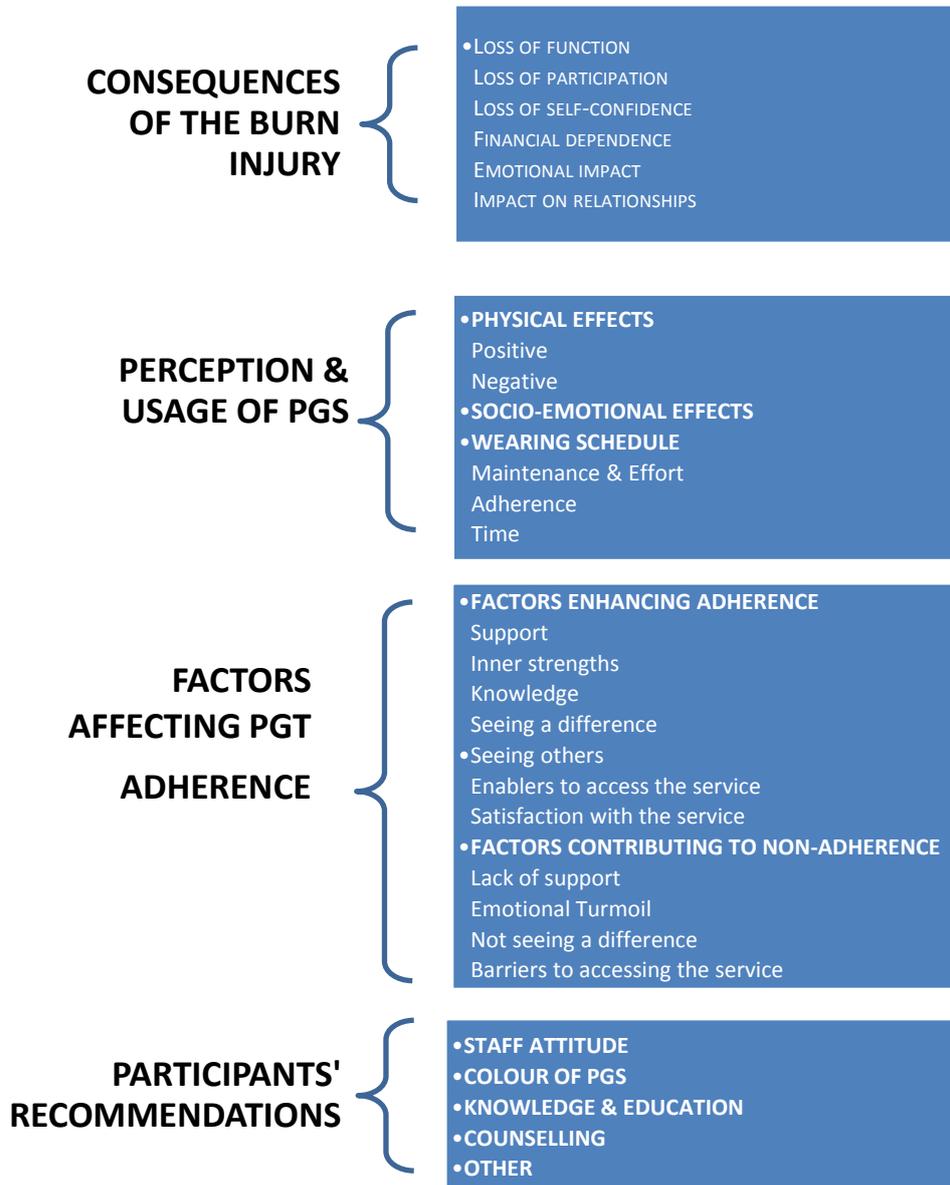
<b>Depth of burn*</b>	
Superficial burns (mixed)	1
Partial thickness burns	4
Full thickness burns (mixed)	4
<b>% TBSA</b>	
5-10%	3
11-20%	2
21-25%	1
26-30%	2
<b>Body parts involved</b>	
Face	2
Hands	3
Torso (chest or back)	3
Upper limbs	4
Lower limbs	3
Feet	4
<b>Cause of Injury</b>	
Accident: Household	5
Accident: Social	2
Accident: MVA	1
<b>Number of Different Types of Garments Received</b>	
1	1
2	3
3	2
4	1
5	1
<b>Type of Garments required</b>	
Face Mask/Chinstrap	1
Jacket	2
Gloves/mittens	3
Sleeves	2
Pants	5
Socks	4
<b>Therapy</b>	
Completed	4
Current	4
<b>Other medical factors</b>	
Hypertension	1
Diabetes Mellitus	1
Asthma	1
Pregnancy	1
Lymphoedema	1
Amputation	1

\* With regard to the depth of the burn, some participants fell into more than one category hence total number exceeds eight.

### 4.3 Themes Emerging from the Data

Table 4.3 presents the core concepts and the emerging themes derived from the analysis of the interview data.

**Table 4.3 Broad overview of core concepts and themes**



### 4.3.1 Consequences of the Burn Injury

Due to the nature of the semi-structured interview all participants were given an opportunity to tell their story of how they sustained their burns. Six themes emerged from the story-telling regarding the consequences of the burn injury.

Consequences of the burn injury have an impact on overall burn intervention which includes PGT. For example, if a patient has physical limitations such as contractures of the fingers, he or she may not be able to apply the garment. Likewise, if the patient is depressed he or she may not have the motivation to wear the garment. In-depth analysis of the findings resulted in the emergence of the themes as presented in Table 4.3.

#### 4.3.1.1 Loss of function

Although temporary in some instances, participants experienced a wide range of physical and functional limitations.

Physical limitations included direct impact on the skin or joints such as pain, loss of ROM, contractures, scars, changes in skin colour, itching and swollen limbs.

Severe pain was the most common consequence, especially during in-patient stay due to the dressings/baths that needed to be performed:

*Mandy: I couldn't handle the pain...and I was like screaming...I was probably the one who screamed the loudest...it's traumatic...yor... like burning all over again. It's like you're raw...your nerves are like raw and someone is just like wiping it with this disinfectant...it's horrible...it was the worse pain ever.*

*Sipho: Yor it was very painful!...This pain, this one was like uh uh something that you know one can experience...very, very bad.*

*Ann: I was from one room to the other, look I was on my own here...one bed to the other and that's me with being with pain. So it was very painful. I don't look back at pain you know...I'm not one of those people who...in Afrikaans you'd say 'kleinseerig' [low pain threshold], you know...*

Other physical impairments described by the participants included:

- Loss of ROM and contractures:

*Phindi: ...but I was also injured here, so I couldn't bend my knees*

*John: Ek het mos kontrakture gehad op my hande...hy was baie styf...my joints was net so styf dat ek net so [wys] vasgesit [het]. (I had contractures on my hands...they were very stiff...my joints were so stiff that they [shows] stuck together)*

- Scars

*Mandy: So now I have a scar on my leg [donor area] which is probably almost bigger than the scar that I originally got, for no reason...it's healed but it hasn't healed properly so it's almost healed like a scar...hypertrophic scar. So it's raised a bit, it's almost like this...this [shows] see this piece here...it's thick like that...*

- Skin colour changes

*Phindi: Because it [the healed skin] was very very very dark! As black as that computer. And I'm not as dark as that...but my legs were as dark as that!*

*Sipho: I was more worried about the colour because I [arms] was really, really dark.*

- Itching:

*Sipho: There was a lot of itching because I remember especially when it's cold and when it's very, very hot. In summer I was complaining about itching...and the back mostly was like itching, itching....*

- Swelling:

*Bongani: ...my leg and my feet was very big, was swollen...*

- Other complications:

*Ann: It [burn injury] seems to have brought out a lot of ailments that I didn't have before. And then I realize you know you're over eighty...*

*Phindi: ...it's hard, and I'm growing infection in between my toes...They will erm, they will have to cut me again...on...my toes, they will have to take skin from me to put there again.*

Functional limitations included physical difficulty in performing activities in their daily lives such as inability to walk, eat or toilet independently.

*Ann: And yeah then I couldn't walk hey. My feet were too sore, I couldn't sit down...you know now I have got problem with getting slippers and that on...I was supposed to go in the wheelchair because I couldn't er , even now I can't stand too long.*

*Sipho: It was like difficult before though it was bad because at first I couldn't even take a spoon and put it in my mouth...*

*Ann: So somebody had to help me to get off the toilet...*

#### **4.3.1.2 Loss of participation**

Participants described instances of not being able to continue with previous roles such as mothering, socialising, studying or working.

Phindi describes how she was unable to breastfeed her child as her child was in her mother's care whilst she was in hospital:

*Phindi: She [baby] was with my mother...she was only nine months at the time, er eight months...and I was still breastfeeding...*

John recalls that his sister stated during a psychology session that he did not want to socialise with them anymore:

*John: Toe vra hulle vir haar wat kan sy onthou van my, my suster ...toe sê sy vir haar "hy was altyd 'n man, hy was altyd 'n mannetjie, hy het altyd die spannetjie getrek", sien. "Maar hy wil nie nou saam met ons uitgaan nie" en daar het sy uitgebars het met die huil. (Then they*

*asked her [sister] how she remembers me...then she [sister] tells her [psychologist] "He was always a guy, he was always a youngster, he pulled everyone together", see. "But now he doesn't want to go out with us anymore," and there she burst out into tears.)*

Andiswa describes how she was unable to return to college due to lack of support from the institution:

*Andiswa: No I'm still studying and then I dropped out in that electrical just because I was burnt, I was here in Tygerberg for a month, and then when I get back then they said they don't have time for that, to give me assignments and those things...it's not their problem to get burnt.*

The following quotes highlight the impact on work and how some participants felt that the injury resulted in loss of work, change in job and difficulty in finding work again:

*Phindi: ...You know [clears throat], you know that, um, you know how you used to look and then suddenly you're looking like I'm looking like this, very very bad, um....so that was, that was very hard for me [tearful] but I had to do it and I, um, knowing that, um, my legs...um...you know I used to be a model...and, er, knowing that now I won't be able to do any of those things...*

*Phindi: Ja, so I was only doing the modelling at that time of my accident. So after that I, er, I wasn't working. I only started working now this month, um, I'm working for Woolworths now...as a till operator...*

Sipho describes how his scars may impact finding work even though he is physically capable of performing the job:

*Sipho: For me [coughs], for me I'm confident I can work but the only thing you know your hands are...your hands and face they are just like your ID because you cannot just go for the interview with your hands hidden like this. I think maybe it's going to affect me when I go to the interviews...*

#### **4.3.1.3 Loss of self-confidence**

The burn injury affected the self-esteem of some participants which impacted their lifestyle. Lifestyle changes included changes in what one would wear, avoiding daily tasks such as bathing and not liking social situations.

*Phindi: But whilst you are at home then it gets more difficult for you because it's no longer painful now it's more difficult for you, I mean for me it was, it was a mission for me to take a bath because I was...I don't know if I was scared to take my clothes off, so that I don't have to see my scars everyday. I won't be able to wear, my own...like, I had to buy new things now, most of the time because I couldn't wear the clothes that I used to wear. I couldn't wear my shorts, I couldn't wear my three quarters, and not to mention the shoes. I couldn't wear my shoes...like, if I'm wearing them it can only be a boot so that it will cover ...*

*Phindi: ...you just know that, um, in summer you're used to wearing your shorts and now you won't be able to wear those and, um, you know that you're supposed to, in summer you're supposed to, you're supposed to wear your sandals, I can't wear those, so it's like...*

Mandy described feeling self-conscious because of people staring:

*Mandy: Like if I...especially in the summer, I...and I'm not wearing my pressure suit or if I wear the shorts, I wear the shorts and people look at it, it's annoying...Especially when it was worse and in my face and my neck...they would look, they would stare at me, everyone...I don't like it when people stare at me and look what is that or actually come and ask you...or they will stop and they will look at you and talk to each other and then talk about you.*

Sipho describes how his scars affected his self-esteem and how this 'fear' altered his perception of applying for work. He also shared Mandy's description of feeling of self-conscious in public.

*Sipho: Ja, it affected me a lot...because at times...you know it makes me lose some er, er...some self-esteem at a certain point because*

*you know even when I go to maybe put my CV, to go give my CV...right now the first thing is like 'What happened to your hands?' and it affects me by that thing. I'm still even scared to go to those hotels...Maybe it's scared...I'm scared of that but now I can feel that I'm healed now. I can try again. I can try again but it affected me a lot because, you know, you used to have the normal hands but now the best thing even if you get in the shops the first thing...the people look at you or they stare at you. They say okay...ja, it affected me.*

#### **4.3.1.4 Financial dependence**

Participants required financial assistance from family and friends. This included the provision of a place to stay, food to eat and clothing to wear:

*Sipho: The others are working but we're mostly dependent on my older sister who was working as a medical technician there in Eastern Cape Hospital.*

*Andiswa: No, I don't know, last time I have money...My sister send me a R50, R70...ja...I just get the money wherever, I get the money...I don't know but I have everything I want but these things that cost so much, my friend, a friend of mine give it to me. She was staying in Vredenburg she was, she got a job here in Cape Town, so she gives me all the clothes that she don't use, she don't want to wear again...*

*Andiswa: Ja, he's fine just because he's [cousin] the one who buying food everything to eat so there's, there will be someone [me] to wash the clothes, all those things, so everything's fine...*

*Ann: I've got two sons and, er, but unfortunately if you know they have helped me where they can but they both got families you know and all that so it's not as though they, they can give me an abundance of money so I'm actually just virtually a state pensioner...but as I said I can't, they helped me with support [financially] of having a carer but other than that they can't help me.*

*Ann: then the girls [daughters-in-law] have given me groceries and things like that so I don't have to have a lot of you know...I'm not short of food...*

*Phindi: She's [mother], she's very supportive, er, you know she buys those bio-oils [laughs]... she would even go to the chemists to find if they have that same aqueous cream which they don't have...they would have the other range of the aqueous cream, they won't have this. But because she knows that I put that aqueous cream she will rather buy another aqueous cream that is more closer to this one and, er, I can use the aqueous cream while I'm waiting to get another one and, um, in terms of the shoes, she will go to Green Cross and ask around for the right shoe for me so that I could go the whole day without feeling any pain [crying].*

Andiswa noted a withdrawal of financial support from her aunt and not wanting to burden her aunt or her boyfriend financially:

*Andiswa: Ja, and sometimes my aunt from Eastern Cape they send me money, but they don't send me money anymore now, they tell me they have their own children and all those things, so I don't want to bother them with my life. So I have a boyfriend but my boyfriend also has his own parents so I don't know...*

#### **4.3.1.5 Emotional impact**

Participants expressed various emotions that were of significance to them. Some of these were experienced during their hospitalisation, others after being discharged and returning home. Emotions highlighted included feelings of disbelief, worry/anxiety of not being able to cope, being violated or dehumanised, awkwardness, vulnerability and despair, being ashamed and trying to make sense of things.

*John: Daai was die eerste keer wat ek op van die bed uitgestaan en basin toe gaan...Toe ek by die basin kom, toe's ek nog gebandaged, toe staan ek kyk in die spieel...toe vra ek vir myself...toe sê ek maar net vir myself "Yor?!" Daai's al wat ek kan onthou ek het gesê, net yor, ek het nie iets anders gesê nie... (That was the first time when I*

*got out of bed and went to the basin...When I got to the basin, I was still bandaged, I was standing and looking in the mirror...I just said to myself "Wow!" That's all that I can remember saying, just 'wow', I didn't say anything else.)*

*Mandy: The thing was when this happened, I thought maybe eventually the scars would go away. They're just gonna help me now, they just gonna...it's going to be like any other scar, it will just fade. That's what I was thinking in my head and then she came to me and she [social worker] was like "Oh so how do you feel now that you will be scarred for the rest of your life?'. And I was, like, 'excuse me?!'*

Sipho described his anxiety about not being able to manage his pain once out of the hospital. He also shared his concern of being referred to another department and not knowing what to expect of that department's staff:

*Sipho: So I said okay but that's the only thing that kills my pain. And then I was worried when they discharged me...I said yor...I asked the other doctor where can I get, can I get the morphine there [laughs]*

*Sipho: Now they're discharging me to another...now I don't have to come here to the burn clinic, I have to go to...I was worried like that about this, eish, another department. I wonder how are they going to work with me ...*

Sipho also shared his worries and anxiety of not being able to cope on his first day at work:

*Sipho: And on the first day [of work] I was just asking myself 'Oh God am I going to make it, am I going to cope with this?' ... But it came as a surprise to me that I didn't feel any pain, I was like normal working... ja.*

Mandy shared that she did not want to burden her family and friends with her worries:

*Mandy: Ja, I don't...I don't...I feel sort of I don't want to annoy people with complaining about the same thing over and over so I just keep it in, you know...just get hold of it.*

Sipho and Mandy shared a sense of being violated or dehumanised during the dressing changes, to a point where Mandy felt like running away.

*Sipho: They said "Okay", you know after giving me three injections, they say "You know what, it's better for you to just look at that thing, don't focus at us" and then they took my...other one, the other one was on the left and the other one was on the right and they were like peeling the banana...I said yor!*

*Mandy: I was actually thinking about running away [laughs]...before they...the second time I had to get my skin cleaned, I was planning to run out of here, I go home...I just didn't want to do it again.*

John described repeated moments of awkwardness with family and friends who visited him in the hospital or people from the community who would walk by his house:

*John: Dit was net daai silence gewees het... hulle [familie en vriende] wiet nie wat om te sê in daai tyd... Sien, dus maar nou net...dus awkward man. (It was just that silence... they [family and friends] don't know what to say at that moment... See, it's just now...it's awkward man.)*

Several participants shared a sense of vulnerability and despair:

John describes 'breaking down' the first time he went home after being discharged from the hospital.

*John: Die eerste dag wat ek by die huis gekom het, toe kom haal hulle my by die aand, toe hulle intrek in die yard in, toe het ek 'n moment gehad...ek het net begin trane....sien ek het net begin huil. (The first day when I got home, they came to fetch me that evening,*

*when they pulled into the yard then I had a moment...I just began crying....see I just started crying.)*

Mandy and Phindi shared feelings of sadness, being 'depressed' and emotionally vulnerable, to a point where Phindi considered suicide.

*Mandy: I was miserable, I was very miserable...*

*Interviewer: What were you miserable about?*

*Mandy: About the scars and stuff...*

*Phindi: I'm still here, you know I, er, there's some days, you know days I would feel down! Because when I think about it, but I no longer cry about it now because I used to cry whenever I'm in my wardrobe or looking for something to wear.. I would cry, I would cry but now I'm no longer crying...*

*Phindi: And, erm, it's not only that you might need assistance but emotionally you're not okay, physically you might be okay but emotionally you're not ok and, erm, your [crying]...if I can tell you what this...what this has done to me...I, I even thought of, um, suicide because of this...*

Mandy and Andiswa tried to make sense of what had happened to them by questioning themselves. Andiswa attempted to rationalise this by thinking that God had punished her:

*Mandy: And I was like thinking, why'd this happened to me and whatever...*

*Andiswa: Every time I go, I want to go to the bath I told myself God is punishing me, really...*

On the other hand some participants expressed positive emotions such as not being angry, being thankful and being strong for others.

John stated that he did not allow himself to get angry with himself or others:

*John: ...ek het nou gewas en hulle het nou my gewas, ek het nie nou kwaad gewees het vir myself nie of kwaad vir die wêreld gewees het nie of*

*net kwaad vir iemand gewees het nie... (I just had the wash and they just washed me...I didn't get angry with myself or the world or anyone else...)*

Fleur and Mandy shared feelings of being thankful. Fleur was grateful that she sustained a small burn injury that was limited only to her thigh and Mandy was thankful that her brother didn't get injured as well:

*Fleur: `Cos I was burnt all over here (shows). Lucky, lucky it only got this part!*

*Mandy: I actually said like when it happened and I was laying there at the back, I was telling everyone that I was just so thankful that it wasn't him [her brother]...*

Phindi stated that she was determined and motivated herself by being strong for her baby:

*Phindi: I guess it's me. I'm just telling myself that I need to get used to this, there's no other way. I just need to be strong for my baby, I just need to ...*

#### **4.3.1.6 Impact on relationships**

Phindi and Andiswa noted avoiding intimate contact with loved ones and fear of losing loved ones because of their scars:

*Phindi: It's getting better now, I'm still not feeling as sexy as I was before and I still feel uncomfortable when he touches me because I know that he would feel, he won't feel my skin, he won't feel all that bumps, you know...*

*Andiswa: He don't have a problem...but he like...when we are together or doing something, the first time I was feeling like uncomfortable....I told him not to touch me...I don't know, maybe it's because I was afraid, I told him not to touch my burns. He said "What must I do? Must I not touch you mos?" I said no, but don't touch that part of burns...*

*Interviewer: Were, were you afraid that it would be painful or were you afraid that he wouldn't like it?*

*Andiswa: No I was afraid that maybe that he, he's not gonna like it, just because I'm burnt and I was afraid to lose him just because of my burns...*

Other consequences of the burn injury resulted in altered relationships with family members and friends.

For John it resulted in a stronger bond with his brother and a breakdown of relationship with his friends.

*John: Toe ek en my broer wat nou in die huis is, ons het nooit eye to eye gesien nie, was nooit vriende gewees nie...maar toe ek in kom by die huis was dit hy by my sy...maar hy het ook maar gevra "Kan ek maar vir jou 'n drukkie gee?"...sien daarvan af het ek klaar sag geraak het...die was my enemy gewees...buite was hy my enemy gewees maar toe hy my 'n drukkie gee, toe voel ek alright...(When my brother and I were in the house, we never saw eye to eye, were never friends...but when I came into the house, it was him who was by my side...but he also asked "Can I give you a hug?"...you see from that moment onwards I softened up...he was my enemy...on the outside he was my enemy but when he gave me a hug, then I felt okay...)*

*John: Vir my voel ek net dat hulle [vriende] het vergeet, sien daai's wat ek vir myself gesê ...dat hulle het vergeet...maar daai tyd het ek nie swak geraak nie dat hulle sê...dat ek kon sien dat hulle vergeet van my. Ek het op die selfde tyd gesê, is nie...ek verwag nie hulle lewe moet nou op hold sit nie, net omdat ek gebrand het nie...dan moet hulle 24/7 by my wees...hulle moet my 'pied piper'...dit doen and dat doen, sien...mmm en na 'n tyd toe voel ek dis alright, okay nou weet ek hulle gaan nie by my weer kom visit nie (For me it felt that they [friends] forgot, see that's what I told myself...that they forgot...but I didn't feel bad that they did that...that they forgot me. At the same time I told myself, it's not...I don't expect them to put their lives on hold just because I got burnt...that they need to be by me 24/7...that they must be pied piper...do this and do that...see. And*

*after a while I felt alright, now I knew they were not going to visit me again.)*

Mandy noted a lack of emotional support from her family and boyfriend. She also noted that as a coping strategy she maintained her distance from family and friends.

*Mandy: I don't think they [family] want to be on that journey...I don't know, they just...it's over now for them...or I don't know what they thinking...It's like they just...I think everyone [family] just assumes like okay, I'm over it...you know what I mean...it's not that I'm not over, it's just that it is what it is...you know...*

*Mandy: Things were already so complicated `cos we [she and boyfriend] used to argue about nothing but then when this happened he [boyfriend] really couldn't understand what I was going through. Like he didn't know how to deal with me, he couldn't understand why I was so sad but he wasn't supportive, I didn't feel like...maybe he did and he didn't show it? Well, I felt like he didn't care or I don't know or...I was, I was just so...I was pushing a lot of people away from me...*

#### **4.3.2 Perception and Usage of Pressure Garments**

This section deals with the physical and socio-emotional affects, and issues around wearing, of PGs. Participants highlighted both positive and negative physical effects.

##### **4.3.2.1 Physical effects**

Some of the positive effects as perceived by the participants included that the PGs were pleasant to wear and although hot in the summer they had their advantages during winter.

*Ann: But it wasn't tight tight, you know. It wasn't like those tight elastic ones...They were actually quite nice, pleasant to wear on you know.*

*John: Dit was baie warm...maar winter time...dan het ek het nou gevoel dis nog 'n sweater gewees [lag] so daai's hoekom...daai's nou*

*wat ek gevoel... (It was very hot...but winter time...then I...I felt that it was another sweater [laughs] [so that's why...that's how I felt)*

Another participant found it useful as coverage when working.

*Sipho: Okay and I used them like that...also to cover my skin when I'm working.*

Relief of symptoms such as improvement of scar appearance, relieving itching and pain and not hindering mobility were also described. The first two quotes below highlight participants' differing opinions of how much the scar improved.

*Sipho: But ja, so I suspect wearing these things was the one that was helping because now my skin is not like rough, like before, even though it cannot be compared to the, to the normal skin but it's soft now...*

*Phindi: It wasn't, um, soft and fine, the skin...but when, er, I started wearing the pressure garment, then I could see, I could feel it's not as, um, it's not as rough as it used to be, it's now more, now more of my skin, its smoother now. It's not different from my own skin...*

*Bongani: Ja this sock....It makes smooth.*

*John: Ek het dit vir myself experience om te sê daai tyd gaan ek dit dra...toe voel ek my vel is 'n bietjie verskil, man dit was baie rowwerig maar as die garments aan is, toe is hy weer smooth man. So, so hulle was hard maar so as ek die garments aansit toe het dit meer die vel straight... (I experienced it myself, told myself at that point that I'm going to wear it...then I could feel that my skin is a bit different, man it was very rough but when the garments were on, then it was smooth again. So, so they [scars] were hard but when I put on the garments then it made the skin straight...)*

*Fleur: Very thick, now it's coming small and thin now. So it's quite...it's helping me...The only time that it's soft is when I massage it or when I put the tights on. Then it's fine...The colour of the skin it's fine now, it*

*used to be red. Now it's fine. Now it's fine, it's like now trying to change the colour, like more clear. It's fine.*

*Phindi: The colour also is getting much, much better...So I guess those are the...I, er, were my explanation for wearing that pressure garments...*

Two participants noted that they did not limit mobility and one (the participant who also suffered with lymphoedema of the lower limbs) noted a reduction in swelling.

*Sipho: And I can feel like I can even use the arms now.*

*Mandy: No, I could move freely...I used to gym in it!*

*Interviewer: And wearing the pressure garment, can you see that, that it's making things better?*

*Bongani: I see it because, this, this leg...also even here in my knee, it was very big [swollen]...*

Mandy described feelings of not being able to cope without the PGs as they helped with the pain and the itching.

*Mandy: ...I couldn't go without it...like if I didn't wear my pressure suit for a day, my body would start paining...it felt like that...it would itch and it would sort of make it like...someone was stabbing me with needles, it felt like that if I didn't wear my pressure suit.*

Some of the negative physical effects of wearing the PGs as perceived by the participants included discomfort, mainly the garments being tight, hot and causing pain:

*Mandy: In the begining...it's hard to start wearing the pressure suit...it's so uncomfortable, it's so tight, it's so sweaty, it's so hot...and it's just not something that you can get used to easily wearing but eventually it becomes like part of your life...it's normal.*

*Sipho: ...ja it was like very tight...even if it's tight, it pains at times, I must wear it.*

One of the participants felt that the PG made walking difficult because it was slippery and another participant felt that it increased urination because it was so tight.

*Ann: The stockings that I wore, um...I'm must show you...They're the silky ones...*

*Interviewer: Do the stockings make you itch?*

*Ann: No.*

*Interviewer: Did it make your skin hot or...?*

*Ann: Just slippery...*

*Interviewer: When you're walking?*

*Ann: Ja...It gets very slippery you know.*

*Ann: My feet slips...my feet's so soft underneath... So, er, a friend of mine gave me...bought me a lot of those socks with the little thingies underneath it...so that I don't slip... I just made the habit of wearing those socks [pressure garments] with the...slipper socks.*

*Mandy: No...it just caused me to pee a lot! ....Cos it's so tight you know! The pants and the top together...it's like really tight!...Yor, and it like presses on your bladder...*

Some participants felt that they caused physical symptoms such as itching, damaging the skin and 'bringing out' the veins in her legs:

*Sipho: Ja, it was a lot of itching. There was a lot of itching because I remember especially when it's cold and when it's very, very hot. Ja when I started I noticed that they [PGs] were scratching my skin, you know like on this arm...er...er...like around the burns...I didn't burn here but I found that when I turned them like this they[PGs] were like scratching...where I don't have the burns.*

*Ann: And then I said to her these stockings are bringing out veins in my legs...*

#### 4.3.2.2 Socio-emotional effects

Female participants felt very strongly that the colour of the PGs was cosmetically displeasing and drew further unwanted attention. The participant below describes how inappropriate the beige colour material is for dark-skinned people:

*Andiswa: Yes! Ja, just...I don't have a problem with this thing ne...just but the colour, the colour of my skin is brown mos ne.... And then if you put it on then the beige, the people they ask you what's wrong?! What's wrong and they will be like asking what's wrong, what's wrong, what's wrong...[whispering]...just because my skin is brown...just at least if it's a white person, its right for her...*

Others felt the PGs were unfashionable and did not complement their outfits.

*Phindi: And on top of that, er, the colour of the pressure garment, I mean, I'm wearing skirts most of the time, um you know mos in the tradition if you're married you can only wear, um, long skirts and now I'll be wearing these um long skirts with my shoe. You can't, and some shoes...you can't wear a skirt and that particular shoe and then you will still have a sock on, on it. You know it doesn't look good, it doesn't look right. It make you look, it just spoils your whole outfit...*

*Mandy: Um, the colour of the pressure suits, it's disgusting [laughs].*

*Interviewer: The beige one that you're wearing now?*

*Mandy: Ja...it's, it's so unfashionable! [laughs]*

*Mandy: I don't like the colour at all...that also...it also makes you not want to wear it, it doesn't go with anything you wear.*

One of the male participants felt that he didn't have the courage to wear the garments out in public.

*John: Ek het dit nie gedra as ek uitgaan nie en so en so... (I didn't wear it when I went out and so...)*

*Interviewer: Deur...omdat jy bang was dat mense gaan...?*

*(Through...because you were afraid people would...?)*

*John: Ja, vrees gehad ja... Maar nog altyd as die mense ingekom, sien...om vir my to kom visit...(Yes, had fear yes....but still if the people come in, see...to visit me...)*

*Interviewer: Okay, so as hulle inkom en jy het dit aan? (Okay, when they come in and you have it on?)*

*John: Dan het ek dit aan. Daai tyd wil ek net met hulle gepraat soos normal...het hulle gevra wat's die doel van die...(Then I have it on. At that time I just wanted to speak with them like normal...they would ask what's the purpose of the....)*

*Interviewer: Wat is die verskil? (What's the difference?)*

*John: Mmm?*

*Interviewer: Is dit omdat as jy in jou eie huis is dan voel jy meer sterk? (Is it because if you are in your own house then you feel stronger?)*

*John: Ja... (Yes.).*

Two participants feared that not wearing the PGs would cause secondary complications such as blisters or pimples as this occurred when they did not wear the tubigrip. Siphon also felt that his skin would 'tighten' if he did not wear the PG:

*Andiswa: I just wear it just because I don't have a choice just because I'm afraid maybe to cause a blister or something...*

*Siphon: You can see this is flat but if it's not healed I noticed that okay if I took them [PGs] off maybe now it's going to be like that after an hour it starts to develop some, er, some...something like, er, pimples or something like that. It [the skin] starts to tighten...*

#### **4.3.2.3 Wearing schedule**

Sub-themes that emerged from the data described the maintenance and effort involved with wearing the PGs. Participants described varying wearing schedules which was further elaborated on in terms of their daily schedules. The overall time period that they used the PGs as a burns survivor was also highlighted.

##### **4.3.2.3.1 Maintenance and effort**

Participants described several difficulties with washing and keeping the garments clean. This was due to the fact that the garment was light in colour and creams or

ointments applied would stain it. Despite this, Phindi stated that it became part of her routine.

*Phindi: So I used that brown one, I liked that brown one because it doesn't get dirty so quickly and even though I put on that Haarmanse [traditional remedy], it doesn't show very quickly, um ja. So that is why if they could at least try to get that brown or any other colour cos... this one [PG] is very light, it gets dirty very easily even with bio-oil `cos bio-oil is oily...[sighs] I'm managing actually very well because, er, it's more like now it's a part of my life.*

The quote below describes the general routine that participant's had to comply with.

*Interviewer: So you managed to wear it everyday? All the time?*

*Fleur: Yes.*

*Interviewer: Except when you're obviously washing?*

*Fleur: Yes. And then when I want to wash it, then I wash it in the hot water and then I take another one and I put it on.*

Ann noted that the weather played a role in the ease of PG maintenance.

*Ann: Well she said I had to [use PG daily] and of course the weather was better now and it was a case of washing and you know... washing and sort of keeping up...*

Mandy described the effort of donning the garments which affects adherence with other treatment interventions such as massaging.

*Mandy: It's not just the removing, it's just like...I don't know...If I told you now go massage yourself three times a day would you be able to? And it's really like gonna help your skin get better...you're gonna know that will help you but you're not going to do it for some reason, you know....I can't explain really...like...*

*Interviewer: Am I understanding you correctly? It's not like you didn't want to do it, it's just that you kinda found it inconvenient?*

*Mandy: Ja...*

*Interviewer: To have to...?*

*Mandy: Ja...*

*Interviewer: And there's a lot of effort involved to make the time to remove the pressure garment?*

*Mandy: Ja...*

John also described the effort of donning the garment and stated that he required assistance because the jacket had a zip and he had contractures of his fingers:

*John: Ja die baadjie het 'n zip gehad...Ja, dus hoekom ek het vir my ma gevra om daar te help... Want jy moet draai en eerste jou arm in sit en jy moet jou draai...so hulle het my gehelp toe ek die baadjie aantrek...ja. (Yes the jacket had a zip...Yes, that's why I asked my mother to help there...because you must turn and first put in one arm and then you must turn yourself...so they [mother] helped me when I put on the jacket...yes)*

John stated that he had to follow a regime of applying his PGs first followed by the splints as the splints limited his ability to use his hands:

*John: Ja ek het altyd so begin drukklere aan te sit dan die spalke...want saam met die spalke aan kon ek eintlik nie baie doen nie...(Yes I always began with putting the PGs on and then the splints...because I couldn't actually do much with the splints on...)*

John and Ann explained that they needed assistance with the maintenance of the PGs:

*Researcher: ...en sê net vir my met die was van jou drukklere, wie het dit vir jou gedoen? (...and tell me about the washing of your PGs, who did that for you?)*

*John: Oh dit was nou eintlik my ma gewees! (Oh, that was actually my mother who did that!)*

*Researcher: Okay and in terms of washing and wearing the garments...did you do that yourself?*

*Ann: no, no, no they [carers] did it for me...*

#### 4.3.2.3.2 Adherence

Some participants persevered and were able to wear their garments daily whilst some chose to go without them for days.

*Phindi: ...So if you're wearing it everyday like I do, I guess that's why maybe the skin is more smooth now, er and, um, the swelling is no longer there, um and um....*

*Sipho: Everyday, everyday...I just say okay, let me just wear it. I didn't take them off, I wear them...*

*Andiswa: I did wear it all the time but the people think it's a bra or something `cos it just crosses like this, they think it's a bra but I don't have a choice...Ja. So I wear it everytime when I sleep but it was not tight.*

*John: Ja...soos die dae aangegaan het, het ek baie lui gewees...want ek het hom nie eintlik aangesit nie...want ek het miskien nou net...mmm...as ek nou slaap...dan sit ek dit aan, dan die dag sit ek hom nie aan nie. (Yes, as the days went by, I got very lazy...because I didn't really put it on...because maybe I just ...mmm ...if I slept...then I put it on, then I don't put it on during the day...)*

*Mandy: Sometimes, there was like maybe...I would like go without it for three days and my body would pain so much and that would be the longest I would go without it. Yes and I would wear it night and day, night and day...There was only some days where I didn't feel like putting it on...then I didn't wear it night and day...*

One participant continued to wear the PG pants during her pregnancy but was advised not to pull the pants over her abdomen.

*Interviewer: And when you were pregnant, how did you manage?*

*Fleur: I had to wear it but I had to put it down...*

*Interviewer: Underneath...so you even wore it while you were pregnant?*

*Fleur: Yes.*

Some participants stated that they just did what they were told even though they had stated that they understood the reason for wearing it.

*John: So wat hulle vir my gegee het, het ek gedra...Hulle werk was gewees om te doen wat hulle gedoen het en ek het maar nou net gedoen soos hulle sê. (So what they [OT] gave [PGs] me, I wore. Their job was to do what they were meant to do so I just did what they told me)*

*Andiswa: I don't have a choice. So I have to do everything they [OT] say I must do...*

*Ann: Why was I still doing that? Because this is what they required of me and I was doing what they told me...And I just automatically did what they [OT] wanted me to...*

#### 4.3.2.3.3 Time

The length of time that participants wore the PGs ranged from one and a half to four years.

*Sipho: It's something like one year, one ...one year, one and a half years.*

*Phindi: ...Almost two years ...No, they said... when they first put me on the pressure garment they said it would take two years.... But, um, because they think they saw the improvement then they say they would still like to keep me on the pressure garment...*

*Mandy: Almost three years...December... two and a half years, December will be three years...*

*Fleur: ... It's been like long! I think four or five years that I had this thing!*

### 4.3.3 Factors Impacting Pressure Garment Therapy

As presented in Table 4.3 there were two distinct themes that describe the participant's experiences that impacted PGT:

- Factors that enhance adherence
- Factors that contribute to non-adherence

#### **4.3.3.1 Factors that enhance adherence**

##### *4.3.3.1.1 Support from family and staff*

Participants described support from the family in terms of encouragement and physical assistance of donning and washing the PGs:

*Fleur: With the support of my husband and them who told me I must wear it [PG], you know. Ja. And my husband encouraged me also to do it and so I said okay. Because I didn't want to have this, this, this, this...*

*John: ...my ma het altyd vir my aangemoedig. Jy moet dit net doen, jy moet dit doen, jy moet dit doen...(...my mother always encouraged me. You must just do it [wear it], you must do it, you must do it....)*

Participants described various interventions by staff that they felt were of significance to them. This included physical and emotional support.

*Researcher: Okay, so het die verpleegsters vir jou gehelp om dit [drukklere] aan te sit? (Okay, so did the nurses help you to apply your PGs?)*

*John: Ja, vir die broekie ja.... (Yes, with the pants, yes...)*

Ann explained that she was able to remove her PG socks independently but required help from her carers (employed by her sons) to apply them. She also noted that the carers washed her PGs:

*Ann: And when I came out [of hospital] I was able to take the socks off ...*

*Researcher: Okay but you needed help to put it on?*

*Ann: Put it on yes... [with carers help]*

*Researcher: Okay and in terms of washing and wearing the garments...did you do that yourself?*

*Ann: no, no, no they [carers] did it for me...*

*John: Ja, okay hulle het mos hulle talks gehad...hulle, hulle...hoe kan ek sê?...hulle speeches wat hulle het....net vir jou om te aanmoedig... (Yes, okay they [OTs] had the talks....they, they...how can I say?...their speeches that they...just to encourage you [to wear your PGs]....)*

*Sipho: Ja it will help you because they were just talking about all things...general things, you know...now I'm not talking about the outside wounds but we were also emotionally affected but she will really, really help me because they were not only giving me the tubigrips and the PGs. They were also advising me like you can still do things...things like that. They did give me that confidence.*

#### 4.3.3.1.2 Inner strength

Participants described personal attributes which helped them cope with their situation. Even though it was difficult participants described that determination and keeping positive made them wear the PGs.

*Mandy: I just started changing the way I think...just be more positive and get rid of all the guilt, it just holds you down...You have to learn to be okay with it, it's just not something that you can get used to easily wearing [PG] but eventually it becomes like part of your life...it's normal.*

*Mandy: Yes...I always try and motivate myself and say okay now I must really start taking care of my scars...*

*Phindi: But I guess you just tell yourself that you have to put them [PGs] on so that they can help, somehow I don't know?*

*Sipho: No because I wanted to wear it, I wanted to heal properly...I just say okay, let me just wear it*

#### 4.3.3.1.3 Knowledge

Participants felt that education and knowledge regarding the burns and their treatment was important to understand and comply with treatment.

*Phindi: ... it's [wearing the PG] alright `cos you know the reason why you're wearing it and it's because you know and they explain it to you before they give it to you, so they explain it, they show you how to wear it...*

*Sipho: This pressure garment...I said "Hey am I gonna wear this like all the time?!" They say "Ja you must wear it all the time". And they show me some pictures there on the wall. "You see if you don't do this then it's gonna look like that. If you do this then it's gonna end up like this." So I said okay I want my skin to be soft ... `cos they explained to me it's gonna take maybe two years for me to wear the tubigrips [PGs]*

*John: ...OTs het vir my geleer wat die garments en so...Ek het verstaan hulle werk, ek het hulle werk gedoen soos hulle gehê... Wat hulle vir my explain het, het ek verstaan. (OTs taught me what the garments and so...I understood their work, I did their work how they wanted...What they explained to me I understood)*

*Mandy: Um, it [OT] just informed me on how to look after my scars...you know...um...I think was really good because, um, she [OT], um, emphasized on how important it is to take care of them [scars] now...because it [wearing PGs] will have an effect on how they [scars] will look later. And she was very strong with that...*

Mandy describes how she was not given a choice in the garment design, but the reason for being given that type of garment was explained to her resulting in her wearing the PGs.

*Interviewer: Did you choose the, the design of the pressure garment? Did you choose to have that `cos you didn't burn on your right hand did you?*

*Mandy: No.*

*Interviewer: But you got a sleeve on the right hand?*

*Mandy: Ja, they say it will, it will...has to balance...otherwise it [PG] doesn't fit properly or something like that...*

#### 4.3.3.1.4 Seeing a difference

Participants explained that seeing a physical improvement motivated them to wear the PGs. This sometimes included feedback from the therapists.

*Bongani: I see it because, this, this leg...also even here in my knee, it was very big [swollen]... I see the difference. Yes that's why I'm always to put it on*

*Fleur: It was pressing my skin but it was fine because now I can see the change than before*

*Sipho: It's really, really working. My skin is soft I can, feel it, it is soft*

*Andiswa: I see what the reason why they give us these things...and then when I checked it, it was coming flat and soft...I think it was helping me a lot...*

*Mandy: I just get feedback on...`cos obviously they only see my scars once every three months so they can maybe see it's getting better and stuff...So they will see if I have been wearing my pressure suits and that I've been massaging and stuff. They would let me know if it's looking better or not so I guess they just give me feedback on something that I can't see really `cos I see my scars everyday.*

*Phindi: Yes I...they are getting better slowly, they are, but the improvement is there, even though it's very, very slowly. But I can see the improvement....Actually my expectations is already been there because, er, it was very rough now its, er, its smooth now*

#### 4.3.3.1.5 Seeing other people's scars

Some participants stated that they could see the difference between their scars and those of other people who did not comply with PGT:

*Phindi: Like I know someone that I'm still in contact with, she stopped coming here for her pressure garments and, er, she asked if I'm still coming. I said yes I am still coming. And she said, um, she said she stopped and now she's regretting that why she stopped because,*

*um...she was burned, at the back. And now she was, er, like itching a lot. Because, er, she was itching a lot, she was scratching and scratching and scratching and so apparently her back was like now, um, I don't know whether it was swelling or but, er, I don't know if the skin is growing...*

In addition they wanted to offer support to others:

*Andiswa: So I told her if you didn't drop out...but she gonna be fine, I told her she must go and wear all those things [PGs]. And then she was, she was telling me "I'm wearing it now."*

*Andiswa: And then I talk to her [burns patient], just wear it [PGs], it's going to help you really...You must not think about what the people are going to say about you, just because you are burnt now. They are going to say something even if they saw your scars mos, so you must wear it [PGs], just because it's your life, it's not theirs...And then I said, I'm like an example to them just because I know when you get to the burns unit, you just lose hope.*

#### 4.3.3.1.6 Enablers to accessing the service

Many participants noted factors that made it possible to access out-patient PGT. This generally included financial and transport assistance, support from the employer and accessibility and referrals to other services.

As a state pensioner Ann received free health care services.

*Ann: ...it didn't cost me anything at the hospital...*

Receiving a DG assisted in paying transport costs:

*John: Ja ek het vir iemand betaal vir petrol tot by die hospitaal, hy was altyd 'n gewillige mannetjie sien...oorkant die pad sien en ons het altyd iets in sy hand gedruk het... (Yes, I paid someone for petrol [with money from the DG] to get to the hospital, he was always a willing guy...over the road...and we would always put something [money] in his hand...)*

*Sipho: ...after coming out from hospital because they give me that six-month temporary disability... Ja it really helped me because that time I was also having a kid and that and I also buy some ointments for my skin `cos my skin is very sensitive after that thing [PG] that I got...Yes I used it sometimes to get to the hospital and also for the food..ja...*

Sometimes family assisted with transport. Being wheelchair-bound at that point made it difficult for John to access public transport and living near the hospital also made it difficult to access hospital transport:

*John: ...my suster het altyd vir ons gedrop hier... (...my sister always dropped us off here)*

*Interviewer: Okay, so jy het vervoer gehad? (Okay, so you had transport?)*

*John: Altyd vervoer gehad... (Always had transport.)*

Phindi noted that her employer was supportive and aware that she needed to attend OT for replacement of her garments and skin checks.

*Phindi: Yes I told them [employer] in...I even told them on my interview that they know, that they know that if they take me, they know I have my appointments to attend. So they, they're fine with that. I just need to tell them in advance...I have the whole day off, like today I'm not working today...*

Referral to other OT services and plastic surgery may determine whether the participant will be able to access PGT elsewhere and if they will be requiring extension of their PGT if further surgery is indicated. Fleur received a referral note for PGT and plastic surgery in France but she was unable to access this. She therefore returned to Tygerberg PGT so that she can access the plastic surgeons there:

*Fleur: So when I went to overseas, when I went back to France, she, she [OT] wrote me a letter what's going on with my skin and everything, so she asked me if I could take that paper to France because I was supposed to go back to France to do the skin, but then we couldn't do it because they didn't have any surgery. So I had to*

*come back here and I came back and I see her and I asked my husband to e-mail her [OT] to see if I could see her because I needed to see her...to talk to her and see if I can get an appointment with the doctor.*

*Sipho: And the, the OT they just send me to the doctors [plastic surgeons] there.*

*Phindi: So they [OT] said that I go to the plastic surgeon... they [plastic surgeon] will, erm, they will have to cut me again...*

#### *4.3.3.1.7 Satisfaction with the OT service*

All participants were generally satisfied with the overall OT service. Most highlighted positive aspects related to the staff and service, such as being friendly, efficient, caring, understanding, approachable and flexible with appointments:

*Sipho: They really, really helped me. I was very impressed with the way they were helping me. I was very, very impressed. Even for me, if I know that my date tomorrow...I got my date tomorrow...I didn't feel like eish, I got this problem to go to the hospital. I just say okay it's alright because I know that they just ask you "How are you?" They check if there's any improvement.*

*Mandy: Nice. It's always nice to be here, everything is fine...Like they help me as soon as they can, sometimes I wait long, sometimes I don't but that just depends on what time you get here. There's nothing bad that I can say about the service...*

*Bongi: No, the, the service is...the service is here [OT] is very good. Really! Because even now I got an appointment...when I'm coming here for Mrs Rogini [OT]...what's the old lady [OTA]...that ma whose always working there for...sewing...Everything is all ready, she knows my appointment, she already takes some measurement, when I came it's ready.*

*Sipho: ...if I call them they say okay we are going to give you another date. And they just check there quickly, oh you were supposed to be*

*on this date...ja maybe yesterday or last week Thursday is it? Okay we are going to book you for another date. And then when I come, it's okay.*

*Phindi: At the OT, um, the service has been, um, has been, has been good. Um, they, it's like you know they're very understanding, more like they...they've been there. They know what you're going through even though they've never been burnt before but it's like they've been burnt themselves. And, um, they make you comfortable, when you... you know when you're in my situation when you go for your appointment it will be, um, it will be, um, very difficult for you to, if you go there and find people who are not friendly and, um, people would be, like, who you know, they're friendly and they're not scared to touch you and they ask you, they ask you every time you go there "How are you feeling?" Um it's like, um, different, um, they're, I don't know how to put it, but they're very understanding and they care about what is going on to you and how you're feeling and the progress...*

*Ann: No I'm sure that if I got any queries that I could phone Dr. Pillay [OT] and she would give me the lowdown on this you know but I just haven't had the occasion to do that...*

Mandy explained that the familiarity with the OT staff made it easier to attend appointments. She considered the staff as 'family' having known them for almost three years:

*Mandy: I feel like even though I only see them once every three months, I feel like oh I know them or like Mrs. Lucas [OTA] is my grandmother or something like that. So I feel very at home when I come here. I feel...ja it's okay, it's nice. It's nice seeing their faces... They, they just, um...I don't know...they're just comfortable like they just make you feel comfortable even sometimes when they scold me if I didn't do this or I didn't wear that, they...Not scold, ja they...but I obviously don't still...It's almost like family, I've been coming here almost three years, every three months, so it's...ja I get along well*

*with them... familiar with them... So just being comfortable with them is a bonus.*

Fleur noted that she was not treated indifferently even though she was a 'foreigner':

*Fleur: The service is fine, I like the service. No, no, they're friendly! They're really friendly, when I ask them something they tell me, they explain to me no you need to do that... Very friendly, I was surprised to see them you see...it's not like other doctors and then they look at you and then like no...They're very friendly, they knew that I'm not from here you see because of my accent.*

Phindi highlighted being treated with dignity by being offered privacy whilst getting undressed during treatment. She also noted that the staff were not scared to touch her:

*Phindi: Yes I, er, feel very comfortable because once I get in the door, close the door, lock it. And then they, they also have something to cover...*

*Interviewer: The screen?*

*Phindi: Yes, the screen, yes. So that if anyone at the door, this person they ...*

*Interviewer: They might be able to come in but they....*

*Phindi: But they won't be able to see me.*

*Phindi :....you know they're friendly and they're not scared to touch you.*

John noted that OT gave him the opportunity to engage in work, whilst Siphon highlighted engagement in leisure and social activities. These are important factors as participants noted earlier that some of the socio-emotional effects of wearing PGs resulted in social avoidance and impacted on aspects of work:

*John: ... hulle het my gehelp dat ek by 'n werk in is...Nee, daai wat hulle vir my gehelp dat ek by die werk is, het hulle vir my exposure gegee. (They [OT] helped me to get work...No, that that they helped me with getting a job, they gave me exposure)*

*Sipho: I like the way you [OT] were just giving people that thing, they must also go there and play some pool.*

Phindi highlighted that she did have some choice or say in her treatment:

*Phindi: Um I can't remember exactly, if had a choice but, er, they did take measurements and, er, I'm the one, I think I'm the one who said it would be better if I, it [PG] goes all the way up so that it can, it can stay more longer because I think if it was like, er, for the thighs and for the, for me it would be uncomfortable because at some point you will have to keep on doing, keep pulling, keep pulling it [PG] up. So I'm not sure about the choice but I think I did have the choice because when they took the measurements I told them that I would prefer it to be...*

#### **4.3.3.2 Factors contributing to non-adherence**

##### *4.3.3.2.1 Lack of support from family and staff*

Just as participants highlighted the value of support, some participants noted that a lack of support negatively impacted adherence to pressure garment therapy.

Mandy stated that she received physical assistance from her sister but this dissipated when she got a boyfriend:

*Mandy: So she used to massage me and then she met this guy and then she stopped it [laughs] because she didn't have time for me!*

John noted that staff attitudes and their unwillingness to assist him made it difficult for him comply with wearing his PGs as he struggled to do things for himself:

*John: Hulle wil nie dit eintlik doen nie...want hulle is gesê by die OTs of by die students "he must learn to do it himself"... (they [nurses] didn't actually want to do it [apply PGs and splints] because they were told by the OTs or the students "he must learn to do it himself")*

##### *4.3.3.2.2 Emotional turmoil*

Many participants described personal difficulties in dealing with their situation and how that negatively impacted PGT adherence. The various emotional reactions are well presented by these three quotes from John:

*John: ...maar ek was net 'n bietjie lui by my kant....ek hoor wat julle sê maar is 'n bietjie swaar vir my...daai tyd (...but I was a bit lazy from my side, I heard what they said but it was difficult...at that time)*

*John: Dan is daar tye waar ek warm gewees dat ek nie smaak nie om aan te sit nie...ek het nie lus gehad nie...ja, dis al wat ek kan vir jou sê...ek het nie lus gehad om dit aan te sit nie... (Then there were times that I got hot and I didn't feel like putting it [PG] on, that's all that I can say. I just didn't feel like putting it on)*

*John: Ek kan dit sien...hulle het vir my aanmekaar gesê ...“Jy moet jou tubigrips aansit...jou, jou, jou splints moet jy aanhou”...maar vir my was dit net “Hey, ek kan nie nou nog eintlik vir jou kop toe vat nie...” in 'n tyd soos nou wat ek beseer...ek hoor wat julle sê maar is 'n bietjie swaar vir my...daai tyd. (I could see it...they told me repeatedly “You must put on your tubigrips, your, your, your splints you must keep on”...But for me it was “I can't actually take you seriously”...not now that I am injured...I heard what they said but it was a little difficult at that time....)*

*Mandy: There were times when I just wanted to give up on it [PG]. This whole...like I didn't want to care anymore...There was only some days where I didn't feel like putting it on...*

Mandy noted that her scars affected her self-esteem. She noted that the PGs were just an attempt to make the scar look better but that the scars itself were not going to go away.

*Mandy: I feel like it's [PG] just trying to make a scar look nicer. A scar that's always going to be there, it's still a scar, it doesn't matter how it looks, it's still there, you know what I mean? It's like putting lipstick on a pig [laughs]...Something like that...*

Andiswa feared that if she didn't attend then it could affect accessing future services and thus preferred to keep her options open by attending.

*Andiswa: I will go there [OT] until they tell me to stop now, it's for my health. What if something happen again then they not gonna take you maybe...*

#### 4.3.3.2.3 Not seeing a difference

Mandy stated that she could not see the improvement in the scars for herself but in the same breath stated that pictures of her scars do show an improvement:

*Mandy: ...the thing is I don't see my scars getting better, maybe someone else will see the improvement...to me they still look the same... something that I can't see really `cos I see my scars everyday. If I look at pictures...I can show you...pictures of when I just got out of hospital how it looked compared to now...big difference...*

#### 4.3.3.2.4 Barriers to accessing the service

Participants described several factors that made it difficult to access the service, such as financial and transport issues and limited burn services. This was their own experience or what they saw or heard from other burns patients. Another factor that made it difficult to attend was personal responsibilities. The first three quotes below describe financial issues experienced by themselves and from other patients:

*Sipho: Ja, sometimes I used to call them, hey I'm not gonna make it because I don't have money. It's a lot of money...The situation is bad...*

*Phindi: you know you need to come for your treatment, you need, you need to come for your things and you're not working, you don't have the money to come, you know...*

*Andiswa: ...The other lady with the...here in burns, we used to call each other. She told me that she don't come here [OT] anymore. I ask her why, she said no, I don't have the money to go there...*

Ann and Andiswa experienced difficulties with accessing the service due to transport challenges. Ann has to arrange private transport to attend appointments:

*Ann: Er, but I find it very difficult to get to the hospital and all that. In the early days they used to sort of have a combi that used to fetch you and you paid them so much, you know to take you for the out-patients and...But they don't have that anymore and it's very difficult and I can't, er, I can't get high up with my body, er, onto the taxis and the lot you know...So I have to depend on somebody taking me.*

Andiswa uses the government health non-emergency transport (HealthNET) but highlighted that problems experienced with this service resulted in missed appointments. However she took initiative and would wait for an available space on the 'ambulance' as there were always patients who would not attend:

*Andiswa: But the only thing I can think about is that I want to drop out for a session to come here just because of the ambulance...that I want to come ne for my appointment but sometimes they gonna say the ambulance is full...they are going to say the ambulance is full until let's say September...so I just go there and just because I know that not all of them [patients] are gonna come yes. And then I used to do that just because ...that's why I do attend my appointments...*

Andiswa was under the impression that there were no OT/PGT services in the Eastern Cape and opted to remain in Cape Town so that she can access the service.

*Andiswa: They said at home I must stay there, I must get the treatment but I said no, there no OT in Eastern Cape, OT only in Cape Town.*

Mandy highlighted the fact that there are limited PGT services. Besides private services, the three hospitals offering PGT in the metropole are Tygerberg, Groote Schuur and Red Cross Children's Hospital. The latter two were not accessible to her because of her age and where she resides geographically.

Participants noted that having other responsibilities to tend to resulted in them not being able to attend PGT appointments:

*Bongi: Yes, it was the first time to skip because my appointment was on the 6th...But I was taking a course...I did phone for Mrs Rogini...*

*Fleur: Like the last month I was supposed...the few months that I was supposed to be here but I couldn't because I had to take my child to the hospital.*

#### **4.3.4 Participants' Recommendations**

Participants gave recommendations to enhance the overall management of burn injuries (not exclusive to OT or PGT). Four distinct themes were identified: staff attitude, colour of the PGs, knowledge and education and counselling.

##### **4.3.4.1 Staff attitude**

Mandy felt that the nurses could be more understanding and supportive. It should be noted that although John stated that the staff (nurses and OTs) could have assisted him in the early stages he didn't actually note this as one of the recommendations.

*Mandy: They just need to be a bit more...um...instead of reprimanding being more supportive or just you know...ja. Don't like shout at me for getting hurt, because it hurts...*

*Mandy: I just think that the nurses must just try to be more supportive...or sensitive...*

##### **4.3.4.2 Colour of pressure garments**

Three of the female participants felt strongly that the colour of the pressure garment material could be changed to more 'natural' colours such as black and brown.

Andiswa felt that darker colours would suit people with darker skin tones better:

*Andiswa: I think I don't like this colour really...Most of the people who are burnt are not like this colour [beige], most of the people who are burnt are like black people ne...if you wear a brown one and the brown one is very nice, I like the brown one...I think if you can try to get this material in brown and even to put it on like this, it's fine. Ja, I think so...At least when it's brown, people will think it's a vest or something...*

Mandy felt that if the material colour was changed it may enhance adherence:

*Mandy: Like they had a brown one for a while and that one was nice, was much nicer because it looked more like a clothes colour. Like if they gave like the normal brown, the other colour that goes with things then that would be fine. You'd want to wear it more.*

Phindi noted that having a choice in colours, not just one colour would also be preferable. Darker colours would also make maintenance easier:

*Phindi: So if they could maybe have more colours like...*

*Interviewer: You mean colours as in... you wear a skirt or something, if you wearing a blue skirt then maybe a blue...*

*Phindi: Or maybe like more black or brown, the natural colours... So I used that brown one, I liked that brown one because it doesn't get dirty so quickly and even though I put on that Haarmanse, it doesn't show very quickly, um ja. So that is why if they could at least try to get that brown or any other colour `cos this one is very light, it gets dirty very easily even with bio-oil `cos bio-oil is oily...*

#### **4.3.4.3 Knowledge and education**

Participants recommended that educating and informing patients about their burns, the interventions and giving them alternative options were essential to improve outcomes:

*Sipho: Mmm, I think that the only thing that you can do is just let the people who got the burns, they must know for the very first time you visit them, the importance of the tubigrip. You mustn't just give the tubigrips to the people and say okay you must wear this. Explain it thoroughly to them. Because for me I think it can even change, it can even make the burns more better...ja things the only thing to do to me is just explain thoroughly to people. They must know the consequences and the results of it...*

*Andiswa: To make them [burns patients] understand why to wear those things just because the other lady who was sitting with her there ...She told me she don't like those things. I told, I talk to her...*

*Mandy: I think, um, there should be someone here that can get in touch with patients, like fully discuss with the patients about the options of treatment...either the injections or the skin grafts or the... Ja more information about the different techniques because when you get burnt you don't know what to do because you didn't expect it to happen so you haven't researched anything...*

Mandy also highlighted the importance of making an informed decision.

*Mandy: So they should give people more information about the different treatments that they, they can do and let people decide what they feel is best and then...someone to give them an opinion what they think is best and decide together instead of just...instead of just rushing with some operation...*

#### **4.3.4.4 Counselling**

Mandy and Phindi felt strongly that the counselling aspects could be significantly improved especially after being discharged home.

*Mandy: Um, I think people take...not for granted but little...um, um, they don't really hear how much power, um, knowledge is or emotional support can be...just preparing people mentally, you know. Focus more on how people are feeling...I think their counselling needs to be better. Yes, ja, I think a little more counselling and talking to the people not just about look after your burns and just do this and do that...like emotionally...It's up to me at the end of the day. That's why I say that's where the counselling comes in as well. You need to...I don't know...not empower...just make people more...just make people see things differently and I think they will...*

*Mandy: The knowledge about accepting it...As well. Helping it look better...Heal and stuff, and looking after your scars and at the same time accepting whether they're going to go away or not.*

*Phindi: You know if they maybe provided therapist or something it would make it much easier for you to deal with the 'new you' because*

*you were not used to yourself being like that and now you're like that...*

Phindi noted the importance of having professional counselling services and being referred appropriately once discharged from the hospital:

*Phindi: Talking to someone who is more experienced, who is more listening because talking to someone, like me talking to my mother, or me talking to, to my husband, they listen but they won't know what the right words to say to me... you know. So it's not the same...I'm just saying that things like that could be very helpful and things like that could prevent more damage that could be done. The hospital needs to make sure that you are maybe transferred to, er, someone to talk to or someone that can help you, you know...once you, once you discharged at the hospital. `Cos while you're in the hospital you just want to, you just want to get better, to go home to be with your family.*

#### **4.4.4.5 Other**

Some recommendations looked at enhancing current OT services on the ward whilst two participants noted that catering could be better.

*Sipho:... and play some pool. I think, I think that the games you were giving people there...I think if we could put more of that in the...the gym equipment...I think that would make it a lot nicer...*

*Mandy: Um...nicer food! [laughs]*

*John: ...hulle kon my meer tee of cooldrink aangedra het of so nie...(They [reception staff at OT] could have offered more tea or cooldrink or something...)*

## **4.4 Chapter Summary**

This chapter started by giving an outline of the participants' demographic and burn profile. It then presented four themes derived from the analysis of the interview data.

The first core concept, consequences of the burn injury, focussed on findings not related to the study objectives but are of significance to gain a perspective of the

participants' overall experiences. Themes that emerged from this core concept included loss of function, loss of participation, loss of self-confidence, financial dependence, emotional impact and impact on relationships.

The remaining three concepts were derived from the objectives of the study. The third core concept focussed on the perception and usage of PGs. Three themes emerged from this concept, namely physical effects, socio-emotional effects and wearing schedule. The fourth core concept looked at factors affecting PGT adherence and the themes of factors that affect adherence and non-adherence emerged. Several sub-themes were derived such as support or lack of support, knowledge, inner strengths or emotional turmoil, seeing a difference or not, seeing others, satisfaction with the OT service and enablers or barriers to accessing the service.

The last concept concluded the chapter by presenting the participants' recommendations on the overall burns service. It highlighted the themes of staff attitudes, colour of PGs, knowledge and counselling.

The following chapter presents the discussion of the results.

## Chapter 5 Discussion

### 5.1 Introduction

This chapter discusses the results of the study in relation to the study objectives. The aim of the study was to explore burn survivor's experiences of PGT. I believe doing this i.e. viewing care "through the patient's eyes," is part of my professional and ethical responsibility (Kravitz, 1998).

The Health Action Process Approach Model (HAPA, Schwarzer, 2011), as presented in Chapter 1 is used as the theoretical framework for the discussion. In addition the Western Cape Department of Health's strategic plan *Healthcare 2030* (Western Cape Department of Health, 2013) is used as a guiding document in this discussion.

*Healthcare 2030* (currently a draft framework) represents the third major review of health services in the Western Cape since 1995. It builds on the *Healthcare 2020* plan and "moves away from a curative paradigm of treating illness and disease to one of prevention, promotion and wellness" (Western Cape Department of Health, 2013, pg. ix). This is in accordance with the WHO definition of health. The vision for quality of care within the 2030 strategy includes an "individual dimension as seen through the eyes of the patient": patient-centred experience (PCE) (Western Cape Department of Health, 2013, pg. xiv). One of the four conceptual pillars of patient-centred care is a person-centred approach (Western Cape Department of Health, 2013, pg. x).

### 5.2 Use of Pressure Garments

The findings revealed that PG usage as described by the participants was contentious. Daily wearing schedules varied. Although most participants felt that they were generally compliant they did not follow the instructions precisely: some only wearing their garments whilst sleeping and others went without them for days. This may result in poor scar outcomes, delayed scar maturation and extended therapy (Zurada, Davids, Kriegel & Davis, 2006, Ripper *et al.*, 2009 and Pendleton & Schultz-Krohn, 2012). The underlying principle of PGT is the application of consistent pressure on the scar tissue (Ripper *et al.*, 2009). Failure to do so, or only doing it intermittently especially in the early stages when the scars are most active and the PGs are most influential, may cause the therapy to be ineffective and result in the

development of hypertrophic scars (Zurada *et al.*, 2006). As the treating clinician, I can report that four of the participants did not comply well in the early stages of therapy and only started wearing their garments more consistently between four and six months into therapy, some even later than that. Zurada *et al.* (2006) noted that PGs may be less effective after six months of treatment. As noted by Malick & Carr (1982) scars are relatively flat in the early stages and patients may not see the need for any intervention. It should be highlighted that the purpose of PGs is to prevent hypertrophic scars from developing in the first place. In my experience once the scar gets hypertrophic, which may be as a result of not wearing the garments consistently, it is almost impossible to revert to a completely flat, 'good looking' scar. Unfortunately it is only at this point when burn patients' intention to initiate health behaviour is activated.

Mandy noted that it is highly unlikely that anybody can comply with the regime (the protocol for PG use at TAH is described under 2.6). This supports Stewart *et al.* (2000, pg. 601) which found that although "70% of the participants stated that they adhered to the prescribed schedule, 30% reported wearing the garments for no more than 10 - 14 hours per day."

Optimal scar outcomes require that garments are worn until scar maturation is attained, usually between one and two years (Malick & Carr, 1982; Zurada, Kreigel & Davis, 2006; Pendleton & Schultz-Krohn, 2012). In this study it was noted that the length of time that participants wore the garments ranged from one and a half years to four years. The extended therapy time may be due to poor adherence, prolonged wound healing which delays the start of PGT and delayed reconstructive surgery (Stewart *et al.*, 2000 and Pendleton & Schultz-Krohn, 2012). All these can result in the scars taking longer to mature. As some participants were still attending PGT and plastic surgery clinics, there may be even further extension of the rehabilitation phase. An example of the above would be Fleur who refused a skin graft initially and is now in her fourth year of PGT and is receiving steroid injections into the scars to soften and prepare them for surgery.

A qualitative study by Williams, Davey and Klock-Powell (2003) described the notion of time as significant to the participant's level of adjustment. Several of the participants in their study referred to the passage of time as part of the recovery

process (Williams *et al.*, 2003). As noted in the literature, burn survivors have to endure long and intensive rehabilitation and the findings of this study have demonstrated this very clearly.

### 5.3 Outcomes of Pressure Garment Use

According to the current findings physical benefits of PGT included scar shrinking and improved scar colour. Anzarut *et al.* (2005) also found a small but statistically significant difference in scar height. Improved colour is probably due to the basic principles of PGs (i.e. constant pressure on the scars decreases oxygen supply to the scars hence accelerating scar maturation) resulting in a less 'red' and active scar (Ripper *et al.*, 2009). This study showed that PGT was perceived as beneficial by the participants in terms of scar appearance and can be described as good outcome expectancy and thus motivational in terms of the HAPA model (Schwarzer, 2011).

Literature shows contrasting findings regarding the impact of PG on mobility. In the study by Ripper *et al.*, 2009 (n=21) 70% of participants complained about 'problems with mobility' resulting from PG usage. Findings from the current study showed that participants felt that although 'tight' the PGs did not limit movement and some even felt it enhanced their mobility. This, however, was congruent with the findings by Ripper *et al.* (2009, pg. 661) which found that "a few even felt an 'improved mobility' of the affected areas right after taking off the garment."

Stewart *et al.* (2000) and Ripper *et al.* (2009) found that the PGs might cause pain and skin breakdown. In the current study participants did not agree on this effect. Most noted that the garments were tight and uncomfortable but did not indicate pain or skin breakdown as a result of wearing the PGs. The one participant in the current study who experienced skin breakdown initially received 'ready-made' PGs that were meant for another patient. There is a possibility that this garment did not fit as well as a custom-made one would and caused the skin breakdown. Due to the low adherence of patients with TAH's PGT service (22, 5%), as described earlier in Table 3.4, garments are often made and not 'collected' by patients. These unused garments are not discarded (due to the costs involved) and are issued to patients who have similar or smaller measurements and need to start PGT immediately. Further delays will be detrimental to scar appearance and impact negatively on

already financially-strapped patients who cannot attend therapy frequently. This also assists in keeping waiting lists (for new patients) to a minimum. These garments are adjusted to meet the needs and measurements of the patient as far as possible. In addition, measurements are taken and custom-made garments are issued to the patient on the next visit. It should be noted that although it appears that this option is easier for the staff, adjusting garments is actually more time consuming, requires extra effort and experience and results in a less 'presentable' garment (after opening, cutting, re-stitching). The situation may not be ideal but it is sometimes necessary.

Stewart *et al.* (2000) noted that none of the clinicians in their study felt that garments were poorly constructed whereas 46% of the patients felt that this could have been the reason for discomfort. These findings, as well as the situation described above with the use of 'ready-made' PGs, highlight the importance of custom-made, well-constructed garments. Although the challenges of staff shortages, work overload, costs saving measures and inexperienced staff are acknowledged, treatment protocols and guidelines need to address these issues to ensure a person-centred approach.

Other complications noted by participants were the perception that the PGs caused increased urination and 'bringing out veins'. No literature that supports or refutes these findings could be identified and this needs further exploration in a quantitative study.

#### **5.4 Facilitators and Barriers to Wearing Pressure Garments**

The study by Ripper *et al.* (2009) looked at impairments caused by PGT whereas this study highlighted specific consequences of the burn injury itself which could have an impact on PGT. Ripper *et al.* (2009) used the HAPA model to describe and discuss the 'impairments' of the PGs, the 'resources' and 'reasons for non-compliance.' The HAPA model was therefore used to analyse the emergent themes of the consequences of the burn injury to understand the health behaviour of the burn survivor prior to commencing PGT (Ripper *et al.*, 2009). The findings from the current study indicated that the consequences of the burn injury that impacted PGT could be viewed as 'facilitators' or 'barriers' to wearing the PGs. These are elaborated further in the discussion that follows.

#### 5.4.1 Factors That Facilitate Wearing Pressure Garments

Although studies by Stewart *et al.* (2000) and Anzarut *et al.* (2009) concluded that the benefits of PGT on scarring remain unproven, participants from this study felt that effect of PGs on scarring was beneficial to them. According to the HAPA model, improvement in scar appearance can be seen as a 'resource' and affects 'outcome expectation', and thus use of the garments. Several of the participants shared the perception that the PG resulted in improved scar appearance and they further explained that seeing a physical improvement motivated them to wear the PGs.

However, participants had differing opinions on how much the scar improved. One participant stated that although there was improvement, the scar cannot be compared to normal skin, whilst another felt that it was not different to her own skin. Skin is a complex structure and the effects of scarring are dependent on the extent of the tissue damage (Groves, 1987). Scar development is also dependent on race (increased risk in non-whites), anatomical regions and age (Wolfram, Tzankov, Pulzi & Piza-Katzer, 2009). As participants had varying severity of burns and surgical procedures, as well as differing levels of adherence, it is understandable that each patient would display varying degrees of progress.

Participants also noted that feedback from the therapists was significant to them. One of the comments I commonly make to patients is that the scars are 'looking good' but the patients sometimes had difficulty believing this. A likely explanation for this is that patients' understanding of what to look for in terms of progress may be lacking or unclear. Another reason could be that the therapist is reviewing the scars from a clinical perspective every 2 - 3 months whereas the patients' see it every day from a personal perspective.

Ripper *et al.* (2009) noted that participants relied on the 'experience and knowledge of medical staff' which is supported in the findings of this study. Taking the above into consideration, it is imperative that therapists explain what they mean when they say scars are looking good. Objective feedback from the therapists needs to be encouraged and explained so that patients have a clear understanding of the progress or lack thereof. This ties in with patient-centred care: it enhances the knowledge of patients and assists them in making appropriate health-behaviour changes. It is especially important when patients start to feel despondent. Williams *et*

*al.* (2003) noted that burn survivors call for health professionals not only to focus on their pathologies but also on the positive aspects and their strengths.

Some participants compared their scars with those of other persons who had burn scars, especially those who did not comply with PGT. This demonstrated the advantages of PGT and assisted them with adherence. Ripper *et al.* (2009) also noted participants using comparison: "Compared to others, I am doing pretty well" (2009, pg.661). Participants also wanted to offer support to other burn survivors. This is important because although participants found that the OT staff was empathetic and understanding, we certainly could not speak from personal experience. Williams, Davey & Klock-Powell (2003) noted that their participants gained comfort from connecting with other burn survivors and by reaching out. A participant in that study noted that it was part of her emotional healing to give to others and to help someone else (Williams, Davey & Klock-Powell, 2003).

Fear of causing further complications by not wearing the garments was noted by two participants. Again, the study by Ripper *et al.* (2009) also highlighted the fear of causing physical harm such as re-opening healed wounds or muscle atrophy. The fear of not complying as this may impact accessing services in the future, is seen as a rational act from the patient's point of view (Stewart *et al.*, 2000). Again, this highlights the importance of knowledge sharing and open communication between therapist and patient. Although the fear itself is viewed in a negative light, the outcomes of that fear resulted in adherence with therapy.

Participants mentioned personal attributes which helped them to cope with their situation. Coping strategies such as 'being positive', 'motivate myself' and 'wanting to get better' showed that participants had good 'self-efficacy' and 'outcome expectancy' as described in the HAPA model. (Ripper *et al.*, 2009; Schwarzer, 2011) Johnson *et al.* (1994, pg. 181) noted that that "the prognosis of outcome in patients with severe thermal hand burns was strongly related to their motivation to co-operate with therapy."

Coping can be equated with resilience, which in turn can be described as an adaptive outcome in response to stress or crisis (Williams *et al.*, 2003). Holaday and McPhearson (1997, pg. 355) noted that "according to the burn survivors, everyone has the gift of resilience within themselves." Williams, Davey & Klock-Powell (2003,

pg. 56) further describe resiliency as a common innate phenomenon and this perspective “implies a belief in the inherent capacity for healing and positive growth in the human experience.” This further explains the self-efficacy and outcome expectancy of those participants described above.

One participant noted that being strong for her baby was the reason for her determination to get better. Williams, Davey & Klock-Powell (2003) noted that participants in their study, especially the women, had the ability to perceive the hardships they had endured as positive outcomes for themselves. These unexpected gains (personal growth such as gratitude, self-esteem and insight) could significantly impact on the individual’s ability to ‘plan, initiate and maintain’ their health behaviour (Schwarzer, 2011).

The above concept can also explain the receiving of a DG as a gain. Impairment during the initial stages of rehabilitation resulted in patients being able to access a much-needed resource, a temporary six-month DG. The money was used to pay for transport and access therapy amongst other things. The criteria for qualifying for a DG are based on individual circumstances, not purely on physical impairments, and qualification is a joint MDT decision. As a state hospital TAH cares for many patients who are unemployed at the time of injury or are unable to return to their casual jobs. This exacerbates the financial stress on the patient and the need for financial support is therefore acknowledged. Patients who sustained more permanent complications were able to access permanent DGs. This is useful to contribute towards living expenses.

Riis *et al.* (1992) found that support from relatives and staff assists patients in attaining optimal long-term psychosocial adjustment. Ripper *et al.* (2009) noted that 90% of participants in their study mentioned that support from family was important when dealing with PGT issues. They further described this support as ‘emotional’ and ‘practical’. In this study participants described support from the family in terms of encouragement, financial, transport and physical assistance with massaging, donning and washing the PGs.

Although not mentioned in the findings, I can recall that family members, and the carer, of five of the participants attended therapy with them. Riis *et al.* (1992) highlighted that the premorbid status of psychosocial support also impacted

adjustment. This implied that patients who had good support structures prior to the burn injury generally could rely on this as a resource. Findings from Williams, Davey & Klock-Powell (2003, pg. 67) described the “deepening of old relationships” and the development of new ones following the burn injury.

Participants in this study also noted practical and emotional support from staff and the employer. Participants elaborated that emotional support from staff was in the form of encouragement, advice and motivation. This can be viewed as the development of new relationships and can also be regarded as a resource according to the HAPA model (Schwarzer, 2011).

Satisfaction with a service is important if patients are expected to comply with therapy. Kravitz (1998, pg. 280) stated that “the only way to determine what patients want and whether their needs are being met is to ask them,” which is what this study aimed to do. “Patient satisfaction is not a unitary concept but rather a distillation of perceptions and values” (Kravitz, 1998, pg. 281). Participants in this study were generally satisfied with the overall OT service and highlighted some of the positive aspects related to service such as the staff being friendly, caring and understanding, and approachable and flexible regarding appointments; and having a choice in treatment.

Hall (2010, pg. 17) stated very aptly that patients “must feel that we care and have their best interest at hand, they come to us when they are vulnerable and in pain. It is not only what we say, but also how we say it”. Findings of this study have shown that at TAH the PGT service has achieved some of this and this had a positive effect on overall adherence with therapy.

#### **5.4.2 Potential Barriers to Wearing Pressure Garments**

Consequences of the burn injury such as loss of function, which included physical impairments and functional limitations, could impact negatively on PGT if they are longstanding or permanent in nature. For instance loss of ROM and itching created what the HAPA terms ‘barriers’, as they affected the planning and performance of the person; for instance struggling to don PGs due to contractures of the fingers. However, results showed that self-efficacy and resources assisted participants to overcome these barriers and still comply with PGT. Siphso sought pharmaceutical

interventions to reduce the itching to comply with his PGT ('coping plan'). John's mother became a resource as she helped him with donning his PGs.

Participants highlighted the effort in maintaining and donning the garments. This was dependent on the colour of the garment, the weather, relying on others to wash and apply the garments and using the garments in conjunction with other therapies such as massaging and splinting. As Téot (2005) and Pillay (2008) noted, scar management is challenging and often involves a combination of treatments which includes PGT and other modalities such as scar massage and splinting. The light coloured garments tended to show 'soil marks' more than the darker material and increased the unwanted 'visibility' of the garments. This was worsened by moisturising or massaging and that fact that the garments fit like a second skin and therefore 'absorb' and 'remove' skin cells due to the sand-papering effect of donning and doffing them. It is possible patients felt conscious that it appeared to others that they were not 'hygienic' enough. Ripper *et al.* (2009) noted that participants highlighted the 'additional effort' such as time getting dressed and washing the garments.

"Patients have little option but to comply with the advice and instructions that they receive" (Stewart *et al.*, 2000, pg. 599). Even though patients were given instructions it does not necessarily imply that they were given options in treatment or that they understood the purpose of the instructions. In my experience, patients often fail to question the treatment and just trust what the clinicians have said is the correct thing to do. Once again this supports findings by Ripper *et al.* (2009) and Hall (2010, pg. 17) who noted that "patients entrust their lives to us". Stewart *et al.* (2000) further noted that poor communication between clinicians and patients is a major determinant of negative health outcomes and hence contributes to non-adherence. However one participant in this study complied with wearing garments even though she stated that she did not understand the purpose of PGT.

One of the main findings of this study was that the colour of the PGs was cosmetically displeasing ('disgusting' and 'unfashionable'). Participants felt that the colour of the garment did not complement specific skin tones or their normal clothing. The South African study by Stewart *et al.* (2000) found that although the OT departments of six provincial hospitals in the Durban metropole had beige/tan and

dark brown material available, the majority of patients were issued the beige/tan coloured garments. This was true for the participants at TAH as well.

At the start of the study (2010), PG material was not on the provincial government tender and needed to be sourced as a buy-out from appropriate suppliers. This resulted in varying qualities, huge delays and often only one colour (beige) being offered. At the end of 2011 PG material was placed on the tender and two colours (beige and dark brown) were available but changes in staff to using the dark material were slow.

Patients were therefore only provided with dark brown pressure garments if they specifically requested it (depending on availability) and this generally occurred if they had received the dark coloured garments previously. The OTA also noted that she preferred working with the lighter material as sewing with the darker material was difficult and required more effort in terms of vision (it was difficult to see the dark thread on dark, shiny material). As the treating clinician at that time I was the one to offer patient's the choice of garment colour, as the OTA avoided giving patients the options due to the reason above. It was challenging and often the request became an 'order' and I would physically assist in sewing the dark-colour garments. As garments were also made in advance, an excuse would often be that the OTA 'forgot' that the garments were meant to be of the dark colour. The reason for providing options was explained to the OTA and protocols were amended accordingly.

Ripper *et al.* (2009), a German study, also noted the PGs were cosmetically displeasing but this was not specific to colour. The study by Thompson, Summers, Rampey-Dobbs & Wheeler (1992) noted that public perceptions of coloured pressure garments were more positive than the traditional beige garments (Johnson *et al.*, 1994). It can only be assumed that developed countries have several options in terms of PG material colour. However having several other colours would not be feasible in terms of budget, time and resources as this would mean having different colour thread, zips, and Velcro, as well as having to change the machine thread frequently. But stocking two or three colours and ensuring the every patient has a choice between the available colours is possible.

One participant described not wearing the garments in public because he did not have the courage or strength to face the outside world. Gilboa (2001) noted that the greater the visibility of the disfigurement, the greater the need to support the patient therapeutically to enhance self-image, self-esteem and assist with social integration. Ripper *et al.* (2009) also highlighted 'negative reactions from others in public', feelings of embarrassment and shame in wearing visible garments in their study. This same participant, who sustained head, face and neck burns, was assisted by obtaining a donation of a wig because he did not want to stop using his mask. The mask covered his ears that were badly disfigured. The wig allowed him to discontinue wearing the PG mask as it no longer served a purpose in scar maturation whilst still providing coverage for his ears.

Pallau *et al.* (2003), as noted in the literature review, found that patients with visible scars appeared less frequently in public and therefore showed 'dysfunction' in social and occupational activity. The negative impact of visible scars, for instance on the hands and face, on self-image was found also in the current study. Stewart *et al.* noted that "patients' personal and social living circumstances are crucial to their decision making" (2000, pg. 599) thus impacting on adherence. Scars and skin colour changes contribute to loss of self-confidence which also affects the 'coping planning' of the individuals and hence affects participation in PGT. As noted in the literature, hypertrophic scars can impact negatively on body image and self-esteem (Malick & Carr, 1982 and Pendleton & Schultz-Krohn, 2012). The changed appearance following the burn injury resulted in lowered self-esteem and hence initiation of behaviour (intent) to improve scar appearance. Participants therefore described wearing their tubigrip in the initial stages which was a precursor for PGT. They also noted that they only truly realised the importance of wearing the tubigrip after the fact.

As noted in the literature review changes and improvements in the scar appearance happen slowly and are only noted by careful observation. This can be seen as a barrier according to the HAPA model. One participant stated that she could not see the improvement in the scars for herself but that pictures provided evidence of this. Ripper *et al.* (2009) noted that the most frequently mentioned concerns in their study were high expectations and frustrations about lack of improvement of the scar appearance.

The same participant noted that the PGs were just an attempt to make the scars look better but that the scars themselves were not going to go away. Grove (1987) noted that scars are permanent reminders of the burn injury. A scar will be there for life and only time resolves the degree of scarring (Grove, 1987). Knowing this makes it difficult for clinicians and patients to persevere with treatment. Grove (1987) also stated that clinicians should guard against making promises that cannot be fulfilled. "Reassurance is necessary but guarded optimism is realistic" (Grove, 1987, pg. 15).

Participants felt that education and knowledge regarding the burns and their treatment was important to understand and comply with treatment. "By helping patients feel more comfortable, lessens their anxiety and they are better able to understand what is going on, their treatment plan, and the importance of following through with their discharge instructions" (Hall, 2010, pg. 17). In the study by Ripper *et al.* (2009, pg. 660), 57% of participants felt "inadequately informed about the purpose and intended" effect of the PG.

Once again this highlights the importance of education and re-education at various stages of treatment, and because health behaviour is a dynamic and changing process constant education needs to be encouraged by the therapists. Therapists also need to bear in mind the 'health literacy' status of the patient. "Patients with adequate health literacy can read, understand and act on written healthcare information," (Schloman, 2004, pg. 15) although it should be noted that many patients cannot read or that language barriers may impact their access to written information. For them constant education by the therapist is even more important.

In my experience, some patients sought traditional or home remedies as recommended by family or friends, sometimes to the detriment of their physical condition or even the garments. As noted in the results, Phindi used traditional remedies which possibly may have caused the darkening of her skin and certainly stained her light-coloured garments. However the advantage of using her grandmother's advice may have deepened this relationship and enhanced her support structure, and may therefore be seen as a facilitator to wearing her garments as described earlier in the discussion. From experience, I noted that some patients used mercurochrome (which is no longer advised due its toxic effects on open

wounds), butter or even toothpaste to help their wounds and scars. The use of home or traditional remedies on burn scars requires further investigation.

Stewart *et al.* (2000) and Ripper *et al.* (2009) noted that patients reported a lack of encouragement, social and practical support from their families to wear their PGs. In this study participants highlighted the value of family and staff support and only one participant noted lack of practical support from staff. However, it should be noted that this perceived lack of support by the participant was regarded by the staff as a means of weaning off dependence. What makes this situation challenging is that this participant did not voice his concerns or needs at that point in time. It was only during these interviews that this information was shared. The possibility of this recurring with other patients is highly probable. This finding has raised awareness of this possibility and staff can be sensitised to it.

Emotional impact and impact on relationships can be seen as barriers or resources which impacted directly on the behaviour of the participants. Participants' experiences within these themes such as feeling 'suicidal' and 'miserable' could significantly impact on the individual's ability to 'plan, initiate and maintain' their health behaviour (Schwarzer, 2011). Again, this looks at the 'action' and 'coping plans' of the participants at a point in time (acute stage of the burn injury). Williams, Davey & Klock-Powell (2003) noted that all their participants described anger as a universal experience apart from the emotional ups and downs. In this study participants' 'worries' and anxieties' experienced in the acute stages impacted on their self-efficacy: as one participant clearly stated that he was not in a good space to comply. In my experience of having worked in the unit itself, patients were just trying to get through the day-to-day management of dressings, surgery and therapy. When dealing with severe, current problems, not focussing on the future can be seen as a normal response. Participants described personal difficulties in dealing with their situation such as lack of motivation, opting not to comply and lowered self-esteem. Ripper *et al.* (2009) describes this as issues within the motivational phase of the HAPA model where participants display 'little outcome expectancy' and 'little self-efficacy.' This was strongly evident in John's statement "it was difficult at that time."

The study revealed that there was a strong need for counselling services other than the little counselling received during occupational therapy or social work

interventions. Due to the high patient load at the PGT service and the lengthy duration involved per session (some sessions take over an hour depending on how many types of garments are required), therapists are under pressure to cover the main purpose of the service i.e. to provide two sets of custom-made, well fitted garments and refer out as far as possible for all other requirements. So even though OTs are skilled in providing counselling, time is a major constraint. It should also be noted that participants felt an outsider's perspective and the need for professional counselling services especially once they were discharged home would be valuable.

Together with the socio-emotional stresses discussed above, socio-economic factors also contributed to the stress of burn survivors. "It is well documented that socio-economic factors are important upstream determinants of health. The National Development Plan identifies poverty, inequality and unemployment as the key triad of socio-economic challenges facing South Africa" (Western Cape Department of Health, 2013, pg. 3). Park *et al.*, 2008 noted that financial stressors could have a significant effect on patient adherence with PGT as the little income that is available (grants in the case of this study) may be used for basic necessities such as providing food for the family. Park *et al.* (2008) further noted that patients who were financially strained stopped therapy or attended less often because of this.

Participants described several factors that made it difficult to access the service such as financial constraints, transport and limited PGT services. Mistry, Pasisi, Chong, Stewart & Wong She (2010) noted that the economic consequences of burn injuries are significant and that ethnic and socio-economic factors are associated with burn injuries. Those from more deprived areas had higher rates of admission (Mistry *et al.*, 2010). Although there is no official statistics for the admission records or status of the patients admitted to the TAH Burns Unit, the general admission is in line with the above statement as most patients are from the Black and Coloured ethnic groups, traditionally known as socio-economically disadvantaged groups formed during the Apartheid era (South African Human Rights Commission, 2002).

This, together with the loss of participation in work and financial dependence, could also be defined as barriers to adherence with PGT. Some participants became financially dependent on others as a result of the loss of work due to the burn injury, whilst others increased their financial dependency on family

members due to the extra expenses required for attending therapy. The South African Human Rights Commission report (2000) noted that a vicious cycle exists where poverty causes disability and vice versa.

John and Sipho noted that participating in OT gave them the opportunity to engage in work activities. This highlights another role of the OT. John was referred to a sheltered workshop where he actively contributes as a working member of society. Although payment is minimal, John enjoyed working there and was promoted. Sipho was provided with job bulletins that were relevant for his level of skill. Even though he is still unemployed he acknowledged and appreciated the assistance. Park *et al.* (2008) highlighted the problem of re-employment and the low levels of social involvement which results in many patients becoming more financially strained.

Park *et al.* (2008) noted that the burden of medical and living expenses were all factors that impacted on rehabilitation and could impact negatively on patient adherence. Participants highlighted the positive effects of receiving a DG, as noted under the facilitators to wearing PGs. However, to receive a DG one has to be unable to procure an income because of a physical or mental disability (South Africa Social Security Agency, 2013). Thus, disfigurement is not recognised as a reason for receiving a DG since the person can still work. Although many burn survivors are ostracised because of images from scary movies that display scarred and deformed images of 'monsters' (Williams, Davey & Klock-Powell, 2003) and they might struggle to find employment in an already strained employment sector, because of these prejudices, they are not eligible for a permanent DG. As many of the TAH patients have little or no tertiary education, seeking suitable alternative employment adds to the challenge. A shift towards the social model of disability which acknowledges the impact of societal barriers on disability would benefit persons with disfigurements caused by burn injuries in this regard (SAHRC report, 2000).

Participants added that a lack of money to pay for transport prevented them from attending therapy. The White Paper on an Integrated National Disability Strategy (1997) notes the need for rapid progression in public transport as people with disabilities cannot benefit from or participate in services. Due to the rising costs in petrol, public transport is becoming even more difficult to access, even for non-

disabled persons. Although the TAH PGT service is able to provide patients with financial assistance for transport, it has to be used cautiously as funds are limited and are dependent on income generating activities as well as funding from Voluntary Aid Services. Patients who are really in need of this assistance and who demonstrate 'good' adherence are given preference to accessing this fund.

According to *Healthcare 2030* (Western Cape Department of Health, 2013, pg.62) "patient transport services must meet the booking demands of the district health service and the geographic service area for the transport of out-patient or non-acute health clients between facilities, up or down levels of care." As noted in the results, Hospital Non-Emergency Transport (HealthNET) is available for patient use but has its own set of challenges as described by Andiswa. Other problems that arise are when patients request a 'carer' to accompany them. Unless physical or cognitive assistance is required, carers/family will not be accommodated on the bus. This is significant, especially in the early stages of rehabilitation when patients often need someone to assist them with physically donning the garments or when therapists need to conduct family education or counselling sessions. As noted under facilitators to wearing PGs, family support is deemed valuable and the therapist should provide motivations to the transport clerks to allow a family member or carer to attend as well.

*Healthcare 2030* (Western Cape Department of Health, 2013) states that specialist services such as burns and rehabilitation units will be managed at acute level two and three facilities. As noted in the results this limits accessibility to services such as PGT. The fact that only a few OTs have the experience, skill and interest in the field of PGT also adds to the problem. There are many more therapists in the private sector that offer the service but often this is financially not affordable for state patients. "Patients are our customers, and as customers, they have the right to choose where to go for their medical care," (Hall, 2010, pg. 17) clearly outlines patient's rights but when services and finances are limited these rights are challenged.

## **5.5 Chapter Summary**

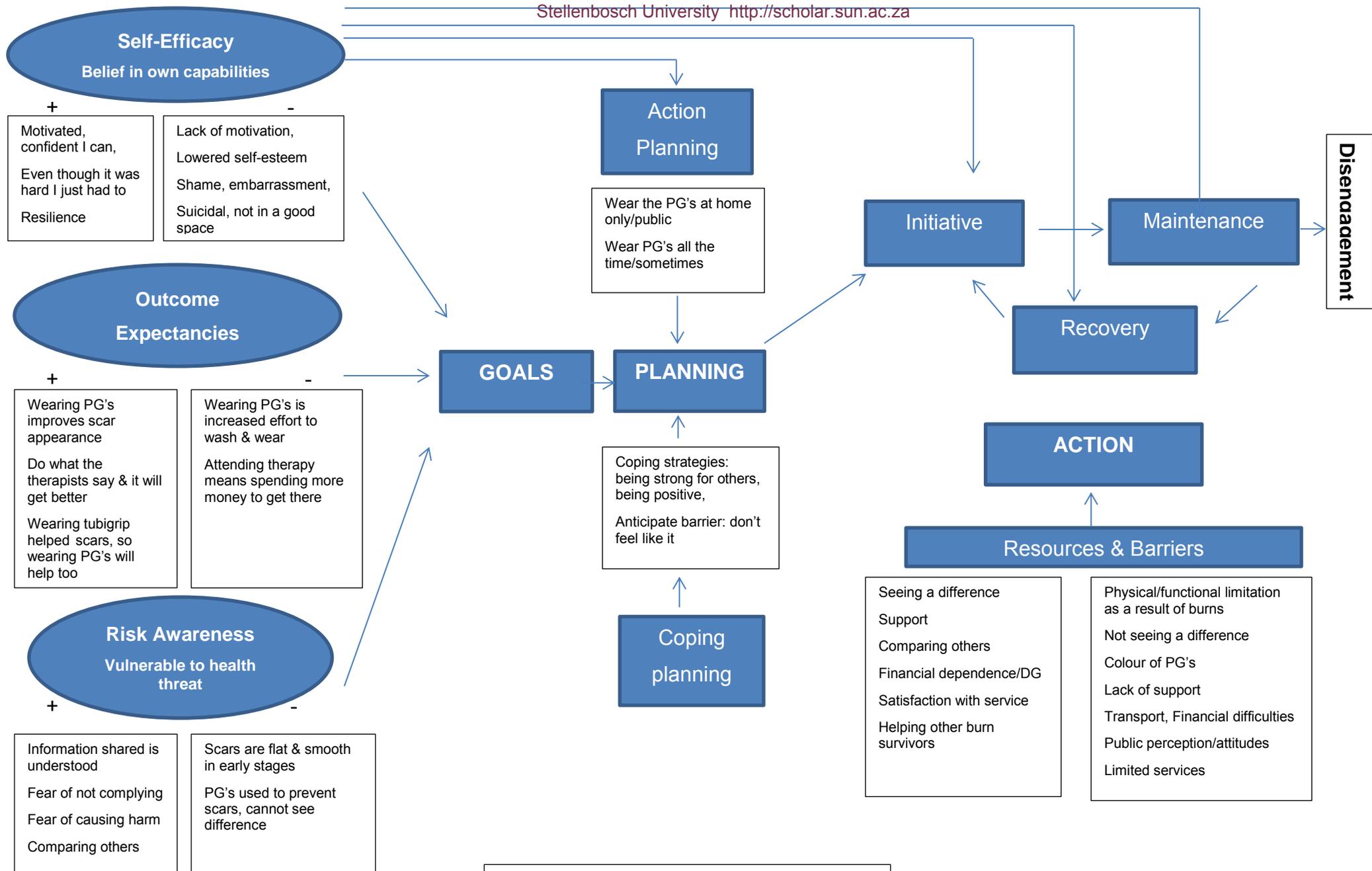
This chapter discussed findings directly related to PGT, hence the objectives of the study. Findings from the literature review, the *Healthcare 2030* plan (Western Cape.

Department of Health, 2013) and the framework of the HAPA Model (Schwarzer, 2011) were used to present the discussion.

The discussion started with a description and understanding the participants' use of pressure garments. This involved both the motivational (factors that impact the intention to wear PGs) and volitional phases (factors that impact the actual use of the PGs) of the HAPA model. Factors that impacted on the self-efficacy, outcome expectations and risk awareness either resulted in a negative or positive response within the motivational phase of the health-action behaviour of the participants (see Figure 5.5). As described in Chapter 1, this is where the patient weighs up the pros and cons of initiating the health behaviour.

The discussion then looked at the positive and negative effects of wearing the garments as perceived by the participants. These can be further defined as resources or barriers within the volitional phase and impacts the person's planning behaviour resulting in either adherence or non-adherence to PGT. Finally the factors that impacted PGT adherence were presented and also discussed as facilitators and barriers to wearing the garments (see Figure 5.5). Unlike other studies, which focussed on the impairments caused by PGT, this study also looked at the direct consequences of the burn injury that impacted on PGT; this was incorporated in the discussion.

The following chapter presents the conclusions and recommendations of the study.



**Figure 5.5 Summary of HAPA Model**

Motivational Phase

Volitional Phase

## Chapter 6

### 6.1 Conclusion

Previous studies on PGT, which were mainly quantitative in nature, focussed on the technical aspects of whether the garments are effective or not. The study by Ripper *et al.* (2009, pg. 662) was the “first to investigate supportive factors and psychosocial resources of PGT from the patients’ perspective”. The current study explored burn survivors’ experiences of PGT, at a selected hospital in the Western Cape, South Africa, and any factors that impacted their perception of this. The findings from this study complement and add to the findings of Ripper *et al.* (2009).

Ripper *et al.* (2009) looked at impairments caused by PGT whereas this study also highlighted specific consequences of the burn injury itself which had a direct impact on PGT. Factors such as contractures, the impact of the scars, the loss of work, emotional impact and being financially reliant on others impacted the health behaviour of study participants hence affecting participation in PGT.

The findings of the study showed that participants perceived PGT as a beneficial intervention. The most significant benefit as described by the participants was the improvements noted in scar appearance. This included the height, texture and colour which resulted in flatter, smoother and lighter-coloured scars.

Although the perceived benefits differed amongst individuals, there were several complex factors that impacted adherence to PGT. One of the main factors that may have negatively impacted on the outcomes is the actual wearing schedule of the garments. Over half the participants did not adhere to the prescribed schedule, yet they too found the garments beneficial. These benefits generally outweighed the many negative effects experienced by the participants. Although other studies have shown significant problems with reduced mobility, itching and skin breakdown due to the PGs, findings from this study were less suggestive of this but it is still of importance and needs to be taken into consideration when providing therapy.

Another important finding was that the PGs were unfashionable, due mainly to the colour, and drew unwanted public attention. This was especially important to the

female participants. There were several other factors affecting adherence and these were either seen as barriers or facilitators to participating in PGT.

Although there are many positive aspects to the service itself, several factors need to be considered to ensure that the service takes a more person-centred approach. These are highlighted in the recommendations which follow.

## **6.2 Recommendations**

The recommendations of this study are based on the findings of the study which include recommendations made by the participants themselves. To achieve a more person-centred approach with regard to intervention, the following recommendations are made:

### **6.2.1 Recommendations Regarding the Occupational Therapy Service**

#### ***6.2.1.1 Colour of pressure garment material***

As noted in the findings participants preferred the dark-coloured garments. It cannot be assumed that all patients would prefer this colour so having a choice between at least the two available colours must be encouraged. OT staff will have to support each other accordingly. Also the fact that the physical environment has been renovated, with much improved lighting, would make working with the darker material easier. The OT must offer patients a choice in colour and encourage the OTA to do the same. Staff who cover in the area also need to be informed of this, which highlights the need to standardise treatment protocols for PGT.

I would strongly recommend that when the tender review is conducted for PG material that the colour black be requested in place of the dark brown material. This colour would complement most clothing items. In addition the beige colour can be replaced with a more suitable colour that doesn't resemble underwear.

#### ***6.2.1.2 Standardisation of treatment protocols for pressure garment therapy***

The following needs to be reiterated or added to the PGT protocol. This includes patients who receive, *as an interim measure*, 'ready-made' rather than customized garments:

- All patients must receive custom-made garments ultimately, using the basic guidelines set out per garment type. 'Ready-made' garments must only be

issued as a last resort when starting PGT immediately is prescribed, the patient is on-site and the patient is constrained by socio-economic circumstances from attending fittings for customised garments

- Patients must be informed (knowledge) of the consequences of receiving such ready-made as opposed to customised garments and that they need to return as soon as possible for their customised garments. This means that even though the patients receive two sets of garments they cannot be reviewed in two months (which is the normal procedure), but must be reviewed within three weeks maximum.
- Extra effort, such as financial assistance with transport, must be made to ensure that these patients can get to the follow-up appointment as soon as possible.
- Even if the ready-made garments appear to fit well, new patterns must be constructed with the patient's own measurements.
- The re-use of ready-made patterns must be stopped altogether. OTs must learn how to construct patterns and not only rely on the seamstress or OTA to do so. Learning how to construct patterns will also assist therapists' understanding of what measurements are required to formulate the pattern. Many OTs lack this knowledge as undergraduate training often includes only one lecture on PGT. OTs must work within their scope of practice and ensure that their role of assessing, measuring and evaluating the garment is duly performed. This ensures accountability within the service. The seamstress or OTA is there for technical support and assistance, although their valuable input and experience should not be disregarded. Training with regard to all aspects of PGT is therefore indicated.
- Garments must be chosen in conjunction with the patient and not for the patient. Therapists must advise patients what would work best, and why, in terms of functionality with regard to occupation performance (work, self-care and leisure) and in terms of the principles and effects of PGT.
- The use of other assessment tools (such as digital photography of the scars) can be included as part of the progress notes. This can be shown to patients during follow-up visits to help them judge the changes in the scar over time. The Patient and Observer Scar Assessment Scale (Bianci, Rocchia, Fiorini &

Beronne, 2010) can also be introduced as this gives patients an opportunity to 'rate' their scars. This information will be useful for therapists to gauge the patient's perception of progress.

### **6.2.1.3 Staff attitudes**

Participants noted that they complied because they were told to do so. Apart from the recommendations mentioned above patients need to be informed of their overall treatment options, thereby enhancing the knowledge-base of the patient. Patients must be given other treatment options besides PGT, especially for those who struggle to comply with PGT, and not be denied overall treatment because they were not compliant with the garments. We need to consider the possibility that there may be a patient who is allergic to the material and would have no choice but to provide other treatment. In saying this, this should not be the only time that we consider giving patients options; we must give patients the options from the beginning of therapy. This would significantly enhance the person-centred approach within therapy.

It should also be noted that the OT staff need to be mindful and consider all factors when encouraging 'patient independence'. Expecting too much too soon may only make the patient more despondent and perceive the OT as not being caring.

### **6.2.2 Counselling Services**

Findings from this study strongly indicated the need for specific counselling services. Even though OTs and social workers provide some counselling patients felt that they needed an 'outsiders' perspective. Being service providers makes the staff members a part of the patient's experience.

It is recommended that counselling services be provided in patient's communities for easier accessibility once they are discharged home. Two types of counselling services are recommended, namely professional and peer counselling. This may be in the form of group or individual intervention and can be established at community health centres or day hospitals. Burn survivors can perform the role of peer counsellors as some participants felt the need to share and help others. The OTs, together with the social worker working in burns and the PGT service, can initiate and compile a resource list of those burn survivors who are willing to act as peer

counsellors. The same would need to be done for existing counselling services. This can be given to patients so that they can access the service independently as required.

Prospective counsellors will have to undergo basic training and may require the mentorship and guidance from the OT and / or social worker and possible debriefing sessions as well.

### **6.2.3 Recommendations for Overall Burns Service**

All staff, not only nurses, need to be made aware of their 'handling skills' as many have become desensitized due to the routine nature of their work. Dressing changes, undergoing surgery and having active therapy are highly stressful, and often painful, situations for burn patients. Staff therefore need to be more sensitive in their approach when working with these patients. I suggest that a lecture or workshop that focusses on the basics of patient-care, particularly burn patients, and how to adopt a person-centred approach be held at least once a year for all staff.

An information pamphlet or a welcome pack should be compiled for all patients admitted to the unit. This should cover basic information pertaining to burn management, common terminology and what to expect during their rehabilitation, and should be available in English, Afrikaans and isiXhosa. Patients and their families can always refer to this whilst on the ward or even after being discharged home.

### **6.3 Recommendations for Further Research**

- The physical effects of PGT in terms of urination and changes in venous structures need further quantitative investigations
- The effect of PGs in the management of other diagnoses such as lymphoedema and hernias
- The effects of PGT on family or other support structures such as employers or teachers should also be researched further in a qualitative study
- Investigation regarding the use of traditional remedies or interventions in scar management and the effects thereof.

## **6.4 Limitations of the Study**

As noted in the section under data collection (3.8) the interviewer had a bilateral hearing impairment and although this was explained to the participants in advance, it may have affected her ability to interpret the information correctly and sometimes resulted in her not prompting or probing effectively. The interviewer often had to ask the participants to repeat themselves which sometimes disrupted the flow of the conversation. However, she always clarified her understanding of what was said if she was unsure of what she heard.

However, there are very few OTs experienced in the management of burn patients and PGT in the Cape Town metropole, thus leaving me with a limited choice. The interviewer's availability and other skills led me to approach her to perform the interviews even in light of her impairment and the fact that it might have had a negative impact on the data. I was also able to verify information with the participants telephonically in those instances where it was required.

Although Xhosa speaking participants' chose to conduct the interviews in English, the researcher acknowledges retrospectively, that the consent form should have been in their first language to enhance good ethical practice.

Findings of the study cannot be generalised to all burn survivors although elements of this can be taken into consideration when working with burn survivors, especially in settings similar to the study setting.

## **6.5 Dissemination of Findings and Recommendations**

As I am no longer in the PGT service at TAH, I would need to report the findings of the study to the OT staff and stress the importance of giving patients the options of material colour, standardisation of the PGT protocol and the issue of the information pack. The fact that the OTA has been in the service for almost thirty years cannot dominate the manner in which the service functions, despite her valuable experience and skills. Having worked with her for nine years and having developed a professional relationship on trust, I believe that she will be able to handle constructive feedback and will probably appreciate it as well. And as she plans to retire soon the focus should be directed mainly to the therapists who are going to have to implement the recommendations with the new OTA/seamstress.

Findings of this study will need to be presented to the staff working in the burns unit so that they are aware of what the patients' experiences are.

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## **Appendices**

### **Appendix 1: Participant information leaflet and consent form**

#### **TITLE OF THE RESEARCH PROJECT:**

An exploration of burn survivor's experience of pressure garment therapy at Tygerberg Hospital.

#### **REFERENCE NUMBER: N10/11/376**

#### **PRINCIPAL INVESTIGATOR:**

Rogini Pillay

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021 938 6151; 083 581 4539

You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the study staff any questions about any part of this project that you do

not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the **Health Ethics Research Committee at Stellenbosch University** and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

### **What is this research study all about?**

The study is to investigate the patient's experience of wearing pressure garments. The purpose of the study is to gain a deeper understanding of the patients' perspective of wearing pressure garments, which will be used to change or improve the pressure garment service. The study will be done through interviews and questionnaires.

The information gained from the 2 sections of the study will be analysed and presented in a scientific manner as part of the requirements for a master's degree. If you choose, you will receive a summary of the results and recommendations of the study.

Participants will be selected to ensure that there is a good representation of the patients treated in the pressure garment area (i.e. different size burn injuries, different garments received, variations in age, gender & socioeconomic status).

At no time will your real name be used to ensure confidentiality.

### **Why have you been invited to participate?**

As a current (2010) or past receiver (2006-2009) of pressure garment therapy, you are invited to participate in this study.

### **What will your responsibilities be?**

The study involves an interview of approximately one hour which will be tape recorded. This will be done by another occupational therapist. If necessary, further interviews may be held if more information is required. 8-10 people will participate in this part.

A Xhosa translator will be used, if required, for both parts of the study and the interviews will be held at the Occupational Therapy Department, Tygerberg Hospital or at your home if you wish.

### **Will you benefit from taking part in this research?**

You may not benefit from this study. Future patients and some participants who are current patients may benefit from the study. If changes/recommendations can be made to your current treatment, this will be done so.

### **Are there in risks involved in your taking part in this research?**

There are no direct physical risks for participating in this study. The interviews may bring up emotions that will be dealt with professionally and empathically.

### **If you do not agree to take part, what alternatives do you have?**

Remember that your participation is completely voluntary. If you choose not to participate, this will not affect your current treatment. At any point during the study, you have the option to withdraw, with no adverse consequence if you are still receiving treatment.

### **Who will have access to your medical records?**

Only the researcher will have access to your medical records. All information will be treated as confidential. Your real name will not be used in the study. In the qualitative part of the study, pseudonyms will be used to identify participants.

All research data will be stored securely. Only the researcher/research assistant will have access to the data.

**What will happen in the unlikely event of some form of injury occurring as a direct result of your taking part in this research study?**

It is anticipated that you are at little or no direct risk of injury due to participating in this study and therefore no compensation will be made.

**Will you be paid to take part in this study and are there any costs involved?**

No, you will not be paid to take part in the study but your transport costs will be covered for each study visit. There will be no costs involved for you, if you do take part.

**Is there anything else that you should know or do?**

You can contact Rogini Pillay on 083 581 4539 if you have any further queries or encounter any problems.

You can contact the Committee for Human Research at 021-938 9207 if you have any concerns or complaints that have not been adequately addressed by the researcher.

You will receive a copy of this information and consent form for your own records.

**Declaration by participant**

By signing below, I ..... agree to take part in a research study entitled “*An exploration of burn survivor’s experience of pressure garment therapy at Tygerberg Hospital.*”

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) ..... on (*date*) .....  
2010.

.....

**Signature of participant**

.....

**Signature of witness**

**Declaration by investigator**

I (*name*) ..... declare that:

- I explained the information in this document to .....
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did/did not use a translator. (*If a translator is used then the translator must sign the declaration below.*)

Signed at (*place*) ..... on (*date*) .....  
2010.

.....

.....

**Signature of investigator**

**Signature of witness**

**Declaration by translator**

I (*name*) ..... declare that:

- I assisted the investigator (*name*) ..... to explain the information in this document to (*name of participant*) ..... using the language medium of Afrikaans/Xhosa.
- We encouraged him/her to ask questions and took adequate time to answer them.
- I conveyed a factually correct version of what was related to me.
- I am satisfied that the participant fully understands the content of this informed consent document and has had all his/her question satisfactorily answered.

Signed at (*place*) ..... on (*date*) .....  
2010.

.....

.....

**Signature of translator**

**Signature of witness**

## **Appendix 2: Deelnemerinligtingsblad en -toestemmingsvorm**

### **TITEL VAN DIE NAVORSINGSPROJEK:**

’n Ondersoek van brand oorlewendes se ervaring van drukkere terapie by Tygerberg Hospitaal.

**VERWYSINGSNOMMER:** N10/11/376

### **HOOFNAVORSER:**

Rogini Pillay

### **WERK ADRES:**

Arbeidsterapie Departement

Tygerberg Hospitaal

Fransie van Zyl Laan

Parow

7500

### **ADRES:**

Lockerbyweg 24

Lansdowne

7780

### **KONTAKNOMMER:**

083 581 4539

U word genooi om deel te neem aan ’n navorsingsprojek. Lees asseblief hierdie inligtingsblad op u tyd deur aangesien die besonderhede van die navorsingsprojek daarin verduidelik word. Indien daar enige deel van die navorsingsprojek is wat u nie ten volle verstaan nie, is u welkom om die navorsingspersoneel of dokter daarvoor uit te vra. Dit is baie belangrik dat u ten volle moet verstaan wat die navorsingsprojek behels en hoe u daarby betrokke kan wees. U deelname is ook **volkome vrywillig**

en dit staan u vry om deelname te weier. U sal op geen wyse hoegenaamd negatief beïnvloed word indien u sou weier om deel te neem nie. U mag ook te eniger tyd aan die navorsingsprojek onttrek, selfs al het u ingestem om deel te neem.

Hierdie navorsingsprojek is deur die **Komitee vir Menslike Navorsing** van die Universiteit Stellenbosch goedgekeur en sal uitgevoer word volgens die etiese riglyne en beginsels van die Internasionale Verklaring van Helsinki en die Etiese Riglyne vir Navorsing van die Mediese Navorsingsraad (MNR).

### **Wat behels hierdie navorsingsprojek?**

Hierdie projek ondersoek die pasiënt se ervaring van die dra van die drukklere. Die doel van die studie is om 'n beter begrip te kry van die pasiënt se perspektief om die klere te dra, wat gebruik sal word om die drukterapie dienslewering te verander of te verbeter. Die studie sal gebruik maak van 'n onderhoud wat omtrent 'n uur lank is

Die inligting wat gekry word van die onderhoud sal geanaliseer word en op 'n wetenskaplike manier aangebied as deel van die vereistes vir 'n meestersgraad. As u verkies, kan u 'n opsomming van die resultate and aanbevelings kry.

Deelnemers sal gekies word om 'n goeie verteenwoordiging van pasiente wat in die drukklere area behandel is, te verseker (bv. Verskillende grootte van brand beserings, verskillende drukklere stukke gedra, verskillende ouderdom, geslag en verskillende sosiaal-ekonomiese agtergrond).

### **Waarom is u genooi om deel te neem?**

As 'n deurlopende (2010) of oudontvanger (2006-2009) van drukklere, word u genooi om in hierdie studie deel te neem.

### **Wat sal u verantwoordelikhede wees?**

Die studie behels 'n onderhoud van omtrent 'n uur, en die onderhoud sal met 'n bandspeler opgeneem word. Meer onderhoude sal gedoen word as verder inligting benodig word. 8-10 mense sal vir die studie benodig word. Indien nodig sal 'n Xhosa vertaler gebruik word en die onderhoude sal in die arbeidsterapie departement gehou word, of as u verkies, by u huis.

### **Sal u voordeel trek deur deel te neem aan hierdie navorsingsprojek?**

Daar sal geen persoonlike voordele vir u wees. Toekomstige pasiënte en sommige deulopende pasiënte sal moontlik voordeel trek uit die bevindinge van hierdie studie. Indien veranderings of aanbevelings gemaak kan word vir u eie behandeling, sal dit gedoen word.

**Is daar enige risiko's verbonde aan u deelname aan hierdie navorsingsprojek?**

Daar is geen direkte fisiese gevaar om deel te neem aan heirdie studie nie. Die onderhoude mag moontlik emosies uitbring wat dan professioneel behandel sal word.

**Watter alternatiewe is daar indien u nie instem om deel te neem nie?**

Onthou dat u deelname volkome vrywillig is. Indien u weier om deel te neem sal dit nie jou behandeling beïnvloed nie. U regte naam sal nie gebruik word nie. Die studies al gebruik maak van skuilname.

**Wie sal toegang hê tot u mediese rekords?**

Net die narvorser sal toegang hê tot u mediese rekords. Die versamelde inligting sal vertroulik en beskermd hanteer word. Al die narvorsings inligting sal in 'n veilige plek geberê word.

**Wat sal gebeur in die onwaarskynlike geval van 'n besering wat mag voorkom as gevolg van u deelname aan hierdie navorsingsprojek?**

Geen of min gevaar van besering word verwag nie, en daarom is daar geen betaling in geval van besering nie.

**Sal u betaal word vir deelname aan die navorsingsprojek en is daar enige koste verbonde aan deelname?**

U sal nie betaal word vir deelname aan die navorsingsprojek nie, maar u vervoer en etes ten opsigte van elke besoek vir die navorsingsprojek sal betaal word. Deelname aan die navorsingsprojek sal u niks kos nie.

**Is daar enigiets anders wat u moet weet of doen?**

U kan Rogini Pillay by 083 581 4539 kontak indien u enige verdere vrae het of enige probleme ondervind.

U kan die Komitee vir Menslike Navorsing by 021 938 9207 kontak indien u enige bekommernis of klagte het wat nie bevredigend deur u studiedokter hanteer is nie.

U sal 'n afskif van hierdie inligtings- en toestemmingsvorm ontvang vir u eie rekords.

### **Verklaring deur deelnemer**

Met die ondertekening van hierdie dokument onderneem ek,

....., om deel te neem aan 'n navorsingsprojek getiteld " 'n Onderzoek van brand oorlewendes se ervaring van drukkereterapie by die Tygerberg Hospitaal".

### **Ek verklaar dat:**

- Ek hierdie inligtings- en toestemmingsvorm gelees het of aan my laat voorlees het en dat dit in 'n taal geskryf is waarin ek vaardig en gemaklik mee is.
- Ek geleentheid gehad het om vrae te stel en dat al my vrae bevredigend beantwoord is.
- Ek verstaan dat deelname aan hierdie navorsingsprojek **vrywillig** is en dat daar geen druk op my geplaas is om deel te neem nie.
- Ek te eniger tyd aan die navorsingsprojek mag onttrek en dat ek nie op enige wyse daardeur benadeel sal word nie.
- Ek gevra mag word om van die navorsingsprojek te onttrek voordat dit afgehandel is indien die navorser van oordeel is dat dit in my beste belang is, of indien ek nie die ooreengekome navorsingsplan volg nie.

Geteken te (*plek*) ..... op (*datum*) .....  
2010.

.....  
**Handtekening van deelnemer**

.....  
**Handtekening van getuie**

### **Verklaring deur navorser**

Ek (*naam*) ..... verklaar dat:

- Ek die inligting in hierdie dokument verduidelik het aan  
.....
- Ek hom/haar aangemoedig het om vrae te vra en voldoende tyd gebruik het om dit te beantwoord.
- Ek tevrede is dat hy/sy al die aspekte van die navorsingsprojek soos hierbo bespreek, voldoende verstaan.
- Ek 'n tolk gebruik het/nie 'n tolk gebruik het nie. (*Indien 'n tolk gebruik is, moet die tolk die onderstaande verklaring teken.*)

Geteken te (*plek*) ..... op (*datum*) .....  
2010.

.....  
**Handtekening van navorser**

.....  
**Handtekening van getuie**

## Verklaring deur tolk

Ek (*naam*) ..... verklaar dat:

- Ek die navorser (*naam*) ..... bygestaan het om die inligting in hierdie dokument in Afrikaans/Xhosa aan (*naam van deelnemer*) ..... te verduidelik.
- Ons hom/haar aangemoedig het om vrae te vra en voldoende tyd gebruik het om dit te beantwoord.
- Ek 'n feitelik korrekte weergawe oorgedra het van wat aan my vertel is.
- Ek tevrede is dat die deelnemer die inhoud van hierdie dokument ten volle verstaan en dat al sy/haar vrae bevredigend beantwoord is.

Geteken te (*plek*) ..... op (*datum*) .....  
2010.

.....  
**Handtekening van tolk**

.....  
**Handtekening van getuie**

## Appendix 3: Ethics letter



UNIVERSITEIT • STELLENBOSCH • UNIVERSITY  
jou kennisvenoot • your knowledge partner

21-Nov-2012

### Ethics Letter

#### Ethics Reference #: N10/11/376

Title: An exploration of burn survivor's experience of pressure garment therapy at Tygerberg Hospital.

Dear Ms R Pillay,

At a meeting of the Health Research Ethics Committee that was held on 14 November 2012, the progress report for the abovementioned project has been approved and the study has been granted an extension for a period of one year from this date.

Please remember to submit progress reports in good time for annual renewal in the standard HREC format.

Approval Date: 14 November 2012 Expiry Date: 14 November 2013

If you have any queries or need further help, please contact the REC Office 0219389207.

Sincerely,

REC Coordinator

Mertrude Davids

Health Research Ethics Committee 2

## Appendix 4: Approval from Department of Health



# DEPARTMENT of HEALTH

Provincial Government of the Western Cape

**Tygerberg Academic Hospital and  
Mitchells Plain & Tygerberg Oral Health Centres**

lbnde@pgwc.gov.za  
tel: +27 21 938-5752 / fax: +27 21 938-6698  
Private Bag X3, Tygerberg, 7505  
[www.capegateway.gov.za](http://www.capegateway.gov.za)

**REFERENCE : Research Projects**  
**ENQUIRIES : Dr M A Mukosi**

**Date:** 01 FEB 2011

**ETHICS NO: N10/11/376**

Dear Ms R Pillay

**Ref: An exploration of burn survivor's experience of pressure garment therapy  
at Tygerberg Hospital.**

### **PERMISSION TO CONDUCT YOUR RESEARCH AT TYGERBERG HOSPITAL**

In accordance with the Provincial Research Policy and Tygerberg Hospital Notice No 40/2009, permission is hereby granted for you to conduct the above-mentioned research here at Tygerberg Hospital.

**DR D ERASMUS**  
**CHIEF DIRECTOR: TYGERBERG HOSPITAL**  
31.01.2011

## **Appendix 5: Interview schedule**

The qualitative part of the study will use an unstructured interview but these are some guidelines that could be followed to get the participant to explore his/her experience more in depth. Questions are specifically not numbered, as the participant is meant to lead the 'conversation', and is to be used merely to obtain information rich data. Researcher will explain to the participant why she cannot conduct the interview personally and will also obtain consent prior to being interviewed.

Interviewer to introduce herself, explaining that she will be conducting interview using a recorder and taking notes as required. Interviewer will also explain that she does not know any history/circumstances of the participant and would therefore like to start with them explaining how they got burnt.

### **Tell me your story of how you got burnt...**

cause of burn:

when:

circumstances around this:

which body parts burnt/ % TBSA:

hospital stay/readmissions (what was it like for you?):

skingrafts/operations: where/what, donor areas

complications:

dressings changes:

therapy on the ward: (splinting, tubigrip, exercises, groups...)

other (that the patient may mention):

**So when you were discharged from the ward you were referred to the out-patient pressure garment therapy area, what was this like for you?**

Did you understand why you needed pressure garments?

What it was like for you to wear your pressure garments?

How long did you wear them?

What garments did you wear?

How did it make you feel? (problems, benefits)

How often did you wear it and how did you care for it?

Are you currently a patient/still wearing garments?

**Tell me more about how this impacted on your life (how did this make you feel?).**

Work:

Family life:

Friends:

Partner:

Social:

**Tell me about your impression of the pressure garment service**

Needs met/unmet:

Were you given a choice in type of garments? E.g. long sleeve or short sleeve, colour, adjustments considered?

Were your difficulties taken into consideration? (e.g. too hot, uncomfortable, itchy, painful, unsightly/embarrassed, etc)

Were you satisfied/unsatisfied with the service and why (staff, facility)?

**Besides the actual garments that you received, were there any other benefits in attending therapy?**

**If the pressure garment service could be different, what would you like to see change?**

## Appendix 6: Data specification set for participants

Key:

Age: at time of interview (at time of injury)

OC: Other complications

NoG; Number of Garments

ToG: Type of Garments

BP: Body part injured

DATA SPECIFICATION SET FOR PARTICIPANTS												
CASE No.	SEX	AGE	RACE	%TBSA	DEGREE	CAUSE	OC	NoG	ToG	WORK	BP	THERAPY
Ann	F	81 (79)	W	15%	2	accident household	DM, HPT	2	socks	pensioner	feet	completed
Phindi	F	30 (27)	B	27%	1, 2 & 3	accident household		3	socks, pants	unemployed	legs, feet	current
John	M	28 (21)	C	25%	2 & 3	accident social	Amputation AKA	5	pants, jacket, chinstrap, mittens	part-time contract	face, head, torso, arms, hands	completed
Bongani	M	52 (49)	B	20%	2 & 3	accident household	lymphoedema	2	pants, socks	unemployed	feet, lower limbs	current
Fleur	F	24 (22)	W (French)	6%	2	accident household	asthma	1	pants	unemployed	thigh	current
Andiswa	F	24 (22)	B	5-10%	2	accident household		3	sleeve, mitten, sock	student	shoulder, thumb, foot	completed
Mandy	F	23 (20)	C	10%	2	accident social	pregnant	2	jacket, pants	student	chest, arm, face/ear	current
Sipho	M	38 (36)	B	30%	2 & 3	accident MVA		4	sleeves, mittens	casual kitchen help	hands, arms, back	completed
	3M, 5F		4B, 2C, 2W			5 AH, 2 AS, 1 MVA		ave=2				4 DC, 4 cont