



# MONASH University

***The physical and psychological outcomes following burn injury: A 12-month follow-up study***

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## **Abstract**

A burn injury represents perhaps the widest spectrum of any form of trauma. Burns occur in all age groups, and the impact on general health outcomes may range from the minor requiring no treatment, through to the very severe, where the highest levels of intensive care and surgery are required. As the majority of burn injuries result in survival, the goal of a multidisciplinary burns team is to provide the best possible care leading to optimal functional outcomes.

A high proportion of patients presenting to the Victorian Adult Burns Service (VABS) located at The Alfred Hospital, in Victoria, Australia, have sustained minor burns, defined as injuries affecting less than 10% of total body surface area (%TBSA). In particular, these patients generally have a relatively straightforward treatment and recovery pathway. Unfortunately, there is a smaller subset of patients who present with moderate to severe burn injuries, defined here as greater than 10 %TBSA, where much of the burn care treatments can extend over many days, weeks and months after the initial insult, and can result in various impaired physical and psychosocial health outcomes. As a result, little is known about the trends and long-term consequences of those with moderate to severe burn injury at a population level or at discharge from a burns service, including their overall impact on wider health outcomes.

To begin the process of detailing burn injury characteristics along with understanding the potential impact hospital burn care interventions may have on overall generalised health and well-being, there was an urgent need to maintain and improve standardised burn injury surveillance programs. In particular, the aim of this thesis was to use existing datasets from state-wide and hospital administrative datasets, along with collecting generalised and burn-specific health outcomes at various time-points post-hospital discharge, to describe overall trends and outcomes in those with burn injury.

Our results showed that rates of emergency data presentations, hospital admissions and deaths remained the same over a 7-year time frame. However, when collecting generalised health and burn-specific data using various outcome measures and the instruments contained in this thesis, the majority of patients hospitalised with burn injuries at 12-months were still reporting levels of physical functioning that were

significantly below pre-injury levels. When examining a subset of patients affected by a natural disaster, psychological distress was still present at 12-months after injury. This suggests that a more goal-directed therapy and a consistent evaluation of interventions would be required in order to continue improving the physical and psychosocial functioning, particularly at time points where patients were considered to be at their greatest physical and psychosocial risk. More importantly, the rich information gleaned from patient insights and reported in this thesis showcase the need to consider extending the monitoring period beyond the initial period of 12-months post-injury as set out in this thesis.

## **Declaration**

This thesis contains no material which has been accepted for the award of any other degree or diploma at any university or equivalent institution and that, to the best of my knowledge and belief, this thesis contains no material previously published or written by another person, except where due reference is made in the text of the thesis

## **Thesis including published works general declaration**

I hereby declare that this thesis contains no material which has been accepted for the award of any other degree or diploma at any university or equivalent institution and that, to the best of my knowledge and belief, this thesis contains no material previously published or written by another person, except where due reference is made in the text of the thesis.

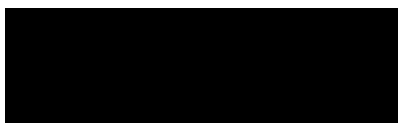
This thesis includes five original papers published in peer-reviewed journals. The core theme of the thesis is to understand the physical and psychosocial health outcomes in those with moderate to severe burn injury post discharge from a state-wide burns service. The ideas, development and writing up of all the papers in the thesis were the principal responsibility of myself, the candidate, working within the Department of Epidemiology and Preventive Medicine under the supervision of Professor Belinda Gabbe.

The inclusion of co-authors reflects the fact that the work came from active collaboration between researchers, and acknowledges input into team-based research. In the case of Chapters 2, 3, 5, 6, 7 my contribution to the work involved the following:

<b>Thesis chapter</b>	<b>Publication title</b>	<b>Publication status</b>	<b>Nature and extent of candidate's contribution</b>
2	The epidemiology of burn injuries in an Australian setting, 2000-2006	Published	Principal author responsible for the concept, design, analysis of literature, the interpretation of results and development of the writing up of the manuscript.
3	Measuring common burn outcome measures and their concepts using the International Classification of Functioning, Disability and Health (ICF): a systematic review	Published	Principal author responsible for the concept, design, analysis of literature, the interpretation of results and development of the writing up of the manuscript.
5	Patterns of recovery over 12 months following a burn injury in Australia.	Published	Principal author responsible for the concept, design, analysis of literature, the interpretation of results and development of the writing up of the manuscript.
6	12-Month generic health status and psychological distress outcomes following an Australian natural disaster experience: 2009 Black Saturday Wildfires.	Published	Principal author responsible for the concept, design, analysis of literature, the interpretation of results and development of the writing up of the manuscript.
7	Predictors of health status and health-related quality of life 12 months after severe burn.	Published	Principal author responsible for the concept, design, analysis of literature, the interpretation of results and development of the writing up of the manuscript.

I have not renumbered sections of submitted or published papers in order to generate a consistent presentation within the thesis.


**Student signature:**



**Date:** 20/11/2015

The undersigned hereby certify that the above declaration correctly reflects the nature and extent of the student and co-authors' contributions to this work.

**Main Supervisor signature:**



**Date:** 20/11/2015



## Awards, Publications and Presentations

### Publications directly relevant to thesis

1. **Wasiak J**, Spinks A, Ashby K, Clapperton A, Cleland H, Gabbe B. The epidemiology of burn injuries in an Australian setting, 2000-2006. *Burns* 2009; 35(8): 1124-32
2. **Wasiak J**, McMahon M, Danilla S, Spinks, A, Cleland H and Gabbe B. Measuring common burn outcome measures and their concepts using the International Classification of Functioning, Disability and Health (ICF): a systematic review. *Burns* 2011; 37(6): 913-24.
3. **Wasiak J**, Paul E, Lee SJ, Mahar P, Pfitzer B, Spinks A, Cleland H, Gabbe B. Patterns of recovery over 12 months following a burn injury in Australia. *Injury*. 2014; 45 (9): 1459-64.
4. **Wasiak J**, Mahar P, Lee S, Paul E, Spinks A, Pfizer B, Cleland H, Gabbe B. 12-Month generic health status and psychological distress outcomes following an Australian natural disaster experience: 2009 Black Saturday Wildfires. *Injury* 2013; 44(11): 1443-1447.
5. **Wasiak J**, Lee SJ, Paul E, Mahar P, Pfitzer B, Spinks A, Cleland H, Gabbe B. Predictors of health status and health-related quality of life 12 months after severe burn. *Burns* 2014; 40(4): 568-74.



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Finally, the candidate wishes to acknowledge the advice and support of the following colleagues who came to my rescue immediately and without fail, but also repeatedly without raising an impatient voice. As a result, deep respect, admiration and heartfelt thanks goes to Dr Patrick Mahar, Dermatology Registrar; Dr Anneliese Spinks, Scientist, CSIRO; Mr Eldho Paul, Statistician, Monash University; and Dr Stuart Lee, Academic, Monash University.

## **Abbreviations**

%TBSA – percentage total burn surface area

HRQoL – health related quality of life

ICF – International Classification of Functioning

SF-36 v.2 – Short Form 36 Medical Outcomes Survey v.2

BSHS-B – Burn Specific Health Scale – Brief Version

VABS – Victorian Adult Burns Service

VAED – Victorian Admitted Episodes Data

VEMD – Victorian Emergency Minimum Dataset

# Chapter 1: Introduction

## 1.1 Overview of burn injury

Advances in burn care management over the last 50 years have resulted in improved survival and reduced morbidity from burn injury. Survival success has been attributed to early surgical burn wound excision and closure, advances in critical care medicine and the development of specialised, multidisciplinary burn centres [1]. Regardless of the number of therapeutic developments used to manage a burn patient, burn injuries still remain one of the most devastating of all injuries and continue to be a major global public health issue [2]. Fire-related burns alone account for more than 300 000 deaths per year, with more deaths resulting from scalds, electrical, chemical and other types of burn. Most of these deaths (95%) occur in low- and middle-income countries. Deaths are only part of the problem, with a reduction in loss of life years also seen secondary to complications leading to prolonged disability [3].

The severity of the burn injury depends on a series of burn- and patient-specific factors, the latter of which include age and gender, along with any associated injuries or pre-burn co-morbidities. Burn-specific factors affecting morbidity and mortality are determined by burn depth and the extent of injury, which is best described by using the percentage of the total body surface area (%TBSA) that is affected by a burn.

When considering depth, superficial burns are limited to the epidermal or superficial dermal part of the skin, whilst deeper injuries penetrate further down to the deep dermal layers (partial thickness burns), or through both the dermis and epidermis extending in some cases to subcutaneous tissue, muscular, neurovascular or skeletal structures (full-thickness burns) [4, 5]. Deeper burns require immediate surgical excision along with the application of skin substitutes classified as either biological skin replacements (i.e. allografts and xenografts) or a bioengineered skin substitutes (i.e. autologous cultured and non-cultured products, or biosynthetic skin substitutes). They require a longer period of time for healing compared to superficial burns, which in the absence of infections or complications, heal with minimal intervention in one to three weeks [5].

When considering the %TBSA or the extent of injury, the measurement of burn surface area will be important during the initial management of people with burn injuries to estimate the need for simple therapeutic care or advanced burn care techniques requiring dedicated specialist services. Broadly speaking, burns can be classified as minor, moderate and major (severe) injury. However, the classification is dependent on a range of variables that describe the mechanism of injury, how the patient is affected by the injury, %TBSA affected and depth of injury. Other injury-specific variables such as age, site of burn, effect on airway, other injuries, co-morbidities, and psychiatric and psychosocial factors also need to be considered.

Minor burns are described as superficial epidermal and/or superficial partial dermal burns that involve less than 10% TBSA, and constitute the majority of all burn injuries sustained in the developed world [4]. The majority of minor burns heal within 10-14 days, with most patients recovering quickly with fewer complications and little disruption to overall physical and personal functioning. Moderate burn injuries are often superficial dermal to deep dermal burns and are within 10-20 % TBSA. In most instances, these patients will be admitted to hospital for various burn interventions that may include fluid resuscitation, pain management, wound care and surgical management [6]. Lastly, major burns are classified as an injury that may involve a mixture of partial dermal as well as deep dermal or full-thickness involving >20% TBSA. These injuries are complex to treat and often result in acute physiological and metabolic derangements [7] and are best managed in a specialist burn centers staffed by a team of professionals with expertise in acute and long-term burn care practices.

## **1.2 Epidemiology of burn injury**

Although burn injuries vary across different ages, genders, incomes and global regions, and with consensus showing that mortality rates have declined from 5.5 to 4.9 per 100 000, in Australia and other developed nations, burns are still one of the leading causes of death and disability from traumatic injury [2]. Data from the World Health Organization (WHO) show that fire-related injuries in 2004 were estimated to be 1.1 per 100,000 populations, with the highest rate in Southeast Asia and the lowest in the American continents.

Currently, flame injuries and scalds are the most common cause in vulnerable groups such as children, women and the elderly in low middle income countries when compared to high income countries (HIC), and can be attributed to the lack of supervision in domestic settings, generalised frailty and the presence of existing co-morbidities [8]. However in HIC, an increased risk of burns is found in minority populations, and in lower socioeconomic households [9]. Regardless of the reduction in mortality, it is still worth noting that even in well-resourced countries such as the United Kingdom just over 81,000 patients attended a specialist burn service for assessment in which 13,000 patients required hospital admission. Of these, 875 died of their injuries [10].

Burn injuries from fire and scalds are the sixth leading cause of injury in Australia and have been identified as one of the seven National Health Priority Areas in 2002 [11]. Similar to a recent international finding [10], the majority of burn injuries are secondary to thermal or scald injuries within vulnerable populations such as the very young and the elderly. In 1997-2005 the rate of total burn-injury related deaths for Australia was 0.5 per 100 000 persons. During the period of 1999/00 to 2003/04, more than 46,000 people were hospitalised as a result of burn or scald-related injury, equating to an age-adjusted rate of 47.9 cases per 100 000/population [12]. Of these, over a 1,000 incident cases of full-thickness burns were admitted annually, representing about 0.1% of all injury hospital separations and an age-adjusted rate for severe burns of 5.3 hospital admissions per 100 000/population, with a male and female incidence ratio of approximately 2:1.

### **1.3 Modern burn care**

#### *1.3.1 Historical and current practices*

During the first quarter of the 20th century patients with severe burn injuries had little chance of survival. Advances in surgery during this period were not applicable to burn patients, with survival rates being very poor and most patients dying from hypovolemic shock, sepsis or multi-organ failure [4]. However, with the introduction of antibiotics, including silver-based topical anti-microbial agents, during the 1950s and 1960s, death rates due to wound infection, cross-infection and sepsis were reduced. At the same time, tangential primary excision of necrotic tissue was

introduced, which not only reduced the risk of wound infection and minimised sepsis, but also led to less scarring and fewer chronic wounds [13].

Augmenting this surgical approach was the concomitant usage of immediate wound coverage and closure in the form of auto-grafts, and decades later with the development of skin substitutes such as cultured epithelial keratinocytes and artificial dermal substitutes. Later with the utilisation of intensive care units in the 1970s and the development of highly specialised burn centres in 1980s, a level of sophisticated care for managing the severely burned injured patients had become standard clinical practice [13]. As a result, the impacts of these strategies and approaches to burns care management have reduced the risk of dying today amongst various patient populations. In the paediatric setting there is at least a 50% chance of surviving a 95% TBSA burn [4]; whilst in the adult clinical setting, patients aged between 15-44 years have at least a 50% chance of surviving a 70% TBSA burn when treated in a specialist burn unit [14].

### *1.3.2 Burn rehabilitation*

Improving overall burn survival also extends the rehabilitation process with the potential for prolonged and focused therapeutic interventions at various time points. In many traumatic injuries, there is often a period of time focused on acute care/surgical treatment followed by a focus on rehabilitation, but the ideal treatment of an individual with a burn injury includes rehabilitation as part of the acute management and long-term rehabilitation coordinated with surgical reconstruction [4]. The treatment of individuals with burn injuries present the rehabilitation treatment team with multiple unique challenges not seen in other areas of rehabilitation medicine. These often include a combination of scarring, contractures, joint deformities, weakness, and amputations along with the psychological consequences of severe burn injuries [4]. Many patients have issues with anxiety, post-traumatic stress, depression, and body image concerns that may benefit from psychological intervention [15]. For optimal outcomes, it is important for patients to have a coordinated rehabilitation treatment plan that includes access to psychological services and to have access to vocational rehabilitation to promote return to previous activities, including the return to work [1].

### *1.3.3 Health outcomes*

With advances in burn care management covering physical and psychological intervention, mortality rates have become a less reliable and sensitive measure of outcome and successful treatment in burns care. As a result, burn outcome measurements have shifted to functional and health-related quality of life (HRQoL). Whilst there have been significant inroads into the development of instruments to assess patient functional outcomes such as the International Classification of Functioning (ICF), created by WHO [16], which uses the four-domain perspective applicable (i.e. body functions, body structures, activities and participation, and environmental factors), there has been no consensus as to which physical and psychological domains are important to measure or what instruments are needed to capture the full spectrum of burn sequelae. This lack of clarity regarding ‘what to measure’ and ‘how to measure’ has also been seen in recent systematic reviews, which have described the difficulties inherent in measuring outcomes in this population, but highlighted the need for an international collaboration to further this agenda [17].

Consequently, there has been a push towards patient self-assessment of post-burn recovery, which has been gaining momentum as the most important gauge of outcome following injury and success of a particular intervention. In particular, the evaluation of patient HRQoL has been seen as a strong indicator of recovery from burn injury. Measurement of HRQoL after major burn has been reported using tools such as the Short Form 36 Medical Outcomes Survey v.2 (SF-36 v.2) and the Burn Specific Health Scale – Brief Version (BSHS-B) [18].

The SF-36 v.2 is a 36-item health survey that provides an eight-scale assessment of functional health and wellbeing (i.e. physical functioning, role-physical, bodily pain, general health, vitality, social functioning, role-emotional, and mental health). These scales collectively provide summary measures for physical and mental health and are referred to as physical component score (PCS) and mental component score (MCS), respectively [19].

The BSHS-Brief (BSHS-B) is a 40-item injury-specific instrument, which measures the subjective response of burn patients regarding their injury across a number of

broad areas including physical, psychosocial and sexual functioning and scar outcomes, with nine smaller subscales capturing the following: Affect, Interpersonal Relations, Sexuality, Simple Abilities, Hand Function, Work, Heat Sensitivity, Treatment Regimens and Body Image [18]. It is scored on a Likert scale of 0 to 4 with higher scores indicating better function after burn injury, it is a self-reported outcome tool that has been studied extensively [18] along with its psychometric properties having been well established by a number of high profile burns researchers [20].

Not surprising, an increasing number of studies have also investigated the impact of burn injury on physical and psychosocial function. In the study by Liang [21], 93 adult patients (mean %TBSA = 45%) had reduced physical needs, but their psychosocial needs had not changed over the two years following burn injury. More extensive burned areas and visible scarred areas were in particular predictive of greater physiological and psychosocial needs at follow-up. A second study conducted follow-up assessments five years post injury on 50 patients (>10% TBSA) and found that 70% of patients reported “good” to “very good” ratings of general HRQoL, although on average patients reported “moderate” difficulties in heat sensitivity and body image, and approximately one-quarter of patients reported elevated levels of trauma or depressive symptoms [22].

A further study that conducted a matched-comparison of 49 burn patients (mean TBSA = 35%) on average five years after burn and a control group found that the groups did not significantly differ on any health status domains of the Short-Form 36 (SF36), whereas twice as many burn patients reported clinically significant psychological distress [23]. Thus, it can be confirmed that a significant proportion of patients with burn injury have significant negative physical and psychological effects.

Predicting the quality of eventual recovery in the early stages following burn injury can also be useful for burn clinicians and health services. Identification of the demographic and injury factors that are associated with good outcomes is useful in assisting burn care providers in streamlining services with minimum risk to selected patients [24, 25]. For instance, McGill [26] noted that lower age, along with shorter hospital length of stays correlated with better functional outcomes and higher return to a pre-injury living situation. In contrast to some other studies more objective hospital



demographics such as length of hospital stay, proportion of patients treated in the ICU and number of surgical procedures did not emerge as important predictors of higher BSHS-B scores [27], although the number of surgical procedures was the best predictor of initial health loss and health status after burn injury. More precisely, patients who underwent one surgical procedure reached normative levels between three and nine months, whilst patients undergoing two or more procedures needed 18 months after burn injury to approximate normative levels. Therefore it would suggest that it may be beneficial to develop rehabilitation programs tailored to the needs of specific patients to promote good overall health care outcomes.

#### **1.4 Chapter summary**

Despite the significant advances in burn care over the last few decades, variability in outcome (i.e. poor to full recovery) still exists in this patient group with a greater understanding of the factors that may influence outcomes still needed. In particular, HRQoL has been seen as a strong factor of recovery from burn injury, which has been measured using various outcome instruments (e.g. SF-36 v.2 and BSHS-B) that are of minimal cost to burns units, but convenient for the patient following hospital discharge [20].

#### **1.5 Thesis aims**

The overarching aim of this thesis was to provide an increased understanding of the short and long-term general and burn-specific health outcomes in patients with moderate to severe burn injury over a period of 12 months following admission to a burns unit.

#### **1.6 Specific thesis objectives**

The specific objectives of this thesis were to:

- 1) Determine the epidemiology, trends and outcomes associated with burn injury in the state of Victoria, Australia.
- 2) Evaluate patient-reported outcome measures used to measure the long-term consequences of burn-related injuries, in regards to their suitability for burn

populations, using the international classification of functioning, disability and health (ICF).

- 3) Quantify the 12-month general and burn-specific health status, including health-related quality of life (HRQoL), in generalised hospitalised burns patients presenting to a burns unit.
- 4) Identify potential key variables (e.g. demographic, injury and clinical factors) that will facilitate the identification of individuals at risk of developing poor outcomes post burn injury.

## **Chapter 2: Current knowledge of burn injury epidemiology in Victoria, Australia**

*Chapter 2* contains a manuscript that was accepted for publication in *Burns*, the international peer review journal of the International Society for Burn Injuries (ISBI), on April 9<sup>th</sup> 2009. The citation is as follows:

**Wasiak J**, Spinks A, Ashby K, Clapperton A, Cleland H, Gabbe B. The epidemiology of burn injuries in an Australian setting, 2000-2006. *Burns*. 2009; 35(8): 1124-32

### **2.1 Introduction**

*Chapter 1* discussed the nature of burn injury characteristics along with clinical therapeutic techniques used in the management of care. Unfortunately, the variability in burn injury severity and treatment can make it difficult to accurately describe the number of patients burned each year and the subsequent health burden it may impose. Although routinely collected injury surveillance systems are in place to monitor trauma populations, little attention has been given to the use of multiple sources of injury data that come from high level data repositories that contain hospital admissions, emergency presentations or coronial data. The high levels of reliability and case ascertainment associated with these high level data repositories, which include the Victorian Admitted Episodes Dataset (VAED) and Victorian Emergency Minimum Dataset (VEMD) results in a low level of bias, and are therefore important when assessing trends in injury incidence [28].

When applied to the burns population, the use of these sources means that changes over time can be attributed to changes in the true incidence of burn-injuries rather than occurring as a result of changes in the accuracy of the data collected or in the types of cases included in the datasets. The availability of identifiable data from these two sources also means that data can be accurately linked to prevent double counting of cases and provide a more comprehensive view of the incidence of major burn injuries and deaths in Victoria, Australia.

Therefore the aim of this chapter was to establish the frequency, pattern, and mechanisms of burn injury leading to death or hospital treatment (i.e. inpatient admissions and emergency department presentations) across the state of Victoria, Australia, for the years 2000–2006 inclusive. Trends in burn-related fatalities and hospital admissions for this period were also determined by using multiple data sets including the VAED and VEMD, along with population estimates from the Australian Bureau of Statistics (ABS) and Census data (years 1996, 2001 and 2006). This paper was considered unique to the Victorian healthcare setting in the presentation of trend analysis using various statewide data collection systems.

## 2.2 Declaration of authorship for thesis Chapter 2

Wasiak J, Spinks A, Ashby K, Clapperton A, Cleland H, Gabbe B. The epidemiology of burn injuries in an Australian setting, 2000–2006. *Burns*. 2009; 35(8): 1124-1132

In the case of Chapter 2, the nature and extent of my contribution to the work was the following:

<b>Nature of contribution</b>	<b>Extent of contribution (%)</b>
Principal author responsible for the concept, design, analysis of literature, the interpretation of results and development of the writing up of the manuscript.	80

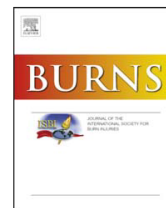
The following co-authors contributed to the work. If co-authors are students at Monash University, the extent of their contribution in percentage terms must be stated:

<b>Name</b>	<b>Nature of contribution</b>	<b>Extent of contribution (%) for student co-authors only</b>
<b>Spinks A</b>		
<b>Ashby K</b>		
<b>Clappterton A</b>		
<b>Cleland H</b>		
<b>Gabbe B</b>		

The undersigned hereby certify that the above declaration correctly reflects the nature and extent of the candidate's and co-authors' contributions to this work\*.

<b>Candidate's Signature</b>		<b>Date</b>
------------------------------	--	-------------

<b>Main Supervisor's Signature</b>		<b>Date</b>
------------------------------------	--	-------------

available at [www.sciencedirect.com](http://www.sciencedirect.com)journal homepage: [www.elsevier.com/locate/burns](http://www.elsevier.com/locate/burns)

## The epidemiology of burn injuries in an Australian setting, 2000–2006

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### ABSTRACT

**Objectives:** To describe presentation characteristics of burn leading to death or hospital treatment (i.e. inpatient admissions and emergency department [ED] presentations) across the state of Victoria, Australia, for the years 2000–2006 inclusive.

**Methods:** Data were provided by the Victorian Injury Surveillance Unit (VISU) from three different datasets pertaining to burn deaths, hospital inpatient admissions and non-admitted ED presentations. Population estimates were derived from census data provided by Australian Bureau of Statistics.

**Results:** During the 7-year period, 178 people died and 36,430 were treated for non-fatal burn injury, comprising 7543 hospital admissions and 28,887 non-admitted ED presentations. Males, children aged less than 5 years of age, and the elderly ( $\geq 65$  years of age) were at the highest risk of injury. Contact with heat and hot substances represented the major aetiological factor contributing to thermal injuries accounting for 64% of all hospital admissions and 90% of ED presentations. Temporal trends indicate no change in the population rate of burn deaths or hospital admissions during the study period.

**Conclusions:** ED presentations and hospital admissions and deaths have remained the same over this study period, but rates of burn remain high in males, children and the elderly. This could be due to variations in the implementation of government prevention and control programs and the divergence in efficient treatments and clinical practices amongst hospital care providers. Therefore, educational efforts for prevention should be the keystone to minimise the incidence of burns.

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### 1. Introduction

Burn represents perhaps the widest spectrum of any form of trauma. Burns occur in all age groups, and may range in

severity from very minor requiring no treatment, through to extremely severe when the highest levels of intensive care and surgery are indicated. This variability in severity and treatment can make it difficult to accurately describe the number of

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people who suffer burns each year and the subsequent imposed health burden [1]. Nonetheless, it is estimated that thermal burns constitute a significant source of morbidity and mortality. It is purported that 1% of the Australian population sustains a burn each year, of which half are severe enough to affect daily life. Approximately 10% of burn victims require hospitalisation, of which 10% are considered to have life-threatening injuries [2].

In Australia, there has been no examination of burn incidence from multiple sources such as records of deaths, hospital admissions and emergency department (ED) presentations. Data from Australia-wide hospital admissions sources [3] and single burn unit studies [2] suggest annual increases in hospital admissions rates, although conclusions drawn from these studies may not be valid because of specific variations in climate, employment patterns, or other socio-economic factors [4]. Similarly, studies based on data from single burn units, although invaluable for the reporting of therapeutic interventions, may not necessarily represent population-based estimates or specific treatment patterns [4].

The purpose of this study was to establish the frequency, pattern, and mechanisms of burn leading to death or hospital treatment (i.e. inpatient admissions and ED presentations) across the state of Victoria, Australia for the years 2000–2006 inclusive. Trends in burn-related fatalities and hospital admissions for this period were also determined.

## 2. Materials and methods

### 2.1. Study design

A retrospective review was performed of all Victorian burn injury cases that either resulted in a fatality or warranted hospital treatment (either inpatient admission or ED presentation). Deaths data were reviewed over a 6-year time period from January 2000 to December 2005 while hospital admission and ED data were reviewed over 7 years from January 2000 to December 2006. The discrepancies in these time periods were due to the availability of data at the time the analysis took place.

### 2.2. Setting

The estimated resident population of Victoria increased from approximately 4.81 million in 2001 to just over 5 million in 2006, at an annual growth rate of 1.2%. The capital city, Melbourne, has 3.74 million people residing and is nearly three-quarters (73.0%) of Victoria's population. Victoria is served by three major trauma centres, has 138 health care services and 38 public hospitals with 24 h ED facilities. The state has two burns units, one adult and one paediatric, both located within major trauma centres.

### 2.3. Population estimates

Population counts for Victoria including age and gender distributions were obtained from the Australian Bureau of Statistics (ABS) Census data (years 1996, 2001 and 2006) [5]. Estimates of the population size for each intervening year

were calculated assuming consistent population change over the period between census years.

### 2.4. Injury data sets

Data were provided by the Victorian Injury Surveillance Unit (VISU) from three different datasets pertaining to injury deaths, hospital inpatient admissions and non-admitted ED presentations. Duplicate cases (e.g. hospital admissions resulting in a fatality) were removed from the dataset to ensure that these datasets were mutually exclusive.

Fatality data were extracted from the ABS Death Unit Record File (DURF). This dataset was obtained from the Victorian State Registrars of Births, Deaths and Marriages and is coded using the World Health Organisation (WHO) International Classification of Diseases (ICD) coding system.

Hospital inpatient admissions data were obtained from the Victorian Admitted Episodes Dataset (VAED), which reports all acute patient information for public and private hospitals in the state. The VAED uses an Australian Modification of the ICD system (ICD-10-AM) which provides more detail than the ICD alone. Admitted cases that were transferred to other acute institutions were removed to avoid duplicative counting of cases. Available data from the VAED included patient age and gender, total length of hospital stay, burn injury intent, total body surface area (TBSA) affected and the thickness of the burn.

Data on emergency department presentations were extracted from the Victorian Emergency Minimum Dataset (VEMD), which gathers demographic, clinical and administrative details for every episode of care occurring in participating Victorian hospital EDs. The number of participating hospitals increased during the study period, from 28 in 2000 to 38 in 2006. It was estimated that 80% of ED presentations in the state of Victoria represented in this data set in 2000. Given that more EDs are now contributing to the database since that time, it is surmised that the total coverage is now greater. The VEMD data are coded to Level 1 National Data Standards for Injury Surveillance [6] which is related to the more extensive ICD codes.

The final dataset therefore included all fatal and hospital admitted burn injuries and a significant majority of non-admitted ED presentations for burn injury across the state of Victoria.

### 2.5. Inclusion criteria

Fatality (ABS) and hospital admission (VAED) burn and scald data were extracted using the ICD-10 External Injury Cause Codes in the ranges X00–X19, X76–X77, X97–X98 and Y26–Y27 incorporating 'Exposure to Smoke, Fire and Flames' and 'Contact with Heat and Hot Substances' that were unintentional, self-harm, assault and of undetermined intent.

Burn and scald data for non-admitted ED presentations were extracted from the VEMD using the injury cause codes: 14 Fire, flames, smoke; 15 Scalds (hot drink, food, water, other fluid, steam, gas or vapour); and 16 Contact burn (hot object or substance). The cause was checked against the text narrative of the injury event, manually re-assigned if misclassified, and then grouped according to the ICD-10 coding system for the purposes of comparison with hospital admissions.

## 2.6. Data analysis

All data were managed and analysed using Microsoft Excel and OpenEpi Version 2.2.1 [7]. Descriptive statistics such as age, gender, intent, site of injury, external cause and injury location were used to summarise the profiles of all burn injury cases. Population-based incidence rates were calculated for age, gender and each 12-month period for fatality and hospital admitted data, and risk ratios were calculated to compare risk differences between age and gender sub-populations. Incident rate ratios for the study period were calculated using Poisson regression model fitted to the temporal data to establish the existence of trends over time in population rates of burn injury deaths and hospital admissions.

Although the non-participation of a number of Victorian ED's in the data surveillance meant that it was not possible to calculate the true population incidence of burn injury resulting in non-admitted ED presentation, an approximate incidence rate was calculated using the available data. This was done in order to illustrate the magnitude of non-admitted burn injury presentations relative to hospital admissions and fatalities, with the understanding that the estimated rates would be an under-representation of the true incidence.

## 3. Results

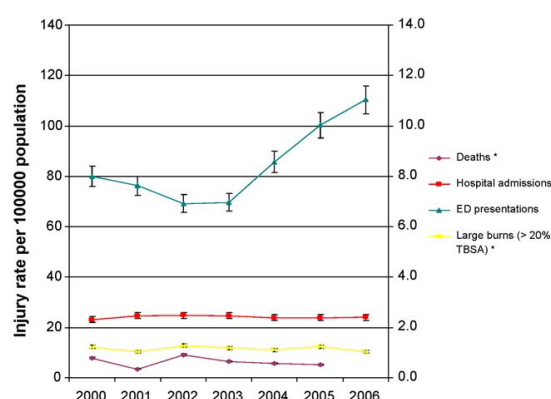
### 3.1. Temporal trends in burn injury

No statistically significant changes in the overall population rate of burn injury deaths (incident rate ratio (IRR) = 0.99, 95% CI: 0.92, 1.07) or hospital admissions (IRR = 1.01, 95% CI: 0.97, 1.05) were observed during the study period (Fig. 1). Nor were there any significant changes in the incidence of large burn injuries affecting more than 20% of the total body surface area (IRR = 0.97, 95% CI: 0.92, 1.03). Examination of burn hospital admissions by age groups revealed that rates decreased by 10 percent amongst children aged 0–4 years; however this trend was not statistically significant (Table 1). In age groups other than those 70 years of age and over, hospital admissions for burn injuries increased non-significantly (Table 1).

The number of Victorian ED contributing data to the VEMD database increased during the study period and hence a corresponding increase in the frequency of ED presentations was also observed (Fig. 1).

### 3.2. Fatal burn injuries

During the years 2000–2005, 178 people died following a burn (Table 2). The population incidence of burn injury mortality was significantly higher among males compared with females, and increased consistently with age. The burn mortality rate was particularly high among the elderly population aged over 80 years compared with the rest of the population (Table 2). One quarter of all burn deaths were due to intentional injury, and three quarters of these were self-inflicted. All intentional deaths were caused by exposure to smoke, fire or flame, whereas nearly one fifth of unintentional deaths were due to contact with heat and hot substances. The majority of these (54%) were due to hot tap water injuries in elderly people aged 70 years and over.



**Fig. 1 – Temporal trends in Victorian burn-related deaths, hospital admissions and emergency department presentations, 2000–2006<sup>\*\*\*</sup>. (\*) Scale for deaths and large burns is shown on the right hand side of the graph. (\*\*\*) The number of contributing ED's increased over time.**

### 3.3. Non-fatal hospital admissions and ED presentations

Data were available for 34,343 patients treated in hospitals for non-fatal burn between January 2000 and December 2006, comprising 7543 hospital admissions and 26,770 non-admitted ED presentations. Table 3 shows the distribution of non-fatal hospital treated burn injury by gender, age-group and intent. Also displayed is the average annual incidence rate of hospital admission and ED presentation (based on available data) for burn over the 7 years. On a per population basis, males were 1.64 (95% CI: 1.57, 1.72) times more likely to be hospitalised and 1.53 (95% CI: 1.43, 1.63) times more likely to present to an ED with a burn injury than females.

During the 7 years study period 2805 children (aged 19 years and below), were admitted to hospital and a further 9740 presented to an ED with a burn, accounting for approximately one third of all burn injury presentations (both unintentional and intentional). The youngest children (0–4 years) were over-represented in hospital admissions and ED presentations compared to other ages groups (Table 3). The frequency of paediatric burns decreased as age increased; although this trend reversed itself with a rise in both hospital admissions and ED presentations for

**Table 1 – Temporal trends in Victorian burn-related hospital admissions by broad age-group: incident rate ratios 2000–2006.**

Age-group	Incident rate ratio <sup>a</sup>	95% CI
0–4 years	0.90	0.74–1.09
5–14 years	1.09	0.79–1.51
15–24 years	1.11	0.89–1.39
25–69 years	1.08	0.96–1.23
70 years +	0.98	0.77–1.24

<sup>a</sup> Based on Poisson regression model.



**Table 2 – Distribution of Victorian burn injury fatalities, 2000–2005.**

	Unintentional deaths		Intentional deaths		All deaths	
	N per year	Rate per 100,000 (95% CI)	N per year	Rate per 100,000 (95% CI)	N per year	Rate per 100,000 (95% CI)
Gender						
Male	15.2	0.65 (0.56–0.76)	4.5	0.19 (0.14–0.26)	19.6	0.84 (0.73–0.97)
Female	7.3	0.30 (0.24–0.38)	2.6	0.11 (0.07–0.16)	10.0	0.41 (0.34–0.50)
Age-group						
Paediatric						
0–4 years	1.2	0.39 (0.31–0.49)	0.2	0.06 (0.03–0.10)	1.4	0.44 (0.35–0.55)
5–9 years	1.0	0.31 (0.24–0.40)	0.2	0.05 (0.03–0.10)	1.2	0.37 (0.29–0.46)
10–14 years	0.2	0.05 (0.03–0.09)	0	0 (0.00–0.02)	0.2	0.05 (0.03–0.09)
15–19 years	0.3	0.10 (0.07–0.16)	0.2	0.05 (0.03–0.09)	0.15	0.15 (0.11–0.22)
Adult						
20–34 years	2.2	0.22 (0.15–0.33)	2.2	0.22 (0.15–0.33)	4.3	0.43 (0.32–0.58)
35–49 years	4.2	0.39 (0.29–0.54)	2.0	0.19 (0.12–0.19)	6.2	0.58 (0.46–0.75)
50–64 years	4.6	0.60 (0.44–0.78)	1.8	0.23 (0.15–0.36)	6.5	0.83 (0.65–1.06)
64–80 years	4.8	0.96 (0.78–1.36)	0.5	0.11 (0.05–0.25)	5.0	1.07 (0.81–1.41)
80+ years	4.3	2.61 (1.92–3.49)	0.2	0.10 (0.04–0.43)	4.5	2.71 (2.03–3.62)
Total	22.5	0.47 (0.42–0.54)	7.2	0.16 (0.13–0.20)	29.6	0.62 (0.56–0.71)

those aged 20–24 years (Fig. 2). The elderly ( $\geq 65$  years of age) shared similar hospital admissions rates with the children less than 4 years although ED presentations that did not require hospital admission were markedly lower among older people (Table 3).

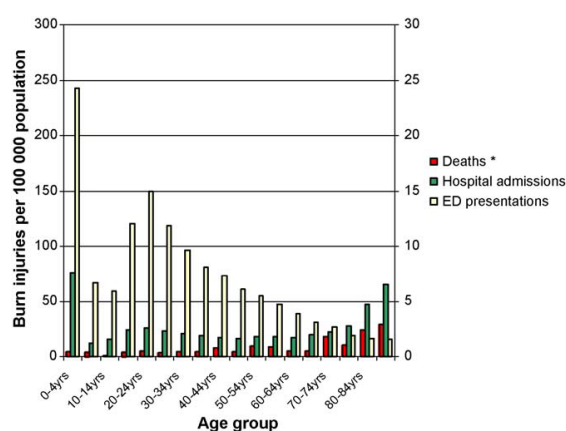
### 3.4. Intent of burn injury

Intentional burn represented 24% of all deaths, 3% of all hospital admissions and 1% of ED presentations. The majority of intentional burns were self-inflicted, although

**Table 3 – Distribution of hospital admissions and emergency department presentations for non-fatal burn injury in Victoria, 2000–2006.**

	Hospital admissions		ED presentations (non-admitted)		Total non-fatal burn injuries N per year
	N per year	Rate per 100,000 (95% CI)	N per year	Rate per 100,000 (95% CI) <sup>a</sup>	
Gender					
Male	736	31.6 (29.4–33.9)	2270	93.8 (90.0–97.7)	3006
Female	465	19.2 (17.5–21.0)	1543	63.8 (60.6–67.0)	2008
Age-group					
Paediatric					
0–4 years	230	76.1 (66.9–86.6)	661	218.7 (202.5–235.9)	891
5–9 years	38	12.0 (8.7–16.4)	195	61.2 (53.1–70.3)	233
10–14 years	51	15.7 (12.0–20.6)	175	53.9 (46.3–62.3)	226
15–19 years	77	23.8 (18.9–29.5)	361	110.8 (99.8–122.7)	438
Adult					
20–34 years	232	23.1 (20.3–26.3)	1160	115.5 (109.0–122.3)	1392
35–49 years	184	17.3 (15.0–20.1)	772	72.9 (67.9–78.2)	956
50–64 years	138	17.6 (14.9–20.8)	359	45.8 (41.2–50.7)	497
64–80 years	106	22.6 (18.8–27.5)	136	29.2 (24.6–34.4)	242
80+ years	91	55.0 (44.7–67.3)	27	16.3 (10.9–23.3)	118
Intent					
Unintentional	1147	24.1 (22.8–25.6)	3670	77.2 (74.8–79.8)	4817
Intentional	38	0.8 (0.6–1.1)	41	0.9 (0.6–1.2)	79
Undetermined	15	0.3 (0.2–0.5)	114	2.4 (2.0–2.9)	129
Total	1200	25.3 (23.9–26.7)	3824	80.5 (78.0–83.1)	5024

<sup>a</sup> Based on available data from participating ED's only.

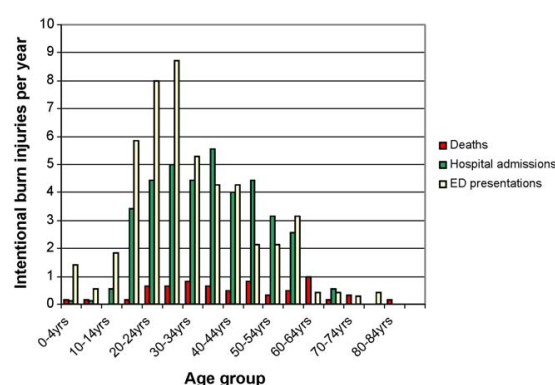


**Fig. 2 – Population incidence of burn injury-related deaths, hospital admissions and ED presentations by age-group, Victoria, 2000–2006. (\*) Scale for deaths is shown on the right hand side of the graph. ED incidence based on available data from participating ED's only.**

assaults accounted for 23% of intentional deaths, 22% of intentional hospital admissions and 47% of intentional ED presentations.

More females than males were the victim of intentional burn injury treated in hospitals and EDs, and females were more likely to sustain an intentional burn injury through self-harm whereas males were more frequently the victims of an assault (Table 3). Fig. 3 shows the frequency of intentional (assault and self-harm) burn injury leading to death, hospital admission and non-admitted ED presentation across the life-span. Intentional burns were infrequent in younger children and among the elderly; however hospital admissions and ED presentations due to intentional burns increased during adolescence and peaked in early adulthood. In contrast, fatal intentional burn injuries were most common among individuals aged 60–64 years.

The characteristics of non-fatal burn injuries requiring hospital admission are shown in Table 4. Self-inflicted burn-related admissions were more likely to result from exposure to smoke, fire and flame than assault-related admissions (Risk Ratio (RR) 1.57, 95% CI: 1.17, 2.11) or unintentional burn injuries (RR 2.04, 95% CI: 1.86, 2.25). Self-inflicted burn patients were generally more serious than unintentional injuries with a higher proportion of patients sustaining an injury covering more than 10% of the total body surface area (TBSA) (24% for self-inflicted injuries vs. 14% for unintentional injuries). Patients with self-inflicted burns had a much greater likelihood of remaining in hospital for longer than 31 days than were patients with unintentional burn injuries (RR 5.77, 95% CI: 4.25, 7.84). The anatomical distribution of burn varied according to intent (Table 4). More than half of self-inflicted burn injuries affected the upper extremity whereas assault-related injuries more commonly involved the head, face or trunk. The extremities were mostly affected in victims of unintentional burn injury (Table 4).



**Fig. 3 – Annual frequency of intentional burn injuries across the life-span in Victoria, 2000–2006. (\*) ED incidence based on available data from participating ED's only.**

### 3.5. Major causes of burn injuries

Exposure to smoke, fire and flames was responsible for 82% of all burn-related deaths. In contrast, the majority of non-fatal burn injuries (64% of hospital admissions and 90% of non-admitted ED presentations) were caused by contact with heat and hot substances (Fig. 4). Scalds from hot drinks and food was the single most common cause for hospital admission, accounting for 19% of all burn-related admissions, followed by scalds from other hot fluids (not including hot tap water) which accounted for 15% of admissions.

However, the leading cause of burn varied by age-group: among older children aged 5–14 years and young people aged 15–24 years the leading cause of burn-related hospital admission was exposure to the ignition of highly flammable material. Hot tap water scalds and contact with hot household appliances and heating devices were responsible for a high number of hospital admissions among young children and the elderly, but were not leading burn hazards for other age groups.

The higher proportion of deaths and hospital admissions due to smoke, fire and flame exposure however indicates the more serious nature of these injuries and more intensive treatment requirements. Twenty-three percent of burn patients hospitalised due to exposure to smoke, fire and flames had a burn injury that covered more than 10% of the body compared with only 9% of patients hospitalised due to contact with hot substances.

### 3.6. Total body surface area burnt

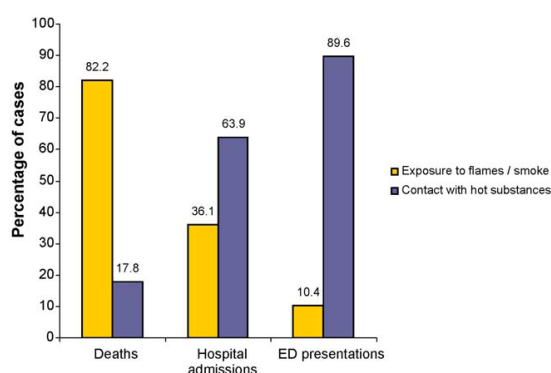
The distribution of burn size (TBSA) for the study population is shown in Table 5. Burn patients with 10% TBSA and less made up the majority of hospital admissions, while patients with >20% TBSA and above accounted for just over 5%.

### 3.7. Body site injured

The most frequently injured body region for hospital admissions was the extremities (57%). Injuries to the neck were more

**Table 4 – Intent characteristics of non-fatal burn injuries admitted to Victorian hospitals, 2000–2006.**

	Intentional burn injuries—self-harm <sup>a</sup>		Intentional burn injuries—assault <sup>a</sup>		Unintentional burn injuries <sup>a</sup>	
	N	%	N	%	N	%
Gender						
Male	51	29%	40	71%	4495	62%
Female	127	71%	16	29%	2726	38%
Age-group						
Paediatric						
0–4 years	0	–	1	2%	1388	36%
5–9 years	0	–	0	–	244	3%
10–14 years	1	0.6%	1	2%	317	4%
15–19 years	12	7%	8	14%	496	7%
Adult						
20–34 years	60	34%	27	48%	1523	21%
35–49 years	67	38%	17	30%	1201	17%
50–64 years	34	19%	2	4%	880	12%
64–80 years	4	2%	0	–	660	9%
80+ years	0	–	0	–	512	7%
External cause						
Exposure to smoke, flame and fire	130	73%	26	46%	2575	36%
Contact with heat/hot substances	48	27%	30	54%	4646	64%
Anatomical location						
Head/face/neck	16	9%	16	29%	1363	19%
Trunk	26	15%	17	30%	1205	17%
Upper extremity	93	52%	15	27%	2441	34%
Lower extremity	29	16%	6	11%	1935	27%
Multiple body regions	2	1%	0	–	32	–
Body region not relevant	8	4%	2	4%	374	5%
Length of stay+						
<2 days	51	29%	21	38%	3879	54%
2–7 days	40	22%	11	20%	1844	26%
8–30 days	49	28%	9	16%	1231	17%
>31 days	38	21%	4	7%	267	4%
Total	178		56		7221	

<sup>a</sup> Totals differ due to missing data.**Fig. 4 – Proportion of burn injury deaths, hospital admissions and ED presentations by major cause category.**

common among hospitalised males than females (23% vs. 14%), while a higher proportion of women sustained trunk injuries than men (22% vs. 15%). The pattern of injury was similar in ED presentations with the extremities accounting for 63%, and upper extremities accounting for nearly half (47%), of all ED presentations.

### 3.8. Place of injury

The place of injury occurrence was not specified for a large number (36%) of hospitalised cases, however of those that were specified, 75% occurred in the home or a residential institution, 7% occurred in schools and 8% occurred in trade, service or industrial areas. Available data also indicated that the majority of burns and scalds presenting to ED occurred in the home (67%).

### 3.9. Length of hospital stay

Over half of the hospital admissions (51%) were in hospital for less than 2 days, while 26% stayed for 2–7 days and the

**Table 5 – Distribution of percentage of total burn surface area (%TBSA) according to age, gender and intent.**

	Total N	<10% TBSA	%	10–19% TBSA	%	20–49% TBSA	%	50%+ TBSA	%
<b>Gender</b>									
Male	4185	3431	81.98	504	12.04	225	5.38	25	0.60
Female	2542	2181	85.80	227	8.93	117	4.60	17	0.67
<b>Paediatric</b>									
0–4 years	1364	1117	81.89	181	13.27	60	4.40	6	0.44
5–9 years	231	196	84.85	17	7.36	16	6.93	2	0.87
10–14 years	303	250	82.51	36	11.88	17	5.61	0	0.00
15–19 years	491	386	78.62	69	14.05	31	6.31	5	1.02
<b>Adult</b>									
20–34 years	1438	1213	84.35	137	9.53	78	5.42	10	0.70
35–49 years	1115	915	82.06	125	11.21	65	5.83	10	0.90
50–64 years	807	674	83.52	80	9.91	47	5.82	6	0.74
65–79 years	553	475	85.90	58	10.49	18	3.25	2	0.36
80+ years	425	386	90.82	28	6.59	10	2.35	1	0.24
<b>Intent</b>									
Unintentional	6447	5390	83.60	711	11.03	317	4.92	29	0.45
Intentional—self-harm	142	108	76.06	10	7.04	16	11.27	8	5.63
Intentional—assault	51	35	68.63	6	11.76	6	11.76	4	7.84
Undetermined intent	87	79	90.80	4	4.60	3	3.45	1	1.15
<b>Year</b>									
2000	845	691	81.78	98	11.60	48	5.68	8	0.95
2001	942	787	83.55	107	11.36	43	4.56	5	0.53
2002	977	805	82.40	112	11.46	54	5.53	6	0.61
2003	985	845	85.79	84	8.53	47	4.77	9	0.91
2004	962	798	82.95	111	11.54	47	4.89	6	0.62
2005	1007	830	82.42	117	11.62	58	5.76	2	0.20
2006	1009	856	84.84	102	10.11	45	4.46	6	0.59
Total	6727	5612	83.43	731	10.87	342	5.08	42	0.62

remainder (27%) stayed for 8 days or more. The proportion of women staying in hospital for longer periods was slightly higher than that for men; however the difference was not statistically significant.

#### 4. Discussion

This epidemiological study has presented data from multiple sources to illustrate the incidence, pattern and cause of burn injuries over 7 years in the state of Victoria. As such, it provides the most comprehensive overview of burn injury available to date. During the study period, 178 burn related deaths were recorded along with over 34,000 episodes of care provided either in a hospital ward or emergency department. The serious nature of burns was attested to by the finding that one quarter of all hospitalised patients (nearly 2000 patients) remained in care for at least 1 week.

##### 4.1. Temporal trends

There was no change in the overall population incidence of burn-related deaths or hospital admissions over the study period. Similarly, we observed no temporal changes in serious burns with a total body surface area of greater than 20%. Although non-admitted ED presentations increased during the study period, it is highly likely that this increase was mainly due to a greater number of EDs contributing data to the injury surveillance system capturing these events. However it

is also possible that there may have been a real increase in minor burn injury cases presenting at EDs across the state, or the capture of such cases within ED surveillance systems may have improved over time.

Analysis of hospitalised burn incidence by age groups revealed a more complex picture, suggesting a non-significant trend for decreasing burns in the very young (0–4 years), and a non-significant increase in all other age groups except for the elderly (>70 years) among who burn incidence remained unchanged. Although Australian data shows that burns among children aged 0–14 years have decreased over time [17], our findings show no decline in burn rates amongst children aged 5–14 years. In particular, hospital admissions among children aged 5–9 years had increased slightly from the number reported by Streeton and Nolan [17] in 1994 from 9.8 to 12.0 per 100,000 for the period 2000–2006.

The overall finding of stable burn rates was in contrast to previous reported Australian studies which reported a general increase in 'all cases' admission rates to hospitals since 2001 [2,8]. However, this trend in itself was in contradiction to international trends in developed countries such as the United States and Sweden where hospital admission rates and ED presentations due to burn have been decreasing over time [4,9].

A number of burn and scald injury prevention initiatives were active during the reported study period and some of these may be linked to the results reported here and previously. For example, there was evidence that success has been achieved in preventing hot tap water scalds among young children and the elderly with the implementation lower

tap water temperatures strategies [18]. More importantly, Australian building codes were changed in 1994 that mandated all new hot water installations in new residential buildings and domestic bathrooms undergoing renovations to be set to deliver hot tap water less than 50°C. Although this legislation was passed some time before the time period investigated in this study, it would be expected that the change in hot tap water temperature across residences in the Victorian community and predicted corresponding decreases in associated scalds would be a gradual process. Under the building code, hot water temperatures need only be lowered in existing residences as they undergo significant renovations, a cycle that may take up to 20 years or longer to be achieved. Therefore, it may still be too soon for the full maximum benefits of this legislation to be observed.

Other fire and burn prevention initiatives have included legislation of smoke alarm installation, educational campaigns and collaborative exercises between Victorian fire authorities who have sought to engage with community members to entrench fire safety knowledge and behaviours. Broader public health campaigns to reduce cigarette smoking have also been in place. Although the messages aim of anti-smoking campaigns is to reduce smoking-related diseases, an additional advantageous spin-off from lower smoking prevalence is the lower likelihood of cigarette-related fires.

However, in spite of success in some areas, the overall picture of burn injuries in Victoria remained unchanged over the study period. This could be because the public health campaigns have simply lacked the necessary breadth to cover all types of possible burn scenarios. It must be remembered that although the burn rate is higher on a per capita basis among very young and very old populations, by sheer numbers, more burn deaths, hospitalisations and emergency department presentations occur among Victorians falling between these two age extremes. However, it is the very young and the very old that are most often targeted by public health campaigns to reduce burn-related injuries. As an alternative explanation for the lack of change despite burn injury prevention efforts, is that burn victims may be bypassing other health care providers (e.g. general or family practitioners) and seeking hospital treatment for their injuries in greater numbers than previously.

#### 4.2. Age and gender

As similarly reported in other studies [10,11] we found ED visit rates and hospital admissions to be greater among males than females. The exception to this was for self-inflicted burn which was seen more frequently among females. The higher proportion of males affected by burn injury has been tentatively explained by a perceived difference and attitude to risk, and greater exposure to risk-type behaviours [9].

There was also a greater variation and different pattern in relation to age. Like similar studies [12,13] the youngest age-group (0–4 years) were over-represented in both hospital admissions and ED presentations, but not at risk of increased mortality. Males in their late teens and early twenties comprised another high-risk group for hospital admission and ED presentation. This peak in burn came after a gradual decrease in injuries in older children, possibly due to safety

regulations in schools and targeted preventative measures that would mainly affect the younger population. At the other extreme, we noted that elderly patients had an elevated incidence rate of hospitalisation for burn compared with the general population, although they had the lowest rates of non-admitted ED presentations. The higher likelihood of admission to hospital for the elderly is most likely due to their relative frailty and higher occurrence of co-morbidities compared with younger individuals.

#### 4.3. Intentional burn injury

Although only 1.5% of burn injuries in Victoria were intentional, they were responsible for a quarter of all deaths and were associated with longer hospital stays. The low detection rate of intentional burn injuries in ED department could signify that cases were misdiagnosed or improperly recorded due to patients trying to avoid embarrassment or further repercussions [14]. Among the types of intentional burns, self-harm, rather than assaults were prevalent, and the former were associated with a much poorer prognosis. These results were not only reflective of observed global trends, but consistent with a common picture that patients trying to harm themselves employed fewer personal defences than those who were burnt accidentally or attacked as a result of impulse by an assailant [14,15].

#### 4.4. Strengths and limitations

The major strength of the current study was the availability of population-based data from a variety of sources, avoiding the limitations associated with presentation of data from single burn units [2,16]. There are, however, some limitations that must be accounted for. Firstly, our hospital admissions data was sourced from administration datasets from hospitals who report to the state-based Department of Human Services who then provide an injury subset to VISU. These administrative data are collected using a standard methodology and the processes are regularly audited which guarantees a level of accuracy of the reporting. However, the level of data available for research purposes is limited which inhibits some of the detailed analyses which would be desirable for planning injury prevention programs.

Secondly, this study was unable to include individuals suffering from burn injuries who did not seek medical attention or who attended a health-care facility not covered by the VEMD dataset. Although perceived to be relatively small number of less severe burn injury cases, this numerical gap is likely to have under-estimated the true incidence of burn injury in Victoria.

### 5. Conclusion

Burn and scalds injuries constitute an important source of mortality and morbidity which has not been reduced despite small successes at reducing the incidence of some types of burn injuries. Our findings suggest that there have been no significant change in Victorian hospital admissions or deaths over a 7-year period, and young children and the elderly

continue to be particularly vulnerable to this type of injury. We believe this to be due to variations in the success of government and health care agencies in burn injury prevention and control. Therefore, educational efforts for prevention should be the keystone to minimise the incidence of burn injuries.

## REFERENCES

- [1] Burd A, Yuen C. A global study of hospitalized paediatric burn patients. *Burns* 2005;31(June (4)):432-8.
- [2] Greenwood JE, Tee R, Jackson WL. Increasing numbers of admissions to the adult burns service at the Royal Adelaide Hospital 2001-2004. *ANZ J Surg* 2007;77(May (5)):358-63.
- [3] Harrison JE, Steele D. Burns and scalds. Cat. no. INJCAT 92. Adelaide: AIHW; 2006.
- [4] Fagenholz PJ, Sheridan RL, Harris NS, Pelletier AJ, Camargo Jr CA. National study of Emergency Department visits for burn injuries 1993 to 2004. *J Burn Care Res* 2007;28(September-October (5)):681-90.
- [5] Australian Bureau of Statistics. Population by age and sex, Victoria. Canberra: ABS; 2006 [ABS Cat. No. 3235.2.55.001].
- [6] Australian Institute of Health and Welfare. National Data Standards for Injury Surveillance Version 2.1. National Injury Surveillance Unit. Research Centre for Injury Studies, Flinders University of South Australia, 1998.
- [7] Dean AG, Sullivan KM, Soe MM. OpenEpi: Open Source Epidemiologic Statistics for Public Health, Version 2.2.1. [www.OpenEpi.com](http://www.OpenEpi.com), updated 2008/04/06.
- [8] Pegg SP. Burn epidemiology in the Brisbane and Queensland area. *Burns* 2005;31(January (Suppl. 1)):S27-31.
- [9] Akerlund E, Huss FR, Sjöberg F. Burns in Sweden: an analysis of 24,538 cases during the period 1987-2004. *Burns* 2007;33(February (1)):31-6.
- [10] Chien WC, Pai L, Lin CG, Chen HC. Epidemiology of hospitalized burns patients in Taiwan. *Burns* 2003;29(September (6)):582-8.
- [11] Han TH, Kim JH, Yang MS, Han KW, Han SH, Jung JA, et al. A retrospective analysis of 19,157 burns patients: 18-year experience from Hallim Burn Center in Seoul Korea. *Burns* 2005;31(June (4)):465-70.
- [12] Foglia RP, Moushey R, Meadows L, Seigel J, Smith M. Evolving treatment in a decade of pediatric burn care. *J Pediatr Surg* 2004;39(June (6)):957-60.
- [13] Sakallioğlu AE, Başaran O, Tarım A, Türk E, Kut A, Haberal M. Burns in Turkish children and adolescents: nine years of experience. *Burns* 2007;33(February (1)):46-51.
- [14] Modjarad K, McGwin Jr G, Cross JM, Rue 3rd LW. The descriptive epidemiology of intentional burns in the United States: an analysis of the National Burn Repository. *Burns* 2007;33(November (7)):828-32.
- [15] Tuohig GM, Saffle JR, Sullivan JJ, Morris S, Lehto S. Self-inflicted patient burns: suicide versus mutilation. *J Burn Care Rehabil* 1995;16(July-August (4)):429-36.
- [16] Duggan D, Quine S. Burn injuries and characteristics of burn patients in New South Wales Australia. *Burns* 1995;21(March (2)):83-9.
- [17] Streeton C, Nolan T. Reduction in paediatric burn admissions over 25 years 1970-94. *Injury Prev* 1997;3: 104-9.
- [18] Cassell E, Clapperton A, Ashby K. Unintentional burns and scalds in vulnerable populations: the very young and the very old, Victoria July 2001-June 2003. *Hazard* 57:1-17. Victorian Injury Surveillance and Applied Research System.

### **2.3 Summary of findings**

The key findings of this paper were that the rates of emergency data presentations, hospital admissions and deaths remained consistent over a 7-year time frame. On a per population basis, males were over 1.5 times more likely to present to an emergency department with a burn injury than females; whilst rates of burn injury among vulnerable subgroup populations such as children younger than five years and adults greater than 65 years, were similar with each representing about one third of all burn injury presentations. Overall, the findings suggested no significant changes to Victorian hospital admissions with specific burn-injured populations, which may in part reflect variations in the success of government and health care agencies in burn injury prevention and control. There is a need for ongoing educational efforts required to minimise the incidence of burn injuries over time.

### **2.4 Update status of burn injury at a national level**

Since the publication of this paper back in 2009, a systematic search of the literature using the OVID MEDLINE database from 2009 to 2013 was undertaken using the search term 'burn injury', 'epidemiology', 'Victoria', and 'Australia'. Results revealed no additional studies specific to Victoria, although six studies published by the same authorship team of Duke et al in the state of Western Australia, provided further information on the epidemiology of burn injury in Australia [29, 30, 31, 32, 33, 34]. The six studies used the same statewide health administrative dataset to assess the incidence, temporal trends, and external cause of burn injury-related hospital admissions and mortality from 1983 to 2008.

In particular, three of the studies examined specific subgroup populations such as children younger than five years, adolescents, young adults and adults older than 60 years. The remaining three studies examined risk of injury based on geographical location (i.e. urban, rural and remote regions), environmental risk (i.e. sun-baking) or pre-disposing factors (i.e. immunosuppression following burn and rates of cancer). Across all studies, the study sample of 23,450 hospitalisations for burn injuries was used to show that hospital admission and mortality rates declined by an average annual rate of 2%. When examining vulnerable populations (i.e. children younger than 5 years, 20- to 24-year-old men, and adults older than 65 years), their results and our own findings showcased how these populations remained at high risk of burn

injuries. In addition, the authors examined the incidence of cancer following a burn injury when compared to all-cause cancers and noted for female burn survivors that there was a greater number of observed versus expected notifications of total cancer. No statistically significant difference in total cancer risk was found for males.

## **2.5 Chapter summary**

The addition of six new studies continues to showcase that burn injuries remain a consistent source of hospital admission, and that vulnerable populations such as the young and the elderly continue to be particularly vulnerable to this type of injury. The addition of examining burn injury according to environmental risk or predisposing risk factors again showcased vulnerable populations, which have not been described as frequently in other subgroups. This review of published epidemiological studies reinforces the need for government and healthcare agencies to maintain ongoing burn injury prevention and control efforts in Australia.



## **Chapter 3: Identifying common outcome measures and reporting tools used in burn-injured populations**

*Chapter 3* contains a manuscript that was accepted for publication in *Burns*, the international peer review journal of the International Society for Burn Injuries (ISBI) on February 28<sup>th</sup> 2011. The citation is as follows:

**Wasiak J**, McMahon M, Danilla S, Spinks, A, Cleland H and Gabbe B. Measuring common burn outcome measures and their concepts using the International Classification of Functioning, Disability and Health (ICF): a systematic review. *Burns*. 2011; 37(6): 913-24

### **3.1 Introduction**

As discussed in *Chapter 1* of this thesis, there have been ongoing advances in burn care management over the last two decades, which have placed burn care clinicians in the midst of an exciting paradigm shift from what used to be a primary concern of mortality to medical, surgical, rehabilitative and psychological outcomes that are more likely to enhance the HRQoL of those with burn injury. Measuring these long-term outcomes is an important aspect of describing the burden of burn injury, and frameworks such as the ICF can provide guidance in terms of how best to measure outcomes in a specified population.

In *Chapter 2*, we demonstrated how accumulated data from statewide data repositories could be used to establish the incidence of burn injuries, and monitor trends in a geographical-specific location, but the datasets described were likely to underestimate the impact of burn injury. Therefore, this chapter will address aim number two of the thesis, which is to evaluate how well the patient-centred outcome measures currently used in the long-term consequences of burn-related injuries are represented by the constructs of the ICF. In particular, information from this chapter served to reinforce the choice of outcome measures used for the main cohort study of this thesis. This paper was considered unique in its ability to show how the ICF tool could be used in developing a common language amongst burn researchers.

### 3.2 Declaration of authorship for thesis Chapter 3

Wasiak J, McMahon M, Danilla S, Spinks, A, Cleland H and Gabbe B. Measuring common burn outcome measures and their concepts using the International Classification of Functioning, Disability and Health (ICF): a systematic review. *Burns* 2011; 37(6): 913-24.

In the case of Chapter 3, the nature and extent of my contribution to the work was the following:

<b>Nature of contribution</b>	<b>of</b>	<b>Extent of contribution (%)</b>
Principal author responsible for the concept, design, analysis of literature, the interpretation of results and development of the writing up of the manuscript		80

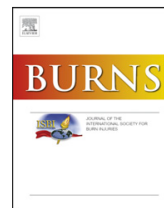
The following co-authors contributed to the work. If co-authors are students at Monash University, the extent of their contribution in percentage terms must be stated:

<b>Name</b>	<b>Nature of contribution</b>	<b>Extent of contribution (%) for student co-authors only</b>
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<b>Gabbe B</b>		

The undersigned hereby certify that the above declaration correctly reflects the nature and extent of the candidate's and co-authors' contributions to this work\*.

<b>Candidate's Signature</b>		<b>Date</b>
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<b>Main Supervisor's Signature</b>		<b>Date</b>
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## Review

## Measuring common outcome measures and their concepts using the International Classification of Functioning, Disability and Health (ICF) in adults with burn injury: A systematic review

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## ABSTRACT

**Purpose:** To identify and quantify the health related concepts contained in the most common outcome instruments used in adult burn care, and to compare the content of these instruments based on their linkage to the International Classification of Functioning, Disability and Health (ICF). The ICF has been validated as a reference tool by the World Health Organization and is a framework that incorporates physical, emotional, environmental and social aspects of daily functioning.

**Methods:** Electronic searches of MEDLINE, EMBASE CINAHL, PsychINFO and the Cochrane Library from 2003 onwards were carried out using a predetermined search strategy. Specific characteristics of the included studies and data pertaining to the outcome instruments were extracted. Two reviewers independently categorised the underlying concepts contained in the most commonly used outcome measures and linked them to ICF categories using standardised linkage rules.

**Results:** Out of a total 132 included studies, 151 outcome instruments were identified. Of these, 14 frequently used generic and burn-specific instruments were selected for linkage to the ICF. From the 381 items contained in the 14 instruments, 356 concepts were extracted and subsequently linked to 99 ICF categories. Nearly 46% of the concepts were linked to body function and 20% to activities and participation, whereas only a few concepts were formally linked to health condition, body structures and personal or environmental factors.

**Conclusion:** The ICF proved highly useful for the content comparison of frequently used generic and burn-specific instruments. The results may provide clinicians and researchers with new insights when selecting health-status measures for clinical studies in those with burn injury.

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## 1. Introduction

Advances in burn care management over the past three decades have resulted in improved survival, at least in the developed world, for those suffering from burn injury [1]. However, burn survivors report a complex set of challenges in their recovery process that can affect every domain of their lives [2,3]. To date, there have been a large number of measures used to assess outcomes in adults with burn injury with no consensus about which domains to measure or whether a battery of measures is needed to capture the full spectrum of burn sequelae from the perspective of the patient as well as the clinician and researcher [2,4]. A recent review has detailed the difficulties inherent in measuring outcomes in this population and highlighted the need for an international collaboration to progress this agenda [3].

The lack of consistency in the use of instruments is not unique to burn care, and can be related to confusion over the definition of domains or 'what to measure', particularly regarding the overlap between functional outcomes and other health concepts such as quality of life, health status and health-related quality of life [5–7]. This, in turn, has resulted in a lack of clarity about the selection of instruments or 'how to measure'. Without a conceptual model, functioning and disability in burns has been defined, by default, by the content of the instruments used in its research output [8].

There has been a call by researchers for a comprehensive bio-psychosocial measurement of injury and disease outcomes that can overcome some of these difficulties [6,9]. The International Classification of Functioning, Disability and Health (ICF), which is based on the bio-psychosocial model of functioning, disability and health, and was approved by the World Health Organization (WHO) in 2001 as the replacement for the International Classification of Impairments, Disabilities and Handicaps (ICIDH-2), could be suitable to address the global issue of burn burden. The ICF could then assign its multipurpose classification and use of a common language to identify the health areas most frequently addressed in clinical studies in

those with burn injury and the areas that have scarcely been measured despite clinical relevance. More importantly, the application of the ICF to outcome measures could also enlighten the current instrument selection for assessing function and health and inform the development of new tools [5,10–13]. The ICF will sit beside the ICD-10 classification of disease and diagnosis as a companion classification to quantify the sequelae of those diseases/conditions. Between them, these two classifications can be used to describe and compare population health on a global basis.

There are a number of ways in which the ICF could be utilised as a framework to classify and describe functioning, disability and health in burn injury. The most thorough approach would involve the development of 'core sets' to identify the ICF subsets of particular relevance for burn injury that could provide minimal standards for the assessment and recording of health and functioning across clinical and research settings [8]. The process of development of 'core sets' would be rigorous and involve an international effort with preliminary studies including a systematic review of all outcome measures used in the field, an empirical study, and an expert survey to capture the complete experience of a burn survivor [8,14,15].

While the development of 'core sets' is ambitious, there are other ways in which the ICF could be employed to assist in establishing the domains or concepts currently captured by existing outcome instruments for particular conditions. These include the use of the ICF for content comparison between commonly reported instruments. This would allow clinicians and researchers to understand what domains are covered (or not) by these instruments and could facilitate a selection of instruments for a variety of study purposes. A number of papers have presented content comparison of instruments with the selection criteria favouring the most commonly reported instruments in the area or those related to particular types of measures such as health related quality of life measures [12,16–19].

The objective of the current study was to identify and quantify the health care concepts contained in the most

commonly reported outcome instruments used in the literature for adult burn care, and to compare the content of these instruments based on their linkage to the ICF as a reference tool. The specific aims of this paper were to stimulate discussion in the burns community about the use of the ICF and the development of a burns core set, to provide an indication of the scope of undertaking a systematic review as part of this exercise and to test the methodology and feasibility of linkage of burn outcome measures to the ICF.

## 2. Methods

### 2.1. Data sources and search strategy

A structured literature search was performed in MEDLINE, CINAHL, EMBASE, PsychINFO and The Cochrane Library from 2003 onwards using keywords such as 'burns' and 'thermal injury' with 'health status', or 'quality of life', or 'recovery of function' or 'outcome assessment (health care)'. The pre-defined search strategy was designed for maximal retrieval using indexing terms and free text searching. The thesaurus vocabulary of each database was used to adapt the search terms. The selected timeframe took into account the systematic search and review process described by van Baar et al. [13] and the burn-specific search strategy designed by the Cochrane Injuries Review Group and used, by permission, in other publications [20]. In addition to the automated search strategies, reference lists of related journal articles, key journals and existing reviews were hand searched for additional trials. All searches were limited to articles in English.

### 2.2. Study selection criteria and procedures

The abstracts retrieved through the search were checked by applying the eligibility criteria as defined as all adult-only published studies presenting empirical data on the health related quality of life and functional consequences of burns, defined as all consequences, both short term and long term, following burn injury [13]. We included studies irrespective of the type of intervention, setting or phase of burn care. Systematic or narrative reviews, case reports, economic evaluations and studies that used a paediatric population, or did not present appropriate information for data extraction, were excluded.

The purpose of this review was not to assess the methodological quality of these trials but to identify the outcome domains that were assessed and the instruments or scales employed for this purpose, irrespective of whether they were standardised or not. To select the appropriate measures for content examination, we relied on the number of included studies from our search strategy, which reported on the application of these instruments. We assumed that measures frequently applied in different fields of burns research had certain relevance in the field and our analysis was based on the content comparison (i.e. the concepts contained in the different items and consequently in the subscales) of the instruments rather than their psychometric validity. For pragmatic reasons we set an a priori cut-off point for the

selection of outcome measures. We self selected seven well-established and commonly used burn-specific instruments and seven frequently used generic instruments for content examination. More so, we selected specific versions of the instruments (e.g. BSHS-B and IES-R) for linkage based on perceived clinical relevance and frequency of use alongside free public access to the instruments.

### 2.3. Data extraction

A standardised data extraction form was used independently by two authors to identify studies that met the requisite inclusion criteria. From the list of identified studies, study characteristics and outcome measures were extracted and documented. Study characteristics included study population area of burn injury, and type of burn care intervention. Outcome measures included reporting on clinician-rated and specific self-rated health status instruments (e.g. Burn Specific Health Scale-B [BSHS-B]), rating scales (e.g. Vancouver Burn Scar Assessment Scale [VBSAB]) and test questionnaires (e.g. Beck Depression Inventory [BDI]). If the items of a questionnaire were not specified in the publication, we obtained the instrument by reference checking, searching medical databases or e-mail consultation with experts in the field.

### 2.4. ICF concept and tool

The concepts contained in the items of the identified instruments and their subscales were selected and linked to the most specific ICF category. A concept was defined as a single health aspect or a personal (internal) or environmental (external) factor with an impact on health [21]. Formally, a concept could consist of a single word or a set of words. Relations between concepts, and also non-health-related information, were not considered for an assignment to the ICF. The framework for the ICF model is illustrated in Fig. 1 [22] and is available for download from the ICF website as a full or a short version at <http://www.who.int/classifications/icf/en/>.

In this instance, the term health condition referred to any disorder or disease for which a patient would seek medical care. So, in the context of burn care, health conditions referred, for example, to the aetiology and sequelae of burn

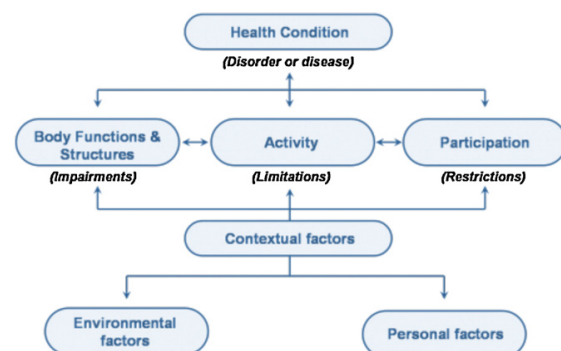


Fig. 1 – Illustration of the ICF model created by the World Health Organization.

injury and any complications that could arise from treatment such as wound infection. The framework would then divide into the *body functions and structure*, in which *function* detailed the physiological and psychological aspects of specific body systems, and the *structure*, listed anatomical parts of the body [23]. Consequently, when deviations in functioning or structural integrity occurred, impairments occurred. For patients with burn injury, these impairments included impairments in system functions (e.g. pain and reduced range of motion). Individual and societal perspectives were then elaborated in the component called *activity and participation*, which in turn detailed the completion of a task or actions by an individual [23]. Tasks could vary within specific domains called general tasks, mobility, self-care, work and education. If an individual had a reduced ability to walk, he or she would be described as having an activity limitation. The *participation* component described the person's involvement in everyday life activities, and when that activity was disrupted, the patient was described as having a participation restriction in the societal context in which a person functions [23].

The remaining two components, *environmental and personal factors*, were considered contextual factors that interact with the other components of the model to either increase or decrease the likelihood of impairment in body structures or functions or activities or participation [23]. In the instance of burn injury, environmental factors could be the availability of surgical treatments; whereas a patient's level of satisfaction following surgery and experience of length of hospital duration could be considered a personal factor.

As in other published studies [12,16,17,19], the concepts contained in the items of the identified instruments were selected and linked to the most specific ICF category. We used standard ICF units where categories were nested within a structure according to each of its components parts, represented by a letter i.e. (b) for body function, (s) for body structure, (d) for activities and participations, and (e) for environmental factors. The components then followed a numeric code starting with the components chapter and its subsequent second, third, and fourth level classification, if available. For example, coding "I often feel sad or blue" from the BSHS would follow the ICF schemata of first code – b1: mental functions, second code – b152: emotional functions, third code – b1522: range of emotion.

## 2.5. ICF linkage procedure

Each item of an instrument was linked to the ICF category that most precisely represented the item's content using standardised linkage rules developed by Cieza et al. [5,15]. Items of an instrument could include one or more concepts, so each concept in each item was defined according to the ICF component parts of (b), (s), (d) or (e). For example, item 40 of the BSHS-B: "My burn has caused problems with my working" would be assigned to the following concepts: burn and problems with work. These two concepts were then linked to the following ICF categories: d850 remunerative employment, b8451 acquiring, keeping and terminating a job – maintaining a job, and hc (health condition). If a concept was too general to allow a decision on the linkage to a specific ICF chapter, domain or category, the concept was considered as 'not defined (nd)'. Not

defined did not imply that the concept was not contained in the ICF, rather that it could not be linked to a specific part of the ICF. A sample concept of 'not defined' included "I am no more worried about my health than usual" taken from the BDI.

If a concept pertained to personal factors, which were not coded within the system of the ICF, the code 'personal factor (pf)' was attributed. A sample concept included "I refused to think too much about my difficulties" taken from the Coping with Burns Questionnaire (CBQ). If a concept described an aspect of functioning and health, which was not covered or contained by the ICF, the code 'not covered (nc)' was attributed. A sample concept of 'not covered' included "People avoid looking at me" taken from the Perceived Stigmatization Questionnaire (PSQ). If a concept pertained to health conditions, which were not coded within the system of the ICF, the code 'health condition' was attributed. A sample concept included "I adjusted something in my everyday life because of the burn-related difficulties I had" taken from the CBQ.

The concepts were also linked to the highest possible level of the ICF. In instances where the concept was too broad to be completely contained by a category, it was linked to the closest more general category. For example, if an item described sensation of pain, but not the location of pain, it was linked to category b280 sensation of pain and not to b28012 sensation of pain – pain in stomach or abdomen. Each relevant measure was linked by two authors, one of whom underwent ICF training in the application of the linkage rules and one who did not. The number of concepts identified in each questionnaire and the ICF categories linked were reported both in total and separated by component. The degree of agreement regarding the identified and linked concepts was assessed by means of the kappa statistic [5,17]. All disagreement was subsequently resolved via discussion between the two raters.

## 2.6. Data analysis

To summarize data, pooled descriptive statistics weighted by study sample size were used. Continuous data were summarized by mean and standard deviation (SD) and categorical data by percentages, unless otherwise specified. Descriptive statistics were also used to examine the frequency of ICF categories linked to the concepts contained in the instruments. The ICF categories are presented on the second level. If a concept within the instrument was linked to a third or fourth level ICF category, the overlying second level category was considered [15].

## 3. Results

A total of 10,326 references were identified by the searches for this review. From independent scrutiny of the titles and abstracts, 321 potentially relevant articles were retrieved and assessed in full text form. Of these, 189 studies did not meet the inclusion criteria and were excluded from the review leaving 132 included studies.

### 3.1. Study characteristics

The included studies involved 17,245 patients and were conducted in 20 different countries, with half coming from



**Table 1 – Frequently used measures in the assessment of burn outcomes.**

Burn specific measures
Burn Specific Health Scale-Brief (BSHS-B) [34]
Burn Specific Pain and Anxiety Scale (BSPAS) [35]
Coping with Burns Questionnaire (CBQ) [36]
Matching Assessment of Scars and Photographs (MAPS) [37]
Patient and Observer Scar Assessment Scale (POSAS) [38]
Satisfaction with Appearance Scale (SWAP) [39]
Vancouver Burn Scar Assessment Scale (VBSAS) [40]
Generic measures
Beck Depression Inventory (BDI) [41]
Brief Symptom Inventory (BSI) [42]
Hospital Anxiety and Depression Scale (HADS) [43]
Impact of Event Scale-Revised (IES-R) [44]
Medical Outcomes Study 36 item Short Form Health Survey (SF-36) [45]
Perceived Stigmatization Questionnaire (PSQ) [46]
Social Comforts Questionnaire (SCQ) [46]

the United States of America ( $n = 66$ , 50%) followed by Sweden ( $n = 18$ , 13.6%) and Canada ( $n = 10$ , 7.6%). Among 122 studies that reported on participant age, mean age was  $39.0 \pm 7.4$  years. Mean total burn surface (%TBSA) was  $22.1 \pm 11.8\%$  (range %TBSA: 3.5–64). The length of follow-up varied greatly between the studies, ranging from one week to 25 years. Follow-up data were reported by 105 studies, with 25% of them having follow-up shorter than 3 months and 50% of them longer than one year. The mean follow-up time was  $39.9 \pm 60.2$  months.

There were 88 (66.7%) cross-sectional studies, 40 (30.3%) cohort studies, two (1.5%) cross-over randomised controlled trials, and two (1.5%) case series. Psychological health and well-being was by far the most prevalent topic cited ( $n = 80$ , 60.6%) followed by general health ( $n = 27$ , 20.5%), rehabilitation ( $n = 17$ , 12.9%), and analgesia ( $n = 8$ , 6.1%). The mean sample size of the studies evaluated was  $129 \pm 148.1$  (range 4–1232).

### 3.2. Outcome instruments

Overall, a total of 151 outcome instruments (different versions and subscales of an instrument were considered as one instrument) were used 381 times, with a median of three instruments used per study (range: 1–8). Details of the most frequently used instruments that were used in ten or more studies and all burn-specific instruments are shown in Table 1. The burn specific instruments were used in 15 (11.4%) of the included studies while the seven most commonly used generic instruments were applied in 66 (50.0%) studies. There remained 51 (38.6%) studies that used instruments that were used fewer than ten times (data not shown). The instruments consisted of three different response formats such as the Likert (i.e. written linear scale anchored in sections with numbers and/or words); graphic (i.e. three-dimensional or pictorial scale with/without word/number anchors); or visual analogue (i.e. visual linear scale anchored at ends with numbers and/or words) scale.

Out of the 381 applications of the outcome instruments described in the included studies, the most frequently used instrument was the BSHS-B, which was used 29 times (7.6% of all studies). Domain specific instruments considered dimen-

sions such as activities of daily living, motor functions, various cognitive functions, as well as many aspects of mental health, mainly depression. The most commonly assessed outcome domain was depression as assessed by the BDI which was used 17 times (4.5% of all studies). Generic health status measures were used 20 times (5.2%) with the SF-36 being the most frequently used ( $n = 18$ , 4.7%).

### 3.3. ICF-based content examination – content

For the ICF-based content examination, both raters identified 329 concepts within 14 instruments. The first rater identified an additional 27 concepts that were included after discussion, meaning that a total of 356 concepts were extracted from the measures. Of these, 284 (79.8%) concepts were linked to the ICF while the remaining 72 (20.2%) were either 'not covered' or 'not defined' (including seven relating to general health, and seven to physical health) for an assignment to the ICF. Most of the concepts were linked to the two components body function ( $n = 164$ , 46.1%) and activities and participation ( $n = 71$ , 19.9%), with fewer linking to personal factors ( $n = 22$ , 6.2%) and health condition ( $n = 21$ , 5.9%). Few concepts were linked to the components environmental factors ( $n = 5$ , 1.4%) and body structure ( $n = 1$ , 0.3%).

Table 2 shows the number of identified concepts for each of the selected instruments. It also shows the number of concepts linked to the ICF and the number of concepts which we denoted 'not definable' or 'not covered'. The CBQ ( $n = 44$ ), alongside the BSHS-B ( $n = 43$ ) and BSI ( $n = 43$ ), contained the highest, and the Vancouver Burn Scar Assessment Scale (VBSAS), the lowest number of concepts ( $n = 4$ ). The Perceived Stigmatization Questionnaire (PSQ) contained the highest number of concepts classified as 'not covered' ( $n = 21$ , 100%). The concepts not covered included statements such as "people feel sorry for me", "strangers are polite to me" or "people bully me". The SF-36 contained the highest number of concepts that were coded 'not definable' ( $n = 10$ , 19.2%). For example, items such as "in general would you say your health is excellent, very good, good, fair, or poor", "I seem to get sick a little easier than other people" and "my health is excellent" could not be mapped to one definitive ICF category.

Tables 3–5 show the coverage of the ICF categories from the components Body Function, Activity and Participation and Environmental Factors by the selected measure. The tables display the linkage summarized at the second level of the ICF. None of the instruments covered all ICF categories. The most frequently used categories were *b152 emotional function*, alongside *b1521 emotional function – regulation of emotion* and *b1522 emotional health – range of emotion*, which were contained in 51 items from 7 different instruments. The next most frequent ICF categories mentioned were *b1801 experience of self and time functions – body image* (19 times in four instruments), *b820 repair functions of the skin* (13 times in five instruments) and *b280 sensation of pain* (12 times in five instruments).

### 3.4. Reliability of linkage process

Of the 329 concepts that were extracted by both raters, discussion was required 73 (22.2%) times to resolve differences between them in their assignment of the ICF categories. Table 6

**Table 2 – Frequencies of items, concepts and International Classification of Functioning, Disability and Health categories.**

	Total	BDI	BSPAS	BSHSB	BSI	CBQ	HADS	IESR	MAPS	POSAS	PSQ	SCQ	SF36	SWAP	VBSAS
Number of items	290	21	9	40	53	33	14	22	5	12	21	8	36	14	4
Concepts linked to ICF component:															
Body function	164	16	9	11	39	8	12	20	5	11	0	0	16	13	4
Body structure	1	0	0	0	0	0	0	0	0	1	0	0	0	0	0
Activity and participation	71	3	0	21	4	4	1	1	0	0	0	6	26	5	0
Environmental factors	5	0	0	2	0	3	0	0	0	0	0	0	0	0	0
Concepts linked to personal factors	22	2	0	0	0	20	0	0	0	0	0	0	0	0	0
Concepts linked to health condition	21	0	0	9	0	9	0	0	0	0	0	0	0	3	0
Total: linked concepts	284	21	9	43	43	44	13	21	5	12	0	6	42	21	4
Concepts not definable (n.d.)	13	0	0	1	3	4	1	3	0	1	0	0	0	0	0
Concepts n.d.: general health	7	1	0	0	0	0	0	0	0	0	0	0	6	0	0
Concepts n.d.: physical health	7	3	0	0	0	0	0	0	0	0	0	0	4	0	0
Concepts n.d.: mental health	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Concepts not covered	45	2	0	6	10	3	0	1	0	0	21	2	0	0	0
Total: unlinked concepts	72	6	0	7	13	7	1	4	0	1	21	2	10	0	0
Total number of concepts	356	27	9	50	56	51	14	25	5	13	21	8	52	21	4

BDI: Beck Depression Inventory; BSPAS: Burn Specific Pain and Anxiety Scale; BSHSB: Burn Specific Health Scale-Brief version; BSI: Brief Symptom Inventory; CBQ: Coping with Burns Questionnaire; HADS: Hospital Anxiety and Depression Scale; IESR: Impact of Event Scale-Revised; MAPS: Matching Assessment of Scars and Photographs; POSAS: Patient and Observer Scar Assessment Scale; PSQ: Perceived Stigmatization Questionnaire; SCQ: Social Comforts Questionnaire; SF-36: Medical Outcomes Study 36 item Short Form Health Survey; SWAP: Satisfaction with Appearance Scale; VBSAS: Vancouver Burn Scar Assessment Scale.

displays the kappa values for the agreement between the raters at the different levels of ICF classification before the discussion took place to decide on the correct code to assign. Agreement was moderate for the decision as to whether or not the concept was able to be linked to one of the ICF categories. For all concepts that were linked to an ICF category by both raters, the agreement was good for linkage to the same component, and very good for agreement at the second and third level of components.

#### 4. Discussion

The goal of this systematic review was to provide an overview of the concepts contained in outcome measures that are frequently used to assess the progress of recovery following a burn injury. This was done by identifying and quantifying concepts that are encapsulated in outcome measures used in the adult burn literature, using the ICF framework with its international global standing and content validity established, as a reference tool [33].

We reviewed 132 papers that contained 151 different assessment instruments of which 14 were selected for linkage to the ICF either because they were a burn-specific, or frequently used generic health status, measure in the adult burn literature. It was possible to link most items (80%) contained in the instruments to the ICF. More specifically, 46% of the concepts were linked to body function and 20% to activities and participation, whereas only a few concepts were formally linked to health condition, body structures and personal or environmental factors. Those which could not be linked were mostly not covered by the ICF, meaning that the content of the concepts did not lie within the defined contents of the ICF framework.

The most commonly reported instrument used in this population was the BSHS-B which was developed and validated specifically for burns patients to reflect the social, psychological and functional adaptation post injury. It was used in 29 studies suggesting not only end-user familiarity, but also its consideration as a component of a minimum data set for assessment of outcome measures following burn injury. Twenty-one of the items of the BSHS-B were linked to activities and participation and body function. The remaining concepts were linked to health conditions.

Among the included studies, psychological health and well-being was by far the most prevalent topic followed by issues surrounding general health, rehabilitation, and analgesia use and requirements. Overall, these measures represented a range of health domains with the concept of b152 *emotional health* the most frequently linked ICF category in seven of the selected 14 instruments. This showed that the concepts about psychological functions were more often represented in outcome measures compared to concepts dealing with the executions of tasks or actions or the participation of an individual in life situations [16]. As a conclusion, this could reflect the perceived importance of psychological symptoms, distress and adjustment as major outcomes in those with burn injury. More so, the dominance may have reflected the literature which reported that burn survivors exhibited higher rates of post-traumatic stress disorder [24], depression [25] and anxiety [26] or the lack of attention paid to other aspects of burn care recovery.

The next most frequent categories were b1801 *experience of self and time functions – body image*, b820 *repair functions of the skin* and b280 *sensation of pain*. We anticipated an even representation of ICF components – activities and participation, body structure and function and environmental factors – in the



**Table 3 – Concepts linked to International Classification of Functioning, Disability and Health: Body function.**

ICF category	Additional information	BDI	BSPAS	BSHSB	BSI	CBQ	HADS	IESR	MAPS	POSAS	PSQ	SCQ	SF36	SWAP	VBSAS
<i>Body functions: global mental functions</i>															
b110	Consciousness functions				X										
b1263	Temperament and personality functions – psychic stability	X													
b1265	Temperament and personality functions – optimism					X	X								
b1266	Temperament and personality functions – confidence				X										
b1300	Energy and drive functions – energy level	X					X						X		
b1301	Energy and drive functions – motivation				X	X									
b1302	Energy and drive functions – appetite	X			X										
b1303	Energy and drive functions – craving					X									
b134	Sleep functions	X													
b1341	Sleep functions – onset of sleep				X			X							
b1342	Sleep functions – maintenance of sleep							X							
b1344	Sleep functions – functions involving the sleep cycle							X							
b140	Attention functions				X										
b1400	Sustaining attention							X							
b144	Memory functions				X			X							
b147	Psychomotor functions				X										
b1470	Psychomotor functions – psychomotor control				X		X								
b152	Emotional functions	X			X			X					X		
b1521	Emotional functions – regulation of emotion	X													
b1522	Emotional functions – range of emotions		X	X	X		X	X							
b160	Thought functions				X										
b1602	Thought functions – content of thought						X	X							
b1603	Thought functions – control of thought				X										
b1641	Higher level cognitive functions – organization and planning					X									
b1644	Higher level cognitive functions – insight					X									
b1801	Experience of self and time functions – body image	X		X			X							X	
b2401	Hearing and vestibular functions – sensations associated with hearing and vestibular function – dizziness				X										
b265	Additional sensory functions – touch function				X										
b2700	Sensory functions related to temperature and other stimuli – sensitivity to temperature			X	X										
b280	Sensation of pain	X	X			X				X			X		
b2801	Sensation of pain – pain in body part				X										
b28011	Sensation of pain – pain in chest				X										
b28012	Sensation of pain – pain in stomach or abdomen	X			X										
b4100	Functions of the cardiovascular system – heart rate							X							
b440	Functions of the respiratory system – respiration functions							X							
b460	Additional functions and sensations of the cardiovascular and respiratory system: sensations associated with cardiovascular and respiratory functions				X										
b525	Functions related to the digestive system: defecation functions – elimination of faeces	X													
b530	Weight maintenance functions	X													

Table 3 (Continued)

ICF category	Additional information	BDI	BSPAS	BSHSB	BSI	CBQ	HADS	IESR	MAPS	POSAS	PSQ	SCQ	SF36	SWAP	VBSAS
b5350	Sensations associated with the digestive system – sensation of nausea				X			X							
b6400	Genital and reproductive functions – sexual functions	X													
b730	Muscle functions: muscle power functions				X										
b810	Functions of the skin – protective functions of the skin								X	X				X	
b820	Functions of the skin – repair functions of the skin		X			X			X	X				X	
b830	Functions of the skin – other functions of the skin							X							
b840	Sensation related to the skin			X						X					
Body structures: skin and related structures															
s810	Structure of areas of skin													X	

BDI: Beck Depression Inventory; BSPAS: Burn Specific Pain and Anxiety Scale; BSHSB: Burn Specific Health Scale-Brief version; BSI: Brief Symptom Inventory; CBQ: Coping with Burns Questionnaire; HADS: Hospital Anxiety and Depression Scale; IESR: Impact of Event Scale-Revised; MAPS: Matching Assessment of Scars and Photographs; POSAS: Patient and Observer Scar Assessment Scale; PSQ: Perceived Stigmatization Questionnaire; SF-36: Social Comforts Questionnaire; SF-36: Medical Outcomes Study 36 item Short Form Health Survey; SWAP: Satisfaction with Appearance Scale; VBSAS: Vancouver Burn Scar Assessment Scale.

outcome measures used for the assessment of the sequelae of burn injury. Various aspects of the activities and participation component were covered by the selected instruments including *learning and applying knowledge, mobility, self-care, interpersonal interactions and relationships and major life areas*. However, there was scope to increase the representation of this important component of functioning. Less than 21% of the retrieved studies contained concepts which could be linked to categories of the components body structures and environmental factors. Environmental factors were confined to *temperature, light and support and relationships*. Given that social and family support is recognised as an important factor influencing coping patterns, prognosis and recovery of patients, the *support and relationships* factor was only covered by one instrument, namely the CBQ.

The large number of different outcomes measures used in the literature indicated the wide variation of approaches used to assess patient recovery. Outside of measures selected for linkage to the ICF, there were multiple studies that devised their own assessment procedures or modified standardised tests or used parts of a test previously not validated. Information regarding the selected measures was frequently inadequate with little detail provided concerning the instrument itself, methods of testing the instrument or any reference to published protocols or the psychometric properties of these tests. This paucity of information raised the question about whether these instruments were implemented in the same way [27]. The lack of standardisation made it difficult to compare results across studies and highlighted the need for a consensus about the use of suitable outcomes measures and instruments. In addition, we detected significant heterogeneity in the timing of the assessments and in length of patient follow-up which indicates a lack of agreement for expected recovery timelines.

Therefore, our results clearly highlight the need for consensus and standardisation of outcome measures to be utilised in burn injury. Recently, a number of reviews identified a series of core outcome measures that should be considered when designing outcome studies [3,13]. Similarly, Offenbächer et al. [21] suggested that when choosing an outcome measure, it is important to define the purpose of the use of the outcome measure and to tailor its specific use. Additionally, the information about the selected outcome measures should be available for validity, reliability and responsiveness; and the instruments chosen should not only be feasible, but pragmatic in their administration, scoring and interpretation [21].

#### 4.1. Study limitations

There were a number of strengths and limitations with this study. Firstly, we used a systematic search strategy and examined five key medical and social science databases. However, we did not include systematic or narrative reviews and case reports, or studies in a foreign language, so we possibly missed studies that were relevant to this review or published in foreign language journals. Secondly, we only searched the literature from 2003, so by doing this the review was at risk of losing publications; however, we tried to overcome this by hand searching reference lists of related

**Table 4 – Concepts linked to International Classification of Functioning, Disability and Health: Activities and Participation.**

ICF category	Additional information	BDI	BSPAS	BSHSB	BSI	CBQ	HADS	IESR	MAPS	POSAS	PSQ	SCQ	SF36	SWAP	VSBAS
d170	Applying knowledge: writing			X											
d177	Applying knowledge – making decisions	X			X										
d230	Carrying out daily routine												X		
d350	Conversation and use of communication devices and techniques							X							
d410	Changing and maintaining body position – changing basic body position – bending												X		
d4102	Changing basic body position – kneeling												X		
d4103	Changing basic body position – sitting			X											
d4105	Changing basic body position – bending												X		
d4300	Lifting and carrying objects – lifting heavy objects												X		
d4301	Lifting and carrying objects – carrying in the hands												X		
d4400	Carrying, moving and handling objects – fine hand use – picking up			X											
d4451	Carrying, moving and handling objects – fine hand use – pushing												X		
d4453	Carrying, moving and handling objects – fine hand use – turning or twisting the hands or arms			X											
d4500	Walking and moving – walking – walking short distances												X		
d4501	Walking and moving – walking – walking long distances												X		
d4551	Walking and moving – moving around – climbing												X		
d4552	Walking – moving around – running												X		
d510	Washing oneself			X											
d5101	Washing oneself – washing whole body												X		
d540	Dressing			X									X		
d5402	Dressing – putting on footwear			X											
d550	Eating			X											
d640	Doing housework												X		
d710	General interpersonal interactions: basic interpersonal interactions				X									X	
d7105	Basic interpersonal interactions – physical contact in relationships			X										X	
d720	Complex interpersonal interactions	X										X			
d7200	Complex interpersonal interactions – forming relationships											X			
d730	Particular interpersonal relationships: relating with strangers													X	
d750	Particular interpersonal relationships: informal social relationships			X		X									
d7500	Informal social relationships – informal relationships with friends			X										X	
d7504	Informal social relationships: informal relationships with peers											X			
d760	Particular interpersonal relationships – family relationships			X										X	
d7702	Particular interpersonal relationships: intimate relationships – sexual relationships			X											
d8451	Work and employment – acquiring, keeping and terminating a job – maintaining a job			X											
d850	Work and employment – remunerative employment	X				X							X		
d920	Recreation and leisure					X									
d9201	Recreation and leisure – sports												X		
d9202	Recreation and leisure – arts and culture						X								
d9205	Recreation and leisure – socializing												X		

BDI: Beck Depression Inventory; BSPAS: Burn Specific Pain and Anxiety Scale; BSHSB: Burn Specific Health Scale-Brief version; BSI: Brief Symptom Inventory; CBQ: Coping with Burns Questionnaire; HADS: Hospital Anxiety and Depression Scale; IESR: Impact of Event Scale –Revised; MAPS: Matching Assessment of Scars and Photographs; POSAS: Patient and Observer Scar Assessment Scale; PSQ: Perceived Stigmatization Questionnaire; SCQ: Social Comforts Questionnaire; SF-36: Medical Outcomes Study 36 item Short Form Health Survey; SWAP: Satisfaction with Appearance Scale; VSBAS: Vancouver Burn Scar Assessment Scale.

Table 5 – Concepts linked to International Classification of Functioning, Disability and Health: Environmental and Other categories.

ICF category	Additional information	BDI	BSPAS	BSPAS	BSPAS	BSI	CBQ	HADS	IESR	MAPS	POSAS	PSQ	SCQ	SF36	SWAP	VSBAS
<i>Environmental factors: natural environment and human-made changes to environment</i>																
e2250	Climate – temperature			X												
e240	Light			X												
e3	Support and relationships			X												
hc	Health condition			X											X	
nc	Not covered								X							
nc-A&P	Not covered – activities & participation			X												
nc-bf	Not covered – body functions	X														
nd	Not defined															
nd-A&P	Not defined – activities & participation															
nd-bf	Not defined – body functions													X		
nd-bs	Not defined – body systems															
nd-gh	Not defined – general health	X												X		
nd-ph	Not definable – physical health	X														
pf	Personal factor	X														

BDI: Beck Depression Inventory; BSPAS: Burn Specific Pain and Anxiety Scale; BSHSB: Burn Specific Health Scale-Brief version; BSI: Brief Symptom Inventory; CBQ: Coping with Burns Questionnaire; HADS: Hospital Anxiety and Depression Scale; IESR: Impact of Event Scale-Revised; MAPS: Matching Assessment of Scars and Photographs; POSAS: Patient and Observer Scar Assessment Scale; PSQ: Perceived Stigmatization Questionnaire; SCQ: Social Comforts Questionnaire; SF-36: Medical Outcomes Study 36 item Short Form Health Survey; SWAP: Satisfaction with Appearance Scale; VSBAS: Vancouver Burn Scar Assessment Scale.

journal articles. Thirdly, we restricted our studies to the adult-literature population only, which in turn eliminated the paediatric population. However, we felt that the sequelae of burn injury in this population warranted separate consideration in view of the impact of development level in child measures [28].

Most of the included studies focused on acute burn care practices or psychological interventions, whereas physiotherapy, nursing, and occupational therapy interventions were under-represented. This introduced a potential bias towards medical and psychosocial health and a shift away from multidisciplinary burn centre team practices (i.e. nursing and allied health approaches) which have been seen to be more traditionally aligned to functional outcomes [29].

We also acknowledged that it was difficult to link outcome measures, concepts and categories to the ICF in a uniform manner [19] because of the subjective nature of the exercise, and therefore, the conclusions reached by us may not have been in an absolute agreement with other researchers. Secondly, we were cognizant that researchers involved in the linkage process required specific ICF training, although this was not possible for this review. In this study, one author attended a training workshop and the other did not. This provided the opportunity to review the process of having one trained and one novice ICF rater. As a result, we attempted to evaluate this unique linkage process by calculating kappa coefficients prior to discussion between the two raters, which showed satisfactory results for linker agreement. In particular, our lower kappa values were achieved for deciding on whether a concept could be linked to an ICF; however, agreement rates improved to perfect for linking within categories.

There were also a number of concepts extracted from the studies which could not be linked to an ICF item, for example, the concepts of “*I am so worried about my physical problems*” taken from the BDI which were considered important in assessing the impact of burn injury on a patient’s functional activity. Specific psychological functions, including “*I felt as if it hadn’t happened or wasn’t real*” taken from the IES-R were identified in assessment instruments but were not easily linked to direct ICF categories and needed to be generalised to lower-level items. Thus, there was some information lost in the linking process, although this was an infrequent occurrence. Comparing this result to other linked states such as breast cancer [16], depressive disorders [30] and obesity [31], our results showed similar findings. Considering the relatively young age of the classification system, it is acceptable that there are ICF categories that are still missing or in need of revision and update [32].

#### 4.2. Study recommendations

In line with other conditions, the development of an ICF core set for burns would be advantageous in terms of providing a conceptual model or framework for the assessment of functional outcome following burn injury. In this instance, an ICF core set would be a subset of the entire classification of 1454 categories that specifies the particular problems with functioning experienced by a person who has sustained a burn injury. The core sets would be both comprehensive and

**Table 6 – Kappa values for agreement of classification to ICF components by 2 independent raters.**

	Able to be linked (N = 329)	ICF components (N = 246)	Body function (N = 149)	Activity and participation (N = 65)
Linked Components	0.564	0.797		
Chapter level			0.960	1.00
Levels 2 and 3			0.898	0.905

brief, meaning that the comprehensive set would be used as a clinical tool for multi disciplinary assessment and the brief set would reflect the outcome measures used in clinical burn studies or clinical episodes for those with burn injury.

As part of this process, there would be a content comparison of adult and paediatric outcome measures used in the area. Given that a core set has not yet been developed, although initial discussions have been held with the WHO ICF Research Branch, this paper has attempted in a systematic way to compare the content of existing outcome measures used in the literature to quantify outcome following burn injury. In line with recent other papers [3], we have sought to contribute to the debate about achieving a consensus regarding the appropriate way to measure outcome following burn injury for the global community consistent with the WHO approach that advocates the use of the ICF as a common language. This approach would incorporate a minimum data set that contains the components of the ICF, namely body functions, body structures, activities and participation and environmental and conceptual factors and thereby attenuating the current debate concerning 'what to measure' and 'how to measure it' in those with burn injury.

### Conflict of interest

Authors do not have conflict of interest.

### REFERENCES

- [1] Potokar TS, Prowse S, Whitaker IS, Ali S, Chamanian S. A global overview of burns research highlights the need for forming networks with the developing world. *Burns* 2008;34(February (1)):3–5.
- [2] Farrell RT, Gamelli RL, Sinacore J. Analysis of functional outcomes in patients discharged from an acute burn center. *J Burn Care Res* 2006;27(March–April (2)):189–94.
- [3] Falder S, Browne A, Edgar D, Staples E, Fong J, Rea S, et al. Core outcomes for adult burn survivors: a clinical overview. *Burns* 2009;35(August (5)):618–41.
- [4] Pereira C, Murphy K, Hemdon D. Outcome measures in burn care. Is mortality dead? *Burns* 2004;30(December (8)):761–71.
- [5] Cieza A, Geyh S, Chatterji S, Kostanjsek N, Üstün B, Stucki G. ICF linking rules: an update based on lessons learned. *J Rehabil Med* 2005;37(July (4)):212–8.
- [6] Jette AM, Staley SM. Contemporary measurement techniques for rehabilitation outcomes assessment. *J Rehabil Med* 2005;37(June (6)):339–45.
- [7] Stucki G, Melvin J. The International Classification of Functioning, Disability and Health: a unifying model for the conceptual description of physical and rehabilitation medicine. *J Rehabil Med* 2007;39(May (4)):286–92.
- [8] Stier-Jarmer M, Cieza A, Borchers M, Stucki G. World Health Organization. How to apply the ICF and ICF core sets for low back pain. *Clin J Pain* 2009;25(1):29–38.
- [9] Simons M, Ziviani J, Tyack ZF. Measuring functional outcome in paediatric patients with burns: methodological considerations. *Burns* 2004;30(August (5)):411–7.
- [10] Geyh S, Kurt T, Brockow T, Cieza A, Ewert T, Omar Z, et al. Identifying the concepts contained in outcome measures of clinical trials on stroke using the International Classification of Functioning, Disability and Health as a reference. *J Rehabil Med* 2004;July (44 Suppl.):56–62.
- [11] Jarrett M, McMahon M, Stiller K. Physical outcomes of patients with burn injuries – a 12 month follow-up. *J Burn Care Res* 2008;29(November–December (6)):975–84.
- [12] Prodingier B, Cieza A, Williams A, Mease P, Boonen A, Kersch-Schindl K, et al. Measuring health in patients with fibromyalgia: content comparison of questionnaires based on the International Classification of Functioning, Disability and Health. *Arthritis Rheum* 2008;59(May (5)):650–8.
- [13] van Baar ME, Essink-Bot ML, Oen IM, Dokter J, Boxma H, van Beeck EF. Functional outcome after burns: a review. *Burns* 2006;32(February (1)):1–9.
- [14] Biering-Sørensen F, Scheuringer M, Baumberger M, Charlifue SW, Post MW, Montero F, et al. Developing core sets for persons with spinal cord injuries based on the International Classification of Functioning, Disability and Health as a way to specify functioning. *Spinal Cord* 2006;44(September (9)):541–6.
- [15] Cieza A, Brockow T, Ewert T, Amman E, Kollerits B, Chatterji S, et al. Linking health-status measurements to the international classification of functioning, disability and health. *J Rehabil Med* 2002;34(September (5)):205–10.
- [16] Brockow T, Duddeck K, Geyh S, Schwarzkopf S, Weigl M, Franke T, et al. Identifying the concepts contained in outcome measures of clinical trials on breast cancer using the International Classification of Functioning, Disability and Health as a reference. *J Rehabil Med* 2004;July (44 Suppl.):43–8.
- [17] Geyh S, Cieza A, Kollerits B, Grimby G, Stucki G. Content comparison of health-related quality of life measures used in stroke based on the international classification of functioning, disability and health (ICF): a systematic review. *Qual Life Res* 2007;16:833–51.
- [18] Mudge S, Stott N. Outcome measures to assess walking ability following stroke: a systematic review of the literature. *Physiotherapy* 2007;93:189–200.
- [19] Scheuringer M, Grill E, Boldt C, Mittrach R, Müllner P, Stucki G. Systematic review of measures and their concepts used in published studies focusing on rehabilitation in the acute hospital and in early post-acute rehabilitation facilities. *Disabil Rehabil* 2005;27(April (7–8)):419–29.
- [20] Danilla S, Wasiak J, Searle S, Arrigada C, Pedreros C, Cleland H, et al. Methodological quality of randomised

- controlled trials in burns care. A systematic review. *Burns* 2009;35(7):956–61.
- [21] Offenbächer M, Cieza A, Brockow T, Amann E, Kollerits B, Stucki G. Are the contents of treatment outcomes in fibromyalgia trials represented in the International Classification of Functioning, Disability, and Health? *Clin J Pain* 2007 Oct;23(8):691–701.
- [22] WHO. ICF-International Classification of Functioning, Disability and Health. Geneva: WHO Library; 2001.
- [23] Riddle DL, Stratford PW, Bowman DH. Findings of extensive variation in the types of outcome measures used in hip and knee replacement clinical trials: a systematic review. *Arthritis Rheum* 2008;59(June (6)):876–83.
- [24] Van Loey NE, Van Son MJ. Psychopathology and psychological problems in patients with burn scars: epidemiology and management. *Am J Clin Dermatol* 2003;4(4):245–72.
- [25] Thombs BD, Bresnick MG, Magyar-Russell G. Depression in survivors of burn injury: a systematic review. *Gen Hosp Psychiatry* 2006;28(November–December (6)):494–502.
- [26] Patterson DR, Everett JJ, Bombardier CH, Questad KA, Lee VK, Marvin JA. Psychological effects of severe burn injuries. *Psychol Bull* 1993;113(March (2)):362–78.
- [27] Jerosch-Herold C, Leite JC, Song F. A systematic review of outcomes assessed in randomized controlled trials of surgical interventions for carpal tunnel syndrome using the International Classification of Functioning, Disability and Health (ICF) as a reference tool. *BMC Musculoskelet Disord* 2006;December (7):96.
- [28] Cremeens J, Eiser C, Blades M. Characteristics of health-related self-report measures for children aged three to eight years: a review of the literature. *Qual Life Res* 2006;15(May (4)):739–54.
- [29] Zochling J, Bonjean M, Grill E, Scheuringer M, Stucki G, Braun J. Systematic review of measures and their concepts used in published studies focusing on the treatment of acute inflammatory arthritis. *Clin Rheumatol* 2006;25(November (6)):807–13.
- [30] Brockow T, Wohlfahrt K, Hillert A, Geyh S, Weigl M, Franke T, et al. Identifying the concepts contained in outcome measures of clinical trials on depressive disorders using the International Classification of Functioning, Disability and Health as a reference. *J Rehabil Med* 2004;July (44 Suppl.):49–55.
- [31] Stucki A, Borchers M, Stucki G, Cieza A, Amann E, Ruof J. Content comparison of health status measures for obesity based on the international classification of functioning, disability and health. *Int J Obes (Lond)* 2006;30(December (12)):1791–9.
- [32] Tschiesner UM, Rogers SN, Harreus U, Berghaus A, Cieza A. Comparison of outcome measures in head and neck cancer – literature review 2000–2006. *Head Neck* 2009;31(February (2)):251–9.
- [33] Cieza A, Stucki G. The International Classification of Functioning Disability and Health: its development process and content validity. *Eur J Phys Rehabil Med* 2008;44(3):303–13.
- [34] Kildal M, Andersson G, Fugl-Meyer AR, Lannerstam K, Gedin B. Development of a brief version of the Burn Specific Health Scale (BSHS-B). *J Trauma* 2001;51:740–6.
- [35] Aaron LA, Patterson DR, Finch CP, Carrougier GJ, Heimbach DM. The utility of a burn specific measure of pain anxiety to prospectively predict pain and function: a comparative analysis. *Burns* 2001;27(June (4)):329–34.
- [36] Willebrand M, Kildal M, Ekselius L, Gerdin B, Andersson G. Development of the coping with burns questionnaire. *Pers Individ Differ* 2001;30:1059–72.
- [37] Masters M, McMahon M, Svens B. Reliability testing of a new scar assessment tool Matching Assessment of Scars and Photographs (MAPS). *J Burn Care Rehabil* 2005;26:273–84.
- [38] Draaijers JL, Tempelman FR, Botman YAM, Tuinebreijer WE, Middelkoop E, Kreis RW, et al. The Patient and Observer Scar Assessment Scale: a reliable and feasible tool for scar evaluation. *Plast Reconstr Surg* 2004;113:1960–5.
- [39] Lawrence JW, Heinberg LJ, Roca RP, Munster A, Spence R, Fauerbach JA. Development and validation of the Satisfaction With Appearance Scale: assessing body image among burn-injured patients. *Psychol Assess* 1998;10:64–70.
- [40] Sullivan T, Smith J, Kermode J, McIver E, Courtemanche DJ. Rating the burn scar. *J Burn Care Rehabil* 1990;11(3):256–60.
- [41] Beck AT, Ward CH, Mendelson M, Mock J, Erbaugh J. An inventory for measuring depression. *Arch Gen Psychiatr* 1961;4:561–71.
- [42] Derogatis LR, Melisaratos N. The Brief Symptom Inventory: an introductory report. *Psychol Med* 1983;13(August (3)):595–605.
- [43] Zigmond AS, Snaith RP. The Hospital Anxiety and Depression Scale. *Acta Psychiatr Scand* 1983;67:361–70.
- [44] Weiss DS, Marmar C. The Impact of Event Scale – revised. In: Wilson J, Keane T, editors. *Assessing psychological trauma and PTSD*. New York: Guilford; 1997.
- [45] Ware JE, Snow KK, Kosinski M, Gandek B. SF-36® Health Survey Manual and Interpretation Guide. Boston, MA: New England Medical Center, The Health Institute, 1993.
- [46] Lawrence JW, Fauerbach JA, Heinberg LJ, Doctor M, Thombs BD. The reliability and validity of the Perceived Stigmatization Questionnaire (PSQ) and the Social Comfort Questionnaire (SCQ) among an adult burn survivor sample. *Psychol Assess* 2006;18(March (1)):106–11.

### **3.3 Summary of findings**

The goal of this systematic review was to provide an overview of the ICF concepts included in outcome measures that are frequently used to assess the progress of recovery following a burn injury. This was achieved by reviewing 132 papers that contained 151 different outcome instruments, of which 14 were selected for mapping to the ICF. It was possible to map most items (80%) contained in the instruments to the ICF. More specifically, 46% of the concepts were linked to body function and 20% to activities and participation, whereas few concepts were formally linked to health condition, body structures and personal or environmental factors.

Whilst these high mapping rates were encouraging, our paper could not establish from the 151 instruments available a single measure that covered all concepts of the ICF. It was proposed that a combination of instruments be identified to measure the impact of burn injury and health, whilst also covering the core set of functions considered important through the ICF. Therefore, the results of this paper were used to reinforce the choice of outcome measures described in *Chapter 1* and used in the main cohort study of this thesis (see *Chapter 4*). Through the use of these carefully chosen outcomes measures, the results of the main cohort study of the thesis were able to provide a comprehensive examination of generalised and burn-specific HRQoL in those with moderate to severe burn injury.

### **3.4 Update of the ICF tool in developing a common burn outcome language**

Since the publication of this paper back in 2011, a systematic search of the literature using the OVID MEDLINE database from 2011 to 2015 was undertaken using Medical Subject Headings (MeSH) or free text terms (tw) search terms ‘ICF’, ‘international classification of disease’ and ‘burn injury’. Results revealed two additional studies that demonstrated the use of the ICF framework to describe complex health care deficits after major burn injury [35] and common subscales within HRQoL instruments that might overlap or complement each other [36].

In the paper by Grisbrook [35], the authors were able to demonstrate how the use of the measures of the ICF could provide a holistic and comprehensive understanding of impairments, limitations and restrictions using a single patient with complex functional limitations following a burn injury. In addition, they simultaneously mapped

clinical, biomechanical and physiological assessments, and assessed environmental, personal and physical activity limitations using a wide variety of instruments such as the BSHS-B, generic Medical Outcomes Study 36-Item Short Form (SF-36), the Canadian Occupational Performance Measure (COPM) and the Quick Disability of the Arm, Shoulder and Hand questionnaire (Quick-DASH). Results revealed that the contextual factors impacting on the patient achieving his functional goals were ICF indicators such as poor self-image, activity limitations at work, participation restrictions in daily and social activities, decreased functional range of motion, and disorganised and inefficient movement patterns. Further therapy and rehabilitation would therefore be recommended to address the patients' specific impairments and limitations in relation to his goals, whilst also focusing on maintaining or further improving his areas of strength.

In the second paper by Meirte [36], the authors undertook a systematic review to map the subscales of the three most frequently used questionnaires – SF-36, BSHS-B and the European Quality of Life 5 Dimensions (EQ-5D) – using the ICF framework. Similar to our published findings in 2011, the BSHS-B was covered by most domains and was the only scale that included the ICF's personal factors. The SF-36 included only one domain in the activity limitations, and similar to the EQ-5D, no contextual factors were included. Environmental factors were not addressed in the questionnaires, even though these could have an impact on the HRQoL in those patients with burn injury. Overall, it appeared that for the authors to capture the full spectrum of disability and dysfunction, a combination of the BSHS-B with a generic-health questionnaire is obligatory.

### **3.5 Chapter summary**

Despite the growing attention over the last two decades in burn outcomes and the use of the ICF within a wide variety of medical and surgical settings, there are only a handful of published English-language only studies within the burns literature looking at this combined topic area. In particular, the studies published by Wasiak [37] and Meirte [36] indicated the importance of the ICF methodological framework, whereas Grisbrook [35] applied the framework to the clinical setting in order to gain a comprehensive understanding of a complex patient's ability following burn injury. Unfortunately, these too few studies make it difficult to establish a level of consensus



regarding the most appropriate way to measure outcomes following a burn injury using the ICF, thereby attenuating the current debate amongst burn clinicians and researchers regarding their concerns over 'what to measure' and 'how to measure it'.

## **Chapter 4: The rationale and methodology of a prospective cohort study design – a burns perspective**

### **4.1 Introduction**

As described in *Chapter 3*, many aspects of the ICF framework could be mapped to a series of 14 burn-specific and general-health instruments; however, there was no clear consensus regarding a single measure, which covered all concepts of the ICF. To comprehensively measure burn injury outcomes multiple instruments covering different ICF constructs would need to be used. Therefore, it was proposed that a cohort study be specifically designed to provide a comprehensive, longitudinal picture of the complex burn patient presenting to a statewide burns service 12-months after injury. This chapter describes the rationale and methodology of the main prospective cohort study of this thesis. *Chapter 5, 6 and 7* report the findings of this cohort study.

### **4.2 Rationale**

Advances in medical management have dramatically decreased mortality rates from severe burn injuries. The growing number of individuals surviving such devastating injuries has prompted an increased focus on problems of rehabilitation, independence, and psychosocial adjustment. In Victoria each year, around 60 people are admitted, treated, and discharged from the Victorian Adult Burns Service (VABS) at The Alfred Hospital with moderate to severe burn injury. No previous published studies were found to have local Victorian data detailing the psychosocial consequences of burns trauma. Therefore, a thorough understanding of the incidence and course of physical and psychological difficulties is required to accurately gauge the efficacy of acute care interventions. Understanding the longer term impact of severe burn injury will assist in defining and implementing appropriate targeted interventions designed to re-integrate burns patients into the community.

## **Hypothesis**

Adults with moderate to severe burn injury will report significant reductions in function, health status and physical activity levels at 12-months post-injury, compared to pre-injury levels.

## **Aim**

The aim of this study was to describe the 12-month health status (i.e. general and burn-specific health) in patients with moderate to severe burn injury over a period of 12 months following admission to a burns unit.

## **4.3 Methods**

### Study design

A prospective cohort study

### Data setting

The Victorian Adult Burn Service (VABS) is a statewide provider of adult burns care, located at The Alfred Hospital, a 390-bed tertiary teaching hospital in Melbourne, Victoria. VABS treats approximately 250 inpatients with acute burn injuries each year.

### Participant inclusion criteria

The following patients were eligible for inclusion:

- i. Age 18 years and above
- ii. Admission to the VABS between February 2008 and October 2009
- iii. Burns involving >10% total body surface area burned (TBSA) or
- iv. Burns to the face requiring skin grafting or
- v. Burns to the hands and/or feet with the potential for functional impairment.

### Participant exclusion criteria

Patients were excluded if any of the following were present:

- i. Insufficient proficiency in English to complete the assessments
- ii. Readmission to the statewide burns unit due to pre-existing burns injuries.
- iii. Complex psychosocial impairment (i.e. any loss or abnormality of psychological or social function)
- iv. Documented diagnosis of pre-existing psychiatric illness by a medical officer in the patient's medical record.

#### Ethics approval

Approval was obtained from the Alfred Health and Monash University Human Research Ethics Committees and approval certificates are provided as Appendix 1.

#### **Participant recruitment procedure**

Participants were recruited during their inpatient stay at the VABS. All participants were recruited within 21 days of admission or following discharge from the intensive care unit (ICU) and given a participant information sheet (Appendix 2) detailing the purpose of the study, the information that would be collected, how the information would be used and stored, and the follow-up procedures. An opt-off method of consent was approved for use in this study. For this method, the information sheet contained a number to call if participants did not wish to be contacted by the research team. Participants who did not choose to opt-off from the study underwent baseline assessments during their hospital stay to retrospectively assess their pre-injury level of health and functioning.

#### **Outcome measures**

Reflecting on the systematic review findings in *Chapter 3*, where a series of outcome measure instruments were found to be commonly used in the burns population and mapped to the ICF, the following general and burn-specific health measures were used to assess participant outcomes prospectively via 60 minute telephone interviews at baseline/hospital admission, 3, 6 and 12 months post-injury. These instruments were designed to measure the health status, physical functioning, pain and psychological distress following a burn injury. None of the outcome instruments required a psychologist, and the perceived relevance of the questionnaires were shown

to influence participation rates and the scales considered to have high face to face or over the phone relevance. Each outcome measure is described in the following sections and copies of the instruments are provided in Appendix 3.

*General health measurement tool: Short Form 36 Medical Outcomes Survey v.2 (v.2)*

The SF-36 v.2 is a 36-item self-report measure of health status providing a measure of overall physical and mental health status through the generation of two summary scores: Physical Component Summary (PCS) and Mental Component Summary (MCS). The PCS and MCS each summarise scores on four sub-scales (PCS: physical functioning, role-physical, bodily pain and general health; MCS: vitality, social functioning, role-emotional, and general mental health). Higher scores indicate better health and functioning. Raw scores are normalized using Australian population means to produce a norm-based score with 50 equated to the population mean and one SD equating a difference of 10 points [38], with the higher scores representing better HRQoL. The SF-36 v.2 currently is the most widely used generic measure of HRQoL in medical settings and has very good psychometric properties in general populations [19] and has also been used in burn care settings [39, 40, 41].

*Burn-specific health scale measurement tool: Brief Version of the Burn Specific Health Scale (BSHS-B)*

The BSHS-B consists of 40 items divided into nine subscales: simple abilities, hand function, work, heat sensitivity, treatment regimens, affect, body image, interpersonal relationships, and sexuality. Responses are rated on a 5-point scale from 0 (extremely) to 4 (none/not at all) for each of the 40 items, and mean scores are calculated for each of the domains. A lower mean score indicates poorer function and lower burn specific HRQoL. The BSHS-B has satisfactory psychometric properties [42, 43] and is used to study the physical and psychosocial functioning of burns patients [42, 43].

*Psychological distress: Kessler Psychological Distress Scale (K-10)*

The K-10 is a scale measuring non-specific psychological distress. This instrument seeks to measure symptoms of depression and anxiety in the previous 30 days. For each item, there is a response option range from 1 (“none of the time”) to 5 (“all of the time”). Scores for the 10 items are then summed, yielding a minimum possible score of 10 and a maximum possible score of 50, with low scores (10–15) indicating

low levels of psychological distress and high scores (>22) indicating high levels of psychological distress [44].

*Pain assessment: McGill Pain Questionnaire (MPQ)*

Although used less frequently in burn research, the McGill Pain Questionnaire is a complex multidimensional assessment [45]. It comprises of a descriptive and numerical quantification of pain. Evaluation of 78 pain descriptor items categorized into 20 subclasses comprises the Pain Rating Index. Each subclass falls into to one of four major subscales; sensory, affective, evaluative and miscellaneous. Selected words are scored according to the ascending rank in their subclass. The Present Pain Intensity scale component indicates pain intensity on a 6-point scale from 0 (none) to 5 (excruciating). A higher score indicates a high level of pain [46].

*Affiliated information: Alcohol Use Disorders Identification Test (AUDIT)*

The AUDIT is a measure to screen, assess and identify people who are at a risk of developing alcohol problems. The test contains 10 multiple choice questions on quantity and frequency of alcohol consumption, drinking behaviour and alcohol-related problems or reactions. The answers are scored on a point system; a score of more than eight indicates hazardous and harmful alcohol use, as well as possible alcohol dependence [47].

**Outcome measures – demographic and burn-injury characteristics**

In addition to the standardized instruments, a chart review of medical records was also undertaken to collect demographic and burn-injury characteristics such as age, gender, burn aetiology, %TBSA, percentage partial and full thickness burn, number of surgical procedures, hospital length of stay (LOS), proportion undergoing admission to intensive care unit (ICU) and mechanical ventilation. The data collection tool used to collect demographic and burn-injury characteristics is in Appendix 4.

**Data analysis**

During the study period, 125 patients were eligible for the 12-month follow-up, with a total of 11 patients being lost to follow-up, leaving 114 for the final analysis. To assess general and burn-specific health along with psychological distress, the level of physical burn burden as described by %TBSA, was classified using %TBSA <10,

%TBSA 10–30 and %TBSA >30. These classifications broadly reflected the numerical value given to minor, moderate and major burn injury as described in other international burn studies [48]. In papers 4 and 6 (see *Chapter 5* and *Chapter 7*), baseline comparisons between groups were conducted using the Kruskal–Wallis test for continuous variables with skewed distribution, analysis of variance for approximately normally distributed continuous variables and chi-square test for categorical variables.

#### Comparison of pre-injury and post-injury scores

As seen in *Chapters 5, 6 and 7*, the three papers detail both parametric and non-parametric analyses to assess changes in pre-injury and post-injury scores. In particular, various longitudinal multivariable techniques such as linear regression and generalized linear models were used.

In particular, the analysis in paper 4 (see *Chapter 5*) saw the use of longitudinal models fitted using the main effects of group and time, with an interaction variable between group and time used to ascertain if the groups behaved differently over the allotted time points. Separate models were then fitted for the two outcome instruments (i.e. SF-36 v.2, BSHS-B) and their subscales.

As reported in paper 5 (see *Chapter 6*), a convenience sample of 19 patients fulfilled the inclusion criteria although this number was reduced to 15 at final analysis due to loss to follow-up or death. Due to the small sample sizes along with variable burn injury characteristics (i.e. %TBSA, ICU admission and hospital LOS etc.), a generalized linear model was chosen to allow for outcome instrument - SF-36 v.2, BSHS-B, MPQ, K-10 and AUDIT – scores to be reported between the groups across time.

In paper six (see *Chapter 7*), linear regression models were used to analyse the association between potential predictors (e.g. gender, %TBSA, presence of full-thickness burn and number of surgical procedures performed) and overall changes to SF-36 v.2 and BSHS-B total and sub-scores at 12 months post-burn injury. In particular, these potential predictors were explored because they were shown to influence recovery and functioning following burn injury in other international studies [25, 27]. In conducting the analyses, analysis of covariance was used to adjust for

baseline pre-burn scores and to predict SF- 36v2 subscale scores. Whereas, with no pre-burn injury BSHS-B scores to adjust for, linear regression was used to predict BSHS-B score at 12 months post-burn injury.

#### **4.4 Chapter summary**

It is now well established that burn injury can impact greatly on general health, physical activity and psychosocial functioning at 12-months post-discharge from a statewide burns service. The use of targeted statistical techniques that report on demographic and burn characteristics using various outcome instruments are now providing burn clinicians with an understanding on the incidence and course of physical and psychological difficulties that may result from the injury itself or the measures employed in the acute care setting that may extend beyond a few days to many weeks and months.



## **Chapter 5: Patterns of recovery 12 months after admission to a Level 1 trauma centre for burn injury**

*Chapter 5* contains a manuscript that was accepted for publication in *Injury*, an international journal dealing with all aspects of trauma care and accident surgery on February 8<sup>th</sup> 2014. The citation is as follows:

**Wasiak J**, Paul E, Lee SJ, Mahar P, Pfitzer B, Spinks A, Cleland H, Gabbe B. Patterns of recovery over 12 months following a burn injury in Australia. *Injury*. 2014; 45 (9): 1459-64.

### **5.1 Introduction**

A number of studies have reported the health status, burn-specific health, psychosocial adjustment and functional impairment following burn injury, but these studies have largely been undertaken in the United States and Europe. Currently, only a handful of Australian studies exist describing generic and burn-specific HRQoL but these studies have been limited by small sample sizes and inconsistent time frames for data collection. Given the limited data available, the third paper presented in this thesis examines 114 burn patients with moderate to severe injury and their ability to return to pre-injury health status at 12 months using selected outcome instruments (i.e. BSHS -B and SF-36 v.2), which were discussed in *Chapter 1* and *Chapter 3*. More so, the paper describes where there is improvement in generic and burn-specific HRQoL between the data collection points of 3 and 12 months post-burn injury.

## 5.2 Declaration of authorship for thesis Chapter 5

Wasiak J, Paul E, Lee SJ, Mahar P, Pfitzer B, Spinks A, Cleland H, Gabbe B. Patterns of recovery over 12 months following a burn injury in Australia. *Injury*. 2014; 45(9): 1459-64.

In the case of Chapter 5, the nature and extent of my contribution to the work was the following:

<b>Nature of contribution</b>	<b>Extent of contribution (%)</b>
Principal author responsible for the concept, design, analysis of literature, the interpretation of results and development of the writing up of the manuscript	80

The following co-authors contributed to the work. If co-authors are students at Monash University, the extent of their contribution in percentage terms must be stated:

<b>Name</b>	<b>Nature of contribution</b>	<b>Extent of contribution (%) for student co-authors only</b>
<b>Paul E</b>		
<b>Lee SJ</b>		
<b>Mahar P</b>		
<b>Pfitzer B</b>		
<b>Spinks A</b>		
<b>Cleland H</b>		
<b>Gabbe B</b>		

The undersigned hereby certify that the above declaration correctly reflects the nature and extent of the candidate's and co-authors' contributions to this work\*.

<b>Candidate's Signature</b>		<b>Date</b>
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<b>Main Supervisor's Signature</b>		<b>Date</b>
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## Patterns of recovery over 12 months following a burn injury in Australia



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### ABSTRACT

**Objective:** To describe patients' generic health status and health-related quality of life (HRQoL) 12-months following admission to a state-wide burns service.

**Methods:** A total of 114 injured adults with >10% total body surface area burned (TBSA) or burns less than 10% TBSA to smaller anatomical areas such as the hands and feet participated in this study. Retrospective assessment of pre-burn injury status and prospective assessment of generic health and HRQoL were followed up at 3, 6 and 12-months after injury using the 36-item Short Form Health Survey (SF-36 v.2) and Burns Specific Health Scale-Brief (BSHS-B). The SF-36 v.2 was administered retrospectively during the initial hospital stay to assess pre-injury HRQoL. Changes in instruments scores were assessed using multilevel mixed effects regression models. Mean scores were compared over time and between severity groups as defined by <10%, 10–30% and >30% TBSA.

**Results:** For the overall sample, the SF-36 v.2 physical component scale (PCS) score between 3 and 12-months post-burn injury were significantly lower than pre-injury scores ( $p < 0.01$ ), with no significant change over time for the mental component scale (MCS) ( $p = 0.36$ ). Significant %TBSA-burden by time interactions highlighted changes from pre-burn injury in overall PCS ( $p = 0.02$ ), physical functioning ( $p < 0.001$ ) and role-physical ( $p = 0.03$ ), with subscales worse for the TBSA >30% group. With respect to the BSHS-B, significant improvement from 3 to 12-months post-burn injury was seen for the entire sample in simple abilities ( $p < 0.001$ ), hand function ( $p = 0.001$ ), work ( $p = 0.01$ ), and treatment regime ( $p = 0.004$ ) subscales. The TBSA >30% group showed a greater rate of improvement in simple abilities ( $p = 0.01$ ) and hand function ( $p = 0.005$ ) between 3 and 12 months post-burn injury.

**Conclusions:** Whilst certain HRQoL measures improve over the 12-months, in most cases they do not reach pre-morbid levels. Patients face ongoing challenges regarding their physical and psychosocial recovery 12-months post-burn injury with respect to generic health and burn-specific health. These challenges vary at different time periods over the 12-month post-burn period, and may provide windows of opportunity in which to address ongoing issues.

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### Introduction

The growing number of individuals surviving severe burn injuries calls for an increased focus on regaining independence and

psychosocial adjustment [1]. Most of the literature on psychosocial rehabilitation after burn injury stems from the United States or Europe [2]. However, burns management in Australia may differ in that many burn centres are geographically distant from each other and that expert services cannot always be easily accessed. This can result in a delayed arrival at a tertiary referral centre with access to resources such as a multidisciplinary team that is equipped to deal with the complex issues arising from a major burn injury. The same

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problem occurs after discharge, with patients facing significant barriers to care due to the long distance from services including prolonged travelling times which may hinder the psychosocial follow up of patients [3].

The physical and psychological consequences of both minor and severe burn injuries are well documented in studies from the United States and Europe [4,5]. It is now recognised that burn injury may result in impaired quality of life (QoL) which can persist for a long time after the injury and develop into chronic long-term problems in these patients [6–9]. This notwithstanding, the psychosocial impact of a burn injury and the perception of health-related quality of life (HRQoL) may differ among patient populations, as it is subject to cultural and economic factors as well as the generic health and psychosocial functioning of patients pre-injury.

A small number of Australian studies have described burn-specific health and HRQoL outcomes, with most studies combining a series of functional and QoL instruments [10–13]. However, these studies have been limited by small sample sizes [10,12], inconsistent time frames for data collection, or substantial attrition at follow-up [10–13]. Given the limited data currently available, and potential distinctive features of an Australian burns population, this study aims to build upon existing knowledge by evaluating the short- and long-term health and social functioning outcomes of patients with burn injury over a period of 12 months and how these outcomes change and progress over defined time periods. In particular this study explored the extent to which burn patients with different burn severity return to pre-injury health status at 12 months, as well as the extent to which there is improvement in health status and burn-specific QoL between 3 and 12 months post-burn injury.

## Methods

### Setting

The state of Victoria, Australia, has a population of 5.62 million people. The Victorian Adult Burns Service (VABS) is a state-wide adult burns service located at The Alfred Hospital, one of two designated major trauma services for adults in the state.

### Study design and inclusion criteria

Patients meeting the following criteria were eligible for participation in this prospective cohort study:

- (i) age  $\geq 18$  years;
- (ii) admission to the VABS between February 2008 and October 2009;
- (iii) burns involving  $>10\%$  total body surface area burned (TBSA) or
- (iv) burns to the face requiring skin grafting or
- (v) burns to the hands and/or feet with the potential for functional impairment.

Patients were excluded for the following reasons:

- (i) Insufficient proficiency in English to complete the assessments.
- (ii) Complex psychosocial impairment.
- (iii) Documented diagnosis of pre-existing psychiatric illness.
- (iv) Readmission due to pre-existing burn injuries.

### Participant recruitment procedures

Participants were recruited during their inpatient stay at the VABS. All participants were recruited within 21 days of admission

or following discharge from the intensive care unit (ICU). The assessments were performed at baseline during their hospital stay to retrospectively assess their pre-injury level of functioning. Telephone interviews were conducted at 3, 6 and 12 months post-injury. In addition, demographic data and information about the nature and extent of the injury was collected from medical records.

### Interview instruments

#### General health measurement tool: SF-36 v.2

The SF-36 v.2 is a brief 36-item measure of health-related quality of life/health status that includes composite or summary scales reflecting perceived physical and psychosocial health and functioning [14]. Individual responses are used to calculate a score for each of the two-summary scales: Mental Component Summary (MCS) and the Physical Component Summary (PCS). The subscales incorporated in the PCS are physical functioning, role-physical, bodily pain and general health. The MCS scores refer to vitality, social functioning, role-emotional and general mental health. Higher scores on the SF-36 v.2 indicate better health and functioning. The SF-36 v.2 currently is the most widely used generic measure of health-related quality of life in medical settings and has very good psychometric properties in general patients [14,15]. The SF-36 v.2 domains are well understood and have been used previously by clinicians in the burn care setting [11,16,17].

#### Burn specific health scale measurement tool: BSHS-B

The BSHS-B is the only condition-specific health status instrument for use with burns patients. It consists of 40 items divided into nine subscales: simple abilities, hand function, work, heat sensitivity, treatment regimens, affect, body image, interpersonal relationships, and sexuality. Responses are rated on a 5-point scale from 0 (extremely) to 4 (none/not at all) for each of the 40 items, and mean scores are calculated for each of the domains. A higher mean score indicates better function and higher burn specific QoL. The BSHS-B has satisfactory psychometric properties [18,19] and is widely used to study the physical and psychosocial functioning of burns patients [15,19,20].

### Statistical analysis

Analysis was performed using SAS version 9.2 (SAS Institute, Cary, NC, USA). To assess HRQoL according to levels of physical burden, %TBSA was categorised into TBSA  $<10\%$ , TBSA  $10\text{--}30\%$  and TBSA  $>30\%$  as described by Fauerbach et al. [7]. Baseline comparisons between groups were conducted using the Kruskal–Wallis test for continuous variables with skewed distribution, analysis of variance for approximately normally distributed continuous variables and chi-square test for categorical variables. A multivariable longitudinal analysis was performed using the PROC MIXED procedure in SAS with each patient treated as a random effect. Longitudinal models were fitted using main effects for group, time, and an interaction between group and time to ascertain if the groups behaved differently over time. Separate models were fitted for the SF-36 v.2, BSHS-B and their subscales. To facilitate specific comparisons, time was treated as a categorical variable. Post hoc comparisons were performed using Bonferroni adjustment for multiple comparisons. Results from the mixed-effects models were presented as means with standard errors. A two-sided  $p$ -value  $< 0.05$  was considered statistically significant.

## Results

During the study period, 540 patients were admitted to the VABS with an acute burn injury. Of these, 415 were excluded because of burns  $<10\%$  TBSA with no potential for functional

**Table 1**  
Baseline characteristics by %TBSA group.

Factor	TBSA <10% (n = 16)	TBSA 10–30% (n = 85)	TBSA >30% (n = 13)	P value
Age, mean (SD)	38.8 (13.7)	41.1 (17.8)	39.2 (12.7)	0.84
Sex: male	9 (56.3%)	67 (78.8%)	10 (76.9%)	0.16
Partial thickness TBSA	0.5 (0–5)	10 (5–15)	25 (14–30)	<0.001
Full thickness TBSA	0.5 (0–5)	2 (0–6)	10 (10–20)	<0.001
Total LOS (days)	13 (9–26)	16 (12–23)	45 (33–84)	<0.001
ICU admission: yes	1 (6.3%)	21 (24.7%)	10 (76.9%)	<0.001
Number of surgeries	1 (1–2)	1 (1–2)	5 (2–7)	<0.001

Data are presented as median (inter-quartile range) or number (percentage) unless stated otherwise.

impairment ( $n = 241$ ), pre-existing diagnosed psychiatric illness ( $n = 15$ ), complex social issues ( $n = 15$ ), insufficient English ( $n = 4$ ), previous burn injury requiring re-admission ( $n = 17$ ), death within 24 h ( $n = 13$ ), conservative burn wound management ( $n = 39$ ), other (i.e. diagnosis of other burn-like conditions such as toxic epidermal necrolysis,  $n = 17$ ) or missed ( $n = 54$ ) leaving 125 eligible patients for 12 month follow-up at hospital discharge. Of the 125 patients, a total of 11 patients were lost at all time points to follow-up, leaving 114 for the final analysis.

Table 1 shows the baseline demographic and burn injury characteristics according to %TBSA involved. There were no significant differences between groups in terms of age or gender. The proportion of patients who required ICU admission increased with increasing burn severity and extent. Overall, participants were more men than women (86 men, 28 female) with a mean (SD) age of 40 (16.7) years, with a median (IQR) %TBSA of 16.5% (12–25%). Nearly a third of patients ( $n = 32$ , 28%) required admission to the intensive care unit (ICU), whilst 58% ( $n = 66$ ) required one of the surgical procedures, 22% ( $n = 25$ ) required two surgical procedures and 18% ( $n = 20$ ) required more than two surgical procedures to manage their burn injury. Follow-up of participants using the SF-36 v.2 instrument was noted at baseline ( $n = 110$ , 96%), 3 months ( $n = 110$ , 96%), 6 months ( $n = 108$ , 95%) and 12 months ( $n = 101$ , 89%).

Scores on the SF-36 v.2 for patients at baseline, 3, 6 and 12 months post-injury are displayed in Tables 2 and 3 (PCS and physical subscales; MCS and mental subscales). For the PCS and

four physical domain subscales, a time effect was evident displaying a reduced health status post-burn injury. With respect to measuring change between 3 and 12 months post-burn, post hoc comparison found that for the PCS significant improvement was only seen by 12 months ( $p = 0.013$ ) and for physical functioning by 6 months ( $p < 0.001$ ). No change post-burn was seen for bodily pain, general health and role physical.

The %TBSA severity by a time interaction effect was also evident for the PCS and physical functioning and role physical subscales. The nature of this interaction is demonstrated in Table 4 which represents the adjusted pair-wise comparisons of change from pre-burn to 12 months post-burn for the three TBSA severity groups. At 12 months, patients with >30% TBSA involvement continued to display marked reductions in PCS, physical functioning and role physical, whereas the two less severely burnt groups had largely recovered to pre-burn levels.

While the SF-36 v.2 MCS overall scale did not show a difference over time, time effects were found for the role emotional, vitality and social functioning subscales with health status poorer post-burn injury across all %TBSA groups. Using post hoc comparisons to measure the change between 3 and 12 months post-burn, no difference was found for the MCS or either mental domain subscale suggesting that there was no improvement between 3 and 12 months post-burn.

Table 5 shows the BSHS-B overall and subscale scores for patients separated by %TBSA severity at 3, 6 and 12 months. Across the whole sample, patients were reporting between 3 (a little bit of

**Table 2**  
SF-36 v.2 physical domain composite and subscale means (standard errors) according to %TBSA categories.

SF-36 v.2 subscale	Time period	TBSA <10%	TBSA 10–30%	TBSA >30%	Interaction P value*	Overall time effect	
		Mean (SE)	Mean (SE)	Mean (SE)		Mean (SE)	P value
PCS (overall scale)	Pre-injury	55.70 (2.81)	55.36 (1.20)	58.45 (3.12)	0.020	56.50 (1.46)	<0.001
	3 months	47.54 (2.81)	48.66 (1.20)	41.37 (3.12)		45.86 (1.46)	
	6 months	51.29 (2.81)	50.78 (1.22)	43.04 (3.05)		48.37 (1.44)	
	12 months	54.16 (2.87)	52.23 (1.24)	45.28 (3.21)		50.56 (1.49)	
Physical functioning	Pre-injury	53.11 (2.53)	52.85 (1.08)	57.22 (2.82)	<0.001	54.39 (1.31)	<0.001
	3 months	45.69 (2.53)	47.60 (1.08)	37.30 (2.82)		43.53 (1.31)	
	6 months	50.04 (2.53)	50.11 (1.10)	41.33 (2.75)		47.16 (1.30)	
	12 months	51.95 (2.58)	49.61 (1.11)	42.71 (2.89)		48.09 (1.34)	
Role-physical	Pre-injury	53.70 (2.92)	52.29 (1.25)	54.73 (3.25)	0.031	53.57 (1.52)	<0.001
	3 months	44.45 (2.92)	46.15 (1.25)	38.89 (3.25)		43.16 (1.52)	
	6 months	49.51 (2.92)	47.60 (1.27)	39.15 (3.16)		45.42 (1.50)	
	12 months	52.47 (2.99)	48.96 (1.29)	40.97 (3.36)		47.47 (1.56)	
Bodily pain	Pre-injury	59.88 (2.83)	58.32 (1.21)	60.73 (3.15)	0.347	59.64 (1.47)	<0.001
	3 months	52.39 (2.83)	50.67 (1.21)	47.39 (3.15)		50.15 (1.47)	
	6 months	54.93 (2.83)	52.02 (1.22)	46.68 (3.05)		50.21 (1.45)	
	12 months	53.39 (2.90)	55.05 (1.25)	50.43 (3.26)		52.96 (1.51)	
General health	Pre-injury	57.59 (2.54)	53.00 (1.09)	54.99 (2.82)	0.097	55.19 (1.32)	0.013
	3 months	51.00 (2.54)	51.41 (1.09)	51.37 (2.82)		51.26 (1.32)	
	6 months	54.50 (2.54)	54.43 (1.10)	50.18 (2.76)		53.04 (1.30)	
	12 months	53.51 (2.58)	52.26 (1.11)	53.81 (2.89)		53.20 (1.34)	

\* F-test probability for model testing interaction between time and TBSA burden.

**Table 3**

SF-36 v.2 mental domain composite and subscale means (standard errors) according to %TBSA categories.

SF-36 v.2 subscale	Time period	TBSA <10%	TBSA 10–30%	TBSA >30%	Interaction <i>P</i> value <sup>*</sup>	Overall time effect	
		Mean (SE)	Mean (SE)	Mean (SE)		Mean (SE)	<i>P</i> value
MCS (overall scale)	Pre-injury	56.19 (2.92)	50.46 (1.25)	53.43 (3.25)	0.481	53.36 (1.52)	0.355
	3 months	53.12 (2.92)	50.45 (1.25)	50.98 (3.25)		51.51 (1.52)	
	6 months	53.80 (2.92)	51.08 (1.27)	47.29 (3.18)		50.72 (1.50)	
	12 months	53.48 (2.99)	51.79 (1.29)	50.83 (3.34)		52.03 (1.55)	
Mental health	Pre-injury	54.96 (2.77)	51.76 (1.19)	54.52 (3.09)	0.092	53.74 (1.44)	0.080
	3 months	51.35 (2.77)	50.23 (1.19)	49.53 (3.09)		50.37 (1.44)	
	6 months	55.86 (2.77)	51.21 (1.20)	46.76 (3.02)		51.28 (1.42)	
	12 months	53.03 (2.83)	52.96 (1.22)	48.22 (3.16)		51.40 (1.47)	
Role-emotional	Pre-injury	55.29 (2.84)	49.02 (1.21)	52.22 (3.16)	0.459	52.18 (1.47)	0.039
	3 months	50.23 (2.84)	47.80 (1.21)	43.82 (3.16)		47.28 (1.47)	
	6 months	50.75 (2.84)	49.65 (1.23)	45.41 (3.06)		48.60 (1.45)	
	12 months	52.89 (2.92)	49.94 (1.26)	47.87 (3.28)		50.24 (1.52)	
Vitality	Pre-injury	62.88 (3.09)	56.79 (1.32)	60.99 (3.43)	0.087	60.22 (1.60)	<0.001
	3 months	53.39 (3.09)	51.31 (1.32)	49.99 (3.43)		51.56 (1.60)	
	6 months	54.64 (3.09)	52.59 (1.34)	46.09 (3.36)		51.10 (1.58)	
	12 months	54.87 (3.15)	53.13 (1.36)	51.59 (3.52)		53.20 (1.64)	
Social functioning	Pre-injury	53.21 (2.91)	51.02 (1.24)	53.75 (3.25)	0.313	52.66 (1.51)	0.034
	3 months	50.43 (2.91)	50.10 (1.24)	47.79 (3.25)		49.44 (1.51)	
	6 months	50.07 (2.91)	50.06 (1.26)	43.00 (3.15)		47.71 (1.49)	
	12 months	53.20 (2.99)	49.89 (1.29)	48.92 (3.36)		50.67 (1.56)	

<sup>\*</sup> *F*-test probability for model testing interaction between time and TBSA burden.

difficulty) and 4 (no difficulty) on average for most subscales suggesting low levels of impairment in most domains. However, with average subscale scores of between 2 (moderate difficulty) and 3 (a little bit of difficulty) for the work, body image and heat sensitivity subscales, these were areas of more persistent difficulty. An effect of time post-burn injury was only found for the BSHS-B overall score, and simple abilities, hand function, work and treatment regime subscales, with each displaying improved scores over time. A %TBSA severity by time interaction effect for simple abilities and hand function subscales suggested that patients with >30% TBSA involvement displayed the greatest improvement, related in part to reporting lower scores at 3 months post-burn injury.

## Discussion

This study describes the level of physical and social functioning in Australian patients with moderate to severe burn injury over a 12-month period, adding to the existing literature base [4,5,7,18,21]. This has helped to achieve a better understanding of the burden of burn injuries, as well as the pattern of recovery and its impact on QoL including patients' independence and functioning overall.

Our main findings showed that the greatest decline in physical functioning was experienced at 3 months in all %TBSA categories, with a small but steady improvement occurring at 12 months.

More specifically, patients with burns of TBSA 10–30% experienced a significant reduction from pre-burn physical functioning to 6 months, while those patients with >30% TBSA experienced the same effect up to 12 months post-injury. Despite this steady improvement, levels on all physical health status sub-scales remained lower than pre morbid functioning. In particular, the sub-scales of vitality, which measures energy and fatigue levels, displayed significant reductions across the three physical burden patient groups for up to 6 months. Overall, a consistent pattern of impaired health and functioning in both physical and psychosocial domains was evident for all patient %TBSA categories.

Our results are consistent with other long-term outcome studies [11,16,21,25]. Moi et al. [16], Cromes et al. [21], and Klein et al. [22] all described patients with significantly lowered SF-36 v.2 scores in multiple domains, consistent with the results in our study. Although the methodology and specific measurement parameter periods differ between these studies, our findings support these studies in that many aspects of physical and mental health status in the burns population may not return to pre-morbid levels by 12 months.

In the present sample, many patients suffered from burn injuries that affected nearly 20% of their TBSA with a moderate number of patients suffering from burns to their upper and lower extremities. In addition, most patients sustained full-thickness

**Table 4**

Changes in outcomes at 12 months relative to baseline according to levels of physical burden (%TBSA).

SF-36 scales	TBSA			Pair-wise comparisons (adjusted <i>P</i> values)		
	<10%	10–30%	>30%	<10% vs. 10–30%	<10% vs. >30%	10–30% vs. >30%
PCS	1.54 (2.89)	3.14 (1.24)	13.17 (3.28)	1.00	0.03	0.01
Physical functioning	1.16 (2.47)	3.24 (1.06)	14.51 (2.81)	1.00	0.002	0.001
Role-physical	1.23 (3.19)	3.33 (1.37)	13.75 (3.63)	1.00	0.06	0.04
Bodily pain	6.49 (3.29)	3.27 (1.41)	10.30 (3.73)	1.00	0.95	0.15
General health	4.08 (2.32)	0.74 (1.00)	1.17 (2.64)	0.52	1.00	1.00
MCS	2.72 (2.95)	−1.33 (1.27)	2.60 (3.36)	0.84	1.00	1.00
Mental health	1.93 (2.63)	−1.21 (1.13)	6.30 (2.99)	0.98	0.96	0.11
Role-emotional	2.39 (3.47)	−0.92 (1.49)	4.35 (3.93)	1.00	1.00	0.48
Vitality	8.01 (2.99)	3.66 (1.28)	9.40 (3.40)	0.71	1.00	0.54
Social function	0.01 (3.38)	1.13 (1.45)	4.84 (3.83)	1.00	1.00	1.00

Values are mean (standard error) unless stated otherwise.



**Table 5**  
Burns Specific Health Scale-B composite and subscale means (standard errors) according to %TBSA categories.

BSHS subscale	Time Period	TBSA < 10% Mean (SE)	TBSA 10–30% Mean (SE)	TBSA > 30% Mean (SE)	Interaction P value <sup>a</sup>	Overall time effect Mean (SE)	P value
BSHS (overall scale)	3 months	3.40 (0.16)	3.28 (0.07)	2.68 (0.18)	0.777	3.12 (0.08)	0.018
	6 months	3.49 (0.16)	3.39 (0.07)	2.74 (0.17)		3.21 (0.08)	
	12 months	3.54 (0.16)	3.42 (0.07)	2.95 (0.18)		3.30 (0.08)	
Simple abilities	3 months	3.76 (0.18)	3.58 (0.08)	2.72 (0.20)	0.014	3.35 (0.09)	<0.001
	6 months	3.96 (0.18)	3.67 (0.08)	3.51 (0.20)		3.71 (0.09)	
	12 months	4.01 (0.19)	3.73 (0.08)	3.47 (0.21)		3.74 (0.10)	
Hand function	3 months	3.88 (0.16)	3.64 (0.07)	2.71 (0.18)	0.005	3.41 (0.08)	0.001
	6 months	3.91 (0.16)	3.80 (0.07)	3.00 (0.18)		3.57 (0.08)	
	12 months	3.92 (0.17)	3.75 (0.07)	3.50 (0.18)		3.72 (0.09)	
Work	3 months	1.94 (0.39)	2.73 (0.17)	1.52 (0.43)	0.067	2.06 (0.20)	0.012
	6 months	2.54 (0.39)	2.95 (0.17)	1.46 (0.42)		2.32 (0.20)	
	12 months	3.12 (0.40)	2.93 (0.17)	1.61 (0.44)		2.55 (0.20)	
Body image	3 months	3.03 (0.27)	3.16 (0.12)	2.65 (0.30)	0.692	2.95 (0.14)	0.346
	6 months	3.20 (0.27)	3.12 (0.12)	2.62 (0.29)		2.98 (0.14)	
	12 months	3.28 (0.28)	3.16 (0.12)	2.85 (0.30)		3.10 (0.14)	
Affect	3 months	3.53 (0.22)	3.48 (0.09)	3.24 (0.24)	0.288	3.41 (0.11)	0.364
	6 months	3.44 (0.22)	3.60 (0.09)	3.15 (0.23)		3.40 (0.11)	
	12 months	3.50 (0.22)	3.54 (0.10)	3.55 (0.24)		3.53 (0.11)	
Interpersonal	3 months	3.69 (0.16)	3.71 (0.07)	3.79 (0.18)	0.538	3.73 (0.08)	0.492
	6 months	3.89 (0.16)	3.84 (0.07)	3.63 (0.17)		3.79 (0.08)	
	12 months	3.77 (0.17)	3.75 (0.07)	3.51 (0.18)		3.68 (0.09)	
Sexuality	3 months	3.85 (0.19)	3.65 (0.08)	3.56 (0.21)	0.356	3.69 (0.10)	0.180
	6 months	3.50 (0.19)	3.68 (0.08)	3.36 (0.21)		3.51 (0.10)	
	12 months	3.71 (0.20)	3.65 (0.08)	3.47 (0.22)		3.61 (0.10)	
Heat sensitivity	3 months	3.25 (0.31)	2.56 (0.13)	1.86 (0.35)	0.581	2.55 (0.16)	0.938
	6 months	3.17 (0.31)	2.65 (0.14)	1.71 (0.34)		2.51 (0.16)	
	12 months	2.96 (0.32)	2.73 (0.14)	1.96 (0.35)		2.55 (0.17)	
Treatment regime	3 months	3.61 (0.24)	3.18 (0.10)	2.21 (0.26)	0.845	3.00 (0.12)	0.004
	6 months	3.79 (0.24)	3.30 (0.10)	2.52 (0.26)		3.21 (0.12)	
	12 months	3.86 (0.25)	3.61 (0.10)	2.72 (0.27)		3.40 (0.13)	

<sup>a</sup> F-test probability for model testing interaction between time and TBSA burden.

burns and 18% required two or more surgical interventions during their hospital stay. These injuries commonly required multiple complex treatment regimens, which may not have led to the persistent reduction in overall function, yet could help to explain the lower SF-36 v.2 PCS scores. The pattern here is consistent with a study reported by Fauerbach et al. [7], where the authors found physical functioning returned to near-normal levels at 12 months in the less physically burdened group, but not in the group with the largest %TBSA. However, in a series of earlier studies [23,24], the authors showed an inconsistent relationship between %TBSA, generic health and QoL. In contrast some later studies by Anzarut et al. [4], Moi et al. [16] and van Loey et al. [5], reported that the presence and localisation of full-thickness burn injury along with two or more operative procedures was more likely to affect long-term generic health than %TBSA.

Beyond the assessment of generic health functioning, improvements over time were found in burn-specific QoL domains. However, the four domains which showed improvement (hand function, work, simple abilities and compliance with treatment regime) were not necessarily independent categories. For example, improvements in hand function may have enabled people to perform simple tasks and work related activities more effectively. Another consideration is that there may be differential patterns of improvement following a burn injury as stated by Cromes et al. [21]. They showed that the physical domains of the BSHS improved over time and that this improvement plateaued at six months after injury; whilst other domain scores did not change. Therefore, the possibility existed that matters of post-burn health such as mobility/self care tasks along with some role resumption activities

were still seen as problematic suggesting a lack of familiarity with the expectation of the aftermath of the injury or the need for patients to adhere to long-term standardised functional rehabilitation programmes. It also suggests that improvements in more complex domains such as work may take longer for measurable improvements to be seen. This highlights the potential need for different interventions at different points in time post-injury which may extend well beyond 12 months.

The results of our study indicated that recovery trajectory differed for patients according to their %TBSA. In line with Fauerbach et al. [7], the most severely burned patients (TBSA >30%) displayed significantly greater reductions from pre-burn functioning in the PCS and physical functioning subscale of the SF-36 v.2. However, our study also found that the most severely injured patients experienced greater reductions from pre-burn functioning in the role-physical subscale, and the mental health, role-emotional, vitality and social functioning SF-36 v.2 subscales. Poorer recovery in physical and mental health status was therefore experienced by the most severely burnt patients. Across multiple domains of burn-specific quality of life, the most severely burnt patients displayed lower scores than both the less severely burnt groups. Hand function, work, body image, simple abilities, heat sensitivity and treatment regime were the domains that were markedly lower at 12 months in the most severely burnt patients. These issues may constitute particular risks in more severely burnt patients, warranting more targeted interventions as part of rehabilitation programmes.

It is important to acknowledge the limitations in the present study. Generic and disease-specific measures were administered at

selected points in time post-burn injury; which may not reflect dynamic changes in health related parameters which could have an impact on HRQoL [26]. Given the natural fluctuations in health over time, it may be difficult to compare the results across different measures. Secondly, although our study comprised a 12-month follow-up similar to studies from other countries, the 12-month mark may not reflect the final stage of burns recovery. Further research, encompassing a longer time frame to investigate may be helpful. While the study sample represented various degrees of burn severity as well as various injury mechanisms, the outcomes for this cohort may not necessarily reflect outcomes for patients treated by other burns services and different patient populations, in particular patients not receiving specialist burn care. Finally, our exclusion criteria may not allow for extrapolation of our results to other burn populations, such as those from a non-English speaking background, or with pre-existing psychiatric illness.

In summary, despite significant advances in burn care over the last few decades, our study shows that at 12 months following a burn injury, many patients were still reporting levels of physical functioning that were significantly below their pre-injury level of functioning. A more goal-directed therapy and a consistent evaluation of interventions may be required in order to continue improving physical and psychosocial functioning particularly at time points where patients may be considered to be at their greatest physical and psychosocial risk. It seems important to monitor these patients for an adequate period of time which may extend beyond 12 months. Further research should address physical and psychosocial risks in this patient population as well as interventions targeted at defined points in time.

#### Conflict of interest statement

The authors do not have a conflict of interest.

#### Acknowledgements

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#### References

- [1] Richard R, Baryza MJ, Carr JA, Dewey WS, Dougherty ME, Forbes-Duchart L, et al. Burn rehabilitation and research: proceedings of a consensus summit. *Journal of Burn Care and Rehabilitation* 2009;30(July–August (4)):543–73.
- [2] Danilla S, Wasiak J, Searle S, Arrigada C, Pedreros C, Cleland H, et al. Methodological quality of randomised controlled trials in burns care: a systematic review. *Burns* 2009;35(7):956–61.
- [3] Gabbe BJ, Sleney JS, Gosling CM, Wilson K, Hart MJ, Sutherland AM, et al. Patient perspectives of care in a regionalised trauma system: lessons from the Victorian State Trauma System. *Medical Journal of Australia* 2013;98(3):149–52.
- [4] Anzarut A, Chen M, Shankowsky H, Tredget EE. Quality-of-life and outcome predictors following massive burn injury. *Plastic and Reconstructive Surgery* 2005;116(3):791–7.
- [5] van Loey NE, van Beeck EF, Faber BW, van de Schoot R, Bremer M. Health-related quality of life after burns: a prospective multicentre cohort study with 18 months follow-up. *Journal of Trauma and Acute Care Surgery* 2012;72(2):513–20.
- [6] Esselman PC, Thombs BD, Magyar-Russell G, Fauerbach JA. Burn rehabilitation: state of the science. *American Journal of Physical Medicine and Rehabilitation* 2006;85(4):383–413.
- [7] Fauerbach JA, Lezotte D, Hills RA, Cromes GF, Kowalske K, de Lateur BJ, et al. Burden of burn: a norm-based inquiry into the influence of burn size and distress on recovery of physical and psychosocial function. *Journal of Burn Care and Rehabilitation* 2005;26(1):21–32.
- [8] Fauerbach JA, McKibben J, Bienvenu OJ, Magyar-Russell G, Smith MT, Holavanahalli R, et al. Psychological distress after major burn injury. *Psychosomatic Medicine* 2007;69(5):473–82.
- [9] Van Loey NE, Maas CJ, Faber AW, Taal LA. Predictors of chronic posttraumatic stress symptoms following burn injury: results of longitudinal study. *Journal of Traumatic Stress* 2003;16:361–9.
- [10] Druery M, Brown TL, Muller M. Long term functional outcomes and quality of life following severe burn injury. *Burns* 2005;31(6):692–5.
- [11] Edgar D, Dawson A, Hankey G, Phillips M, Wood F. Demonstration of the validity of the SF-36 for measurement of the temporal recovery of quality of life outcomes in burns survivors. *Burns* 2010;36(7):1013–20.
- [12] Grisbrook TL, Reid SL, Edgar DW, Wallman KE, Wood FM, Elliott CM. Exercise training to improve health related quality of life in long term survivors of major burn injury: a matched controlled study. *Burns* 2012;38(8):1165–73.
- [13] Kvannli L, Finlay V, Edgar DW, Wu A, Wood FM. Using the Burn Specific Health Scale-brief as a measure of quality of life after a burn-what score should clinicians expect? *Burns* 2011;37(1):54–60.
- [14] Ware Jr JE, Kosinski M, Björner JB, Turner-Bowker DM, Gandek B, Maruish ME. User's manual for the SF-36v2TM health survey. 2nd ed. Lincoln, RI: Quality-Metric Incorporated; 2007.
- [15] Wasiak J, McMahon M, Danilla S, Spinks A, Cleland H, Gabbe B. Measuring common burn outcome measures and their concepts using the International Classification of Functioning, Disability and Health (ICF): a systematic review. *Burns* 2011;37(6):913–24.
- [16] Moi AL, Wentzel-Larsen T, Salemark L, Wahl AK, Hanestad BR. Impaired generic health status but perception of good quality of life in survivors of burn injury. *Journal of Trauma* 2006;61(4):961–8.
- [17] Xie B, Xiao SC, Zhu SH, Xia ZF. Evaluation of long term health-related quality of life in extensive burns: a 12-year experience in a burn center. *Burns* 2012;38(3):348–55.
- [18] Kildal M, Andersson G, Fugl-Meyer AR, Lannerstam K, Gerdin B. Development of a brief version of the Burn Specific Health Scale (BSHS-B). *Journal of Trauma* 2001;51(4):740–6.
- [19] Willebrand M, Kildal M. A simplified domain structure of the burn-specific health scale-brief (BSHS-B): a tool to improve its value in routine clinical work. *Journal of Trauma* 2008;64(6):1581–6.
- [20] Kildal M, Willebrand M, Andersson G, Gerdin B, Ekselius L. Personality characteristics and perceived health problems after burn injury. *Journal of Burn Care and Rehabilitation* 2004;25(3):228–35.
- [21] Cromes GF, Holavanahalli R, Kowalske K, Helm P. Predictors of quality of life as measured by the Burn Specific Health Scale in persons with major burn injury. *Journal of Burn Care and Rehabilitation* 2002;23(3):229–34.
- [22] Klein MB, Lezotte DC, Heltshe S, Fauerbach J, Holavanahalli RK, Rivara FP, et al. Functional and psychosocial outcomes of older adults after burn injury: results from a multicenter database of severe burn injury. *Journal of Burn Care and Rehabilitation* 2011;32(1):66–78.
- [23] Altier N, Malenfant A, Forget R, Choinière M. Long-term adjustment in burn victims: a matched-control study. *Psychological Medicine* 2002;32(4):677–85.
- [24] Doctor JN, Patterson DR, Mann RJ. The 1997 Clinical Research Award. Health outcome for burn survivors. *Journal of Burn Care and Rehabilitation* 1997;18(6):490–5.
- [25] Dahl O, Wickman M, Wengström Y. Adapting to life after burn injury – reflections on care. *Journal of Burn Care and Rehabilitation* 2012;33(5):595–605.
- [26] Oster C, Willebrand M, Ekselius L. Health-related quality of life 2 years to 7 years after burn injury. *Journal of Trauma* 2011;71(5):1435–41.



### **5.3 Summary of findings**

The manuscript presented in this chapter was able to build upon the existing knowledge of general and burn-specific HRQoL in patients with moderate to severe burn injury over a period of 12 months, and detail how these outcomes changed and progressed over defined time periods. In particular this study focused on the extent to which burn patients with different burn severity returned to pre-injury health status at 12 months, as well as the extent to which there was improvement in general and burn-specific HRQoL between 3 and 12 months post-burn injury.

Results showed that SF-36 v.2 PCS scores between 3 and 12-months post injury were lower than pre-injury scores, with those patients fairing worse with burns greater than 30%TBSA. In addition, most patients did not reach their pre-injury levels, which suggested that patients were faced with ongoing challenges regarding their physical and psychosocial recovery 12-months post-hospital discharge. With respect to the burn-specific HRQoL, improvements were seen across all time points in various subscales of the BSHS-B.

### **5.4 Chapter summary**

This chapter has furthered our understanding of the burden of burn-related injuries. The SF-36 v.2 and BSHS-B subscales, either directly or indirectly, addressed many of the aspects of the ICF framework reported in *Chapters 1* and *3*. It demonstrated the effectiveness of both the SF-36 v.2 and BSHS as outcome measure in this population and highlighted the appropriateness of using patient perceived outcome measures. Outcomes related to body pain, social function, physical capacity, mental health and pain were addressed and the extent to which these various aspects were affected. This paper has helped to achieve a better understanding of the burden of burn injuries, as well as the pattern of recovery and its impact on HRQoL, including patients' independence and functioning overall.

## **Chapter 6: Reporting patterns of generic and burn-specific health in a subgroup of patients injured following a natural burn disaster**

*Chapter 6* contains a manuscript that was accepted for publication in *Injury*, an international journal dealing with all aspects of trauma care and accident surgery, on August 29<sup>th</sup> 2013. The citation is as follows:

**Wasiak J**, Mahar P, Lee S, Paul E, Spinks A, Pfizer B, Cleland H, Gabbe B. 12-Month generic health status and psychological distress outcomes following an Australian natural disaster experience: 2009 Black Saturday Wildfires. *Injury*; 2013; 44(11): 1443-47.

### **6.1 Introduction**

As discussed in *Chapter 1*, there is an increasing number of studies investigating the impact of burn on physical and psychosocial function during the first year after injury. Whilst most people are injured in isolation or within familiar surroundings, injury from an unexpected event such as natural disaster, and its impact on mental wellbeing is still emerging. Research on injury from an unexpected event attested to the effects of disasters on physical and psychosocial outcomes of those who survive them [49]. In Australia, there have been multiple bushfire disasters such as ‘Ash Wednesday’ in the early 1980s, and in more recent times, the disaster commonly referred to as the ‘Black Saturday’ bushfires.

Much of the focus of the research has continued to examine the psychological impact, although there is a growing body of research investigating factors that influence the development of mental disorders after these events [49]. Along with characteristics of the traumatic event (i.e. threat to life, loss of a loved one etc.), mental health outcomes are influenced by gender, subsequent negative life and traumatic life events, alcohol use, social support and the speed at which financial compensation was received [50]. In the context of disaster, post-trauma stressors are particularly relevant because the post-disaster period can be fraught with further stressors, such as: rebuilding of family

homes; adapting to changes in the community services and structures; displacement from communities, loss of personal items, loss of employment; the stress that often accompanies dealing with insurers and the recovery system; and these disaster-related stressors are associated with worse mental health outcomes [50]. In addition, no local or national studies have described general and burn-specific HRQoL following injury after a catastrophic event. The fourth paper in this thesis describes the generic and burn-specific HRQoL 12-months following the Black Saturday Bushfires from 2009.

## 6.2 Declaration of authorship for thesis Chapter 6

Wasiak J, Mahar P, Lee SJ, Paul E, Spinks A, Pfitzer B, Cleland H, Gabbe B. 12-Month generic health status and psychological distress outcomes following an Australian natural disaster experience: 2009 Black Saturday Wildfires. *Injury*. 2013; 44(11): 1443-47.

In the case of Chapter 6, the nature and extent of my contribution to the work was the following:

<b>Nature of contribution</b>	<b>Extent of contribution (%)</b>
Principal author responsible for the concept, design, analysis of literature, the interpretation of results and development of the writing up of the manuscript	80

The following co-authors contributed to the work. If co-authors are students at Monash University, the extent of their contribution in percentage terms must be stated:

<b>Name</b>	<b>Nature of contribution</b>	<b>Extent of contribution (%) for student co-authors only</b>
<b>Mahar P</b>		
<b>Lee S</b>		
<b>Paul E</b>		
<b>Spinks A</b>		
<b>Pfitzer B</b>		
<b>Cleland H</b>		
<b>Gabbe B</b>		

The undersigned hereby certify that the above declaration correctly reflects the nature and extent of the candidate's and co-authors' contributions to this work\*.

<b>Candidate's Signature</b>		<b>Date</b>
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<b>Main Supervisor's Signature</b>		<b>Date</b>
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## 12-Month generic health status and psychological distress outcomes following an Australian natural disaster experience: 2009 Black Saturday Wildfires

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### ABSTRACT

**Objective:** To describe the generic health status, health-related quality of life and psychological distress over a 12-month period of burns patients affected by the 2009 Black Saturday Wildfires.

**Design setting and participants:** Cohort study with retrospective assessment of pre-injury status and prospective assessment of physical and psychosocial functioning in the Black Saturday Wildfires burns patients across time. Generic health status and burn specific quality of life using the 36-item Short Form Health Survey (SF-36) and Burn Specific Health Scale (BSHS) were collected at three, six and twelve months post-burn injury. In addition, similar time points were used to measure level of psychological distress and the presence of pain using the Kessler-10 questionnaire (K-10) and the McGill Pain Questionnaire.

**Results:** At 12 months post-injury, patients reported a mean 16.4 (standard error, SE: 3.2) reduction in physical health and a 5.3 (SE 2.5) reduction in mental health scores of the SF-36 as compared to their pre-injury scores, with significant decreases observed in the "bodily pain", "physical functioning", "role physical" and "vitality" subscales. High levels of psychological distress and persistent pain were experienced, with no significant changes during the study period to the overall burns specific quality of life.

**Conclusions:** Even 12 months post-burn injury, patients affected by the 2009 Victorian Wildfires still experienced a significant reduction in generic health, increased psychological distress and persistent pain. The need for early and ongoing identification of physical and psychosocial impairments during hospital admission and upon discharge could be helpful to establish systematic interdisciplinary goals for long-term rehabilitation after severe burn injury.

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### Introduction

An increasing number of studies have investigated the physical and psychological sequelae of burns including alterations in range of motion, strength and appearance as well as psychological distress, depression and posttraumatic stress disorder (PTSD) during the first year after injury.<sup>1–5</sup> However, little is known about the specific problems faced by burns

patients as a result of wildfires. Whilst psychological reactions to major wildfires have been documented<sup>6–8</sup> these studies have not involved assessments of quality of life (QoL) or general health status which may provide a more accurate reflection of the physical, psychological and social functioning as well as individual health perceptions.

On the 7th of February 2009, Victoria experienced one of its worst natural disasters. The Black Saturday Wildfires claimed 173 lives, left more than 400 people injured and resulted in multiple other devastating consequences such as the loss of family members, property and livestock.<sup>9</sup> Nineteen individuals with burn injuries were admitted to the Victorian Adult Burns Unit

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(VABS), the state-wide provider of burns care for all adults with complex major burn injuries in Victoria. Two of the 19 patients died. The 17 surviving patients underwent complex medical procedures, most of them requiring repeated surgical interventions as well as intense assistance from multiple other disciplines. Social and psychological needs were met by staff from the psychiatry and social work departments. We wished to survey these patients post hospital discharge to assess generic health status and burn-specific QoL to 12 months following the Black Saturday Wildfires.

## Methods

### Setting

The VABS is a state-wide provider of adult burns care, located at The Alfred Hospital, a 390-bed tertiary teaching hospital in Melbourne, Victoria. VABS treats approximately 250 inpatients with acute burn injuries each year.

### Ethics

Ethical approval was obtained from Monash University and The Alfred Hospital's Human Research and Ethics Committee.

### Data collection – baseline

Nineteen patients admitted to VABS with burn injuries as a result of the Black Saturday Wildfires were eligible to participate in the study. Within 21 days of admission, patients were approached for informed consent. At recruitment, an in-hospital interview was performed to obtain retrospective pre-injury baseline health data alongside basic clinical demographic and burn injury characteristics.

Patients were contacted for follow-up at three, six and twelve months post injury via a telephone call. As part of the follow-up, patients were asked to complete a series of standardised questionnaires. All assessments took place during February 2009 until February 2010. Due to the complexity of the follow-up, the contact telephone calls were undertaken a week before or after the allotted follow-up date with the support of a burns research nurse.

### Measures

*General health measurement tool: Short Form 36 Medical Outcomes Survey (version 2) (SF-36 v2)*

The SF-36 is a health status measure that contains 36 items measured over eight domains. Items cover a range of physical activities from self-care to participation in strenuous activities. The SF-36 provides separate subscale scores, as well as two-summary scores: a mental component (MCS) and the physical component summary (PCS). Higher scores on the SF-36 indicate greater health and functioning. The SF-36 is the most widely used generic measure of health-related quality of life and has been applied in a variety of settings. Its domains are well understood and have previously been used in burns care.<sup>10–13</sup>

*Burn specific health scale measurement tool: Burn Specific Health Scale – Brief Version (BSHS-B)*

The BSHS-B is a standardised 40-item burn-specific QoL measure which assesses four different modalities (physical, social and mental functioning and general well-being) across nine domains. Responses are rated from 0 (“extremely”) to 4 (“none/not at all”). Mean scores are calculated for each of the domains. A higher mean score indicates an increased level of functioning and

higher QoL. The BSHS-B has satisfactory psychometric properties<sup>14,15</sup> and is widely used for the assessment of physical and psychosocial functioning in burns patients.<sup>16</sup>

*Pain assessment: McGill Pain Questionnaire (MPQ)*

The MPQ consists of 78 pain descriptors as part of four major categories (sensory, affective, evaluative, and miscellaneous) and 20 subcategories, each made up of at least two up to six words, to which pain intensity values are assigned. These values are then added to derive an estimated overall pain score. Higher scores indicate a more severe pain experience.

*Psychological distress: Kessler Psychological Distress Scale (K-10)*

The K-10 is a scale measuring non-specific psychological distress, which seeks to measure symptoms of depression and anxiety in the previous 30 days. For each item, there is a response option range from 1 (“none of the time”) to 5 (“all of the time”). Scores for the 10 items are then summed, yielding a minimum possible score of 10 and a maximum possible score of 50, with low scores (10–15) indicating low levels of psychological distress and high scores ( $\geq 22$ ) indicating high levels of psychological distress.<sup>17</sup>

*Affiliated information – Alcohol Use Disorders Identification Test (AUDIT)*

The AUDIT is a measure to screen, assess and identify people who are at a risk of developing alcohol problems. The test contains 10 multiple choice questions on quantity and frequency of alcohol consumption, drinking behaviour and alcohol-related problems or reactions. The answers are scored on a point system; a score of more than 8 indicates an alcohol problem.

### Analysis

All data were analysed using the SAS software version 9.2 (SAS Institute, Cary, NC, USA). To estimate SF-36, BSHS-B, MPQ, K-10 and AUDIT scores across time, generalised linear models were used with an identity link function. A generalised estimating equation approach with exchangeable working correlation matrix (PROC GENMOD in SAS) was applied to correct the standard errors, as the observations were not independent. Statistical significance was set at a two-sided  $p$  value of 0.05.

## Results

A total of 19 patients fulfilled the inclusion criteria although follow-up data was only available for 15 patients for the following reasons: two patients died from their injuries and two patients declined to participate. Table 1 shows baseline demographic and baseline burn injury characteristics.

**Table 1**  
Baseline characteristics of study population.

Age, mean (SD)	51.3 (11.7)
Gender, number	
Male	10
Female	5
Total mean %TBSA (SD)	17.8 (12.8)
Partial thickness %TBSA	9.2 (9.8)
Full-thickness %TBSA	6.7 (8.7)
Cause of burn, n	
Thermal	10
Radiant heat	5
Number of operative procedures (SD)	2.1 (1.7)
ICU admission, number	5

SD: standard deviation; %TBSA: percentage total body surface area; ICU: intensive care unit.

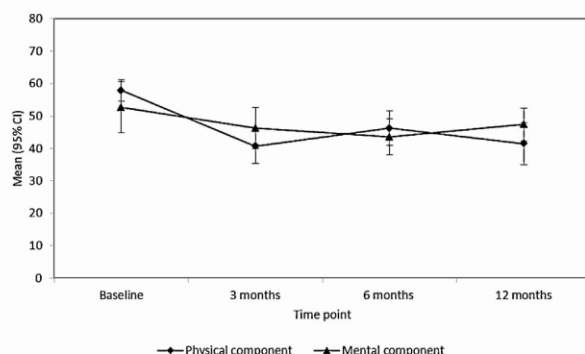


Fig. 1. Average SF-36 physical and mental component scores (95% CI) during follow-up.

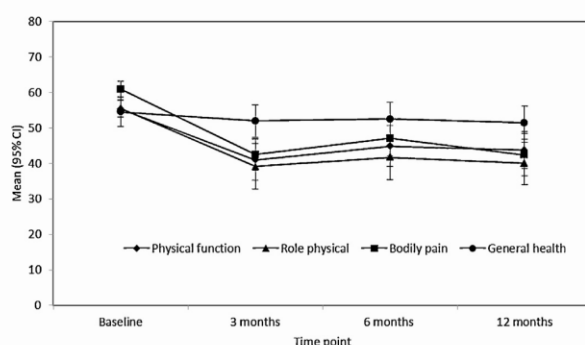


Fig. 2. Average SF-36 physical component subscales (95% CI) during follow-up.

Overall mean SF-36 summary subscale scores are shown in Fig. 1. Mean PCS scores decreased from 57.94 (SE 1.7) pre-injury to 41.51 (SE 3.3) at 12-month post-injury, whereas MCS scores decreased less from 52.74 (SE 3.9) to 47.43 (SE 2.5). The same trend was observed in all other SF-36 sub-scale scores, although the reduction was only significant for the “bodily pain”, “physical functioning”, “role physical” and “vitality” subscales (Figs. 2 and 3). The overall BSHS-B score and changes in the sub-domains from three months to six and 12 months can be observed in Table 2. There were no significant changes seen across these time periods for the nine domains. With regard to psychological distress, five patients (33%) reported high to very high levels of psychological distress ( $K-10 \geq 22$ ) three months and six months post-injury. After a slight decrease, four

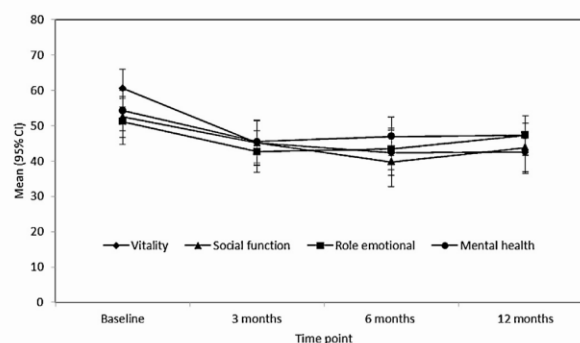


Fig. 3. Average SF-36 mental component subscales (95% CI) during follow-up.

participants reported high levels of psychological distress twelve months post-injury. No significant changes were seen in the AUDIT and MPQ (see Table 2).

## Discussion

The present study was an investigation into the long-term health outcomes in people with burn injuries as a result of the 2009 Black Saturday Wildfires. The main findings of our study showed that in a population that had little or no disability prior to the catastrophic event, a significant reduction in SF-36 scores post-burn injury was observed with regard to physical functioning, role physical, bodily pain and vitality, demonstrating a consistent pattern of worsened health and functioning in both physical and psychosocial domains.

Across time, our patients reported significant limitations in performing a variety of activities not just with regard to vigorous activities like running or lifting heavy objects, but also basic tasks such as self care. In addition, they were less able to work and reported to have less energy. Hence, the findings indicated that 12 months after injury, there was significant level of ongoing disability. The vitality domain was the most affected of the mental health subscales, with non-significant decreases seen in mental health, social functioning and role emotional. The reduction in scores not only suggested some interference with re-establishing previous patterns of personal, social or work-related behaviour prior to the burn injury but also raised concerns about the emergence of a pattern of chronic psychosocial morbidity.

Our findings were consistent with other long-term outcome studies, which showed alterations in the health of burn patients as compared to matched non-injured controls or the general

Table 2

BSHS, Kessler 10, McGill and AUDIT results for those with burn injury followed up at 12-months. Means and standard errors reported.

Outcome	Pre-Injury	3 months	6 months	12 months
BSHS				
Overall scale		116.3 (5.9)	119.7 (6.2)	116.7 (6.7)
Simple abilities		10.1 (0.6)	10.5 (0.5)	10.3 (0.6)
Hand functioning		15.5 (1.2)	17.3 (0.9)	17.2 (0.9)
Work		7.1 (1.4)	8.2 (1.6)	8.4 (1.5)
Body image		12.7 (0.8)	12.3 (1.2)	12.7 (0.9)
Affect		22.5 (1.3)	22.2 (1.2)	21.8 (1.6)
Interpersonal		14.6 (0.7)	15.3 (0.4)	13.6 (0.9)
Sexuality		11.1 (0.4)	9.8 (0.7)	9.5 (0.7)
Heat sensitivity		9.1 (1.5)	10.3 (1.8)	6.7 (1.8)
Treatment regime		13.5 (1.4)	13.7 (1.6)	16.5 (1.0)
Kessler 10 (K-10)		19.5 (1.5)	19.9 (1.6)	18.1 (1.6)
AUDIT scores	4.00 (0.9)	4.3 (1.0)	4.5 (0.8)	4.3 (0.8)
McGill Pain Scale total score		5.1 (1.0)	6.8 (2.2)	12.8 (2.7)



population over time.<sup>2,11,12,18,19</sup> Altier<sup>18</sup> assessed 49 adult burn patients and found their health to be poorer than in matched non-injured controls on all eight subscales of the SF-36 63 months post-injury, whilst Xie<sup>12</sup> showed SF-36 scores to be significantly lower two years after the event. Fauerbach<sup>2</sup> reported that at 12 months post-injury a large number of patient's still demonstrated lower levels of physical and psychosocial health as compared to the general population, even though in his study there was a clear improvement in SF-36 scores during the first year post-burn.

It is important to note that in the present sample patients suffered from burn injuries that affected on average 18% of their total body surface area, with a large number suffering burns to their hands and feet. In addition, most patients sustained full-thickness burns and had a mean of 2.1 surgical interventions during their hospital stay which may have accounted for the lower SF-36 PCS score. In a similar study, Fauerbach<sup>3</sup> demonstrated that physical functioning returned to near-normal levels at 12 months in the less physically burdened group, but not in the group with the largest %TBSA. However, in a series of earlier studies,<sup>18,20,21</sup> the authors showed an inconsistent relationship between %TBSA, generic health and QoL, whereas in later studies by Anzarut,<sup>22</sup> Moi<sup>11</sup> and Van Loey<sup>19</sup> the presence and localisation of full-thickness burn injury along with two or more operative procedures were more likely to affect long-term generic health than %TBSA.

We also examined burn-specific QoL as measured by the BSHS-B because it met the conceptual criteria for QoL as suggested by Bergner<sup>23</sup> and was sensitive to persons with burn injuries.<sup>24</sup> Our results showed that there were no statistically significant changes across time with regard to the overall BSHS score and the other nine domains. In a similar finding, Cromes<sup>24</sup> showed that only the physical domains of the BSHS improved over time, and that this improvement plateaued at six months after injury, whilst other domain scores did not change. It is possible that changes in burn recovery occurred within one to two months after discharge,<sup>10</sup> but this could not be determined since the BSHS-B was not administered at those time points. The possibility exists that mobility/self-care tasks and role resumption activities were still seen as problematic suggesting a lack of familiarity with the expectation of the aftermath of injury or an absence of, or the need for patients to adhere to a long-term standardised functional rehabilitation programme.

The levels of psychological distress observed across the study period was considerably higher than the 9.6% reported for population norms<sup>25</sup> but also consistent with previous burn studies,<sup>26–29</sup> which showed various levels of psychological distress persisting for at least two years post burn injury. In this context, we were unable to comment whether patients were at a particularly increased risk in comparison to matched controls suffering from similar burn injuries. Specific factors (i.e. injury-specific, disaster-related or psychological maladjustment) which may have contributed to the high levels of psychological distress were not identified. Furthermore, a significant amount of national and international media and community attention was focused on the aftermath of the 2009 Black Saturday Wildfires, and it is unclear how these factors interacted with patients' presentations and perceptions of distress. In these matters, further studies, undertaken with careful attention to the sensitive nature of the issues raised, into the specific challenges faced by wildfire burn survivors may be of value.

With regard to pain, study participants reported a change in pain intensity over time. These findings were similar to other studies which reported persistent pain 12 months after the burn injury.<sup>30,31</sup> In these studies the presence of pain correlated with the severity of burns. Even though many studies have reported an increase in alcohol consumption after burn injuries,<sup>32,33</sup> we found little evidence of risky drinking behaviours, alcohol or alcohol

dependence as assessed by the AUDIT. There was no increase in scores from pre-injury to twelve months post-injury.

There were a number of limitations to this study such as the small sample size which made it difficult to undertake an investigation other than a descriptive analysis. Secondly, the generic and disease-specific instruments covered different time points. For instance, the SF-36 asked about the patient's current health status in the last 4 weeks, whereas the BSHS-B had no specific timeframe. As Oster<sup>34</sup> points out in the post-burn rehabilitative stage, dynamic changes in health-related QoL sometimes occur over several weeks, which might in turn have led to differences in comparative assessments. Additionally, the patient care during and after a catastrophic event at one particular burns unit, was not reproducible due to the nature of the specific disaster and the heterogeneity of the population, which could limit the application of data obtained to the burns population generally. As mentioned previously, undertaking matched controls with non-wildfire injured burns patients may provide further information with which to assess applicability to the general burns population and this approach should be considered for future studies assessing mass-casualty burn injured patients. Finally, the length of our study was limited to 12 months of follow-up. Whilst this time-frame has been used in other studies assessing the psychological impact of trauma and burns patients,<sup>19</sup> psychological distress in this population has been noted well beyond the 12 month mark<sup>28</sup> and longer periods of follow-up might yield further results.

In conclusion, the results of our study showed that at 12 months after Black Saturday Wildfire burns patients displayed worsened physical and psychosocial functioning from baseline as well as persistent pain despite intensive multidisciplinary management efforts. Whilst this group of patients has suffered significant associated losses in addition to a burn injury, it is possible that the degree of ongoing disability and distress identified also exists in burn patients injured in other circumstances. Although it seems reasonable to conclude that our population suffered distress in the above mentioned domains in comparison to non-burned members of the general population, conclusions should not be drawn that burns patients as a result of wildfires suffer uniquely in comparison to non-wildfire injured burns patients. The lack of matched controls in this context is a limitation of this study, and an opportunity for further research. However, the data illustrate the crucial importance of a routine assessment of both physical and psychosocial health alongside the need to ensure access to psychosocial and pain management clinicians post-discharge from hospital. As severe burn injury is uncommon in developed societies, the delivery of expert care in the acute phase and also during rehabilitation requires input from highly specialised clinicians for direct care delivery and also for coordination and oversight of community based care. The development of a burn-specific, multi-disciplinary after-care clinic associated with acute burns units would enable clinicians to establish comprehensive rehabilitation treatment plans with input from burn, pain, rehabilitation and psychological specialists. In this way, the long-term efficacy of acute burn care treatments could be determined, whilst the negative long-term impact on psychosocial and physical health could be reduced.

#### Conflict of interest statement

The authors have no conflict of interest.

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## References

- Esselman PC, Thombs BD, Magyar-Russell G, Fauerbach JA. Burn rehabilitation: state of the science. *American Journal of Physical Medicine and Rehabilitation* 2006;85:383–413.
- Fauerbach JA, Lezotte D, Hills RA, Cromes GF, Kowalske K, de Lateur BJ, et al. Burden of burn: a norm-based inquiry into the influence of burn size and distress on recovery of physical and psychosocial function. *Journal of Burn Care and Rehabilitation* 2005;26:21–32.
- Fauerbach JA, McKibben J, Bienvenu OJ, Magyar-Russell G, Smith MT, Holavanahalli R, et al. Psychological distress after major burn injury. *Psychosomatic Medicine* 2007;69(June (5)):473–82.
- Van Loey NE, Van Son MJ. Psychopathology and psychological problems in patients with burns scars: epidemiology and management. *American Journal of Clinical Dermatology* 2003;4(4):245–72.
- Dyster-Aas J, Willebrand M, Wikehult B, Gerdin B, Ekselius L. Major depression and posttraumatic stress disorder symptoms following severe burn injury in relation to lifetime psychiatric morbidity. *Journal of Trauma* 2008;64(May (5)):1349–56.
- McFarlane AC. The Ash Wednesday Wildfires in South Australia – implications for planning for future post-disaster services. *Medical Journal of Australia* 1984;141(5):286–91.
- Valent P. The Ash Wednesday Wildfires in Victoria. *Medical Journal of Australia* 1984;141(5):291–300.
- Yelland C, Robinson P, Lock C, La Greca AM, Kokegei B, Ridgway V, et al. Bushfire impact on youth. *Journal of Traumatic Stress* 2010;23(April (2)):274–7.
- Cleland HJ, Proud D, Spinks S, Wasiak J. Multidisciplinary team response to a mass burn casualty event: outcomes and implications. *Medical Journal of Australia* 2011;194(11):589–93.
- Edgar D, Dawson A, Hankey G, Phillips M, Wood F. Demonstration of the validity of the SF-36 for measurement of the temporal recovery of quality of life outcomes in burns survivors. *Burns* 2010;36(November (7)):1013–20.
- Moi AL, Wentzel-Larsen T, Salemark L, Wahl AK, Hanestad BR. Impaired generic health status but perception of good quality of life in survivors of burn injury. *Journal of Trauma* 2006;61(October (4)):961–8.
- Xie B, Xiao SC, Zhu SH, Xia ZF. Evaluation of long term health-related quality of life in extensive burns: a 12-year experience in a burn center. *Burns* 2011;October. [Epub ahead of print].
- Wasiak J, McMahon M, Danilla S, Spinks A, Cleland H, Gabbe B. Measuring common burn outcome measures and their concepts using the International Classification of Functioning, Disability and Health (ICF): a systematic review. *Burns* 2011;37(6):913–24.
- Kildal M, Andersson G, Fugl-Meyer AR, Lannerstam K, Gerdin B. Development of a brief version of the Burn Specific Health Scale (BSHS-B). *Journal of Trauma* 2001;51(October (4)):740–6.
- Willebrand M, Kildal M. A simplified domain structure of the burn-specific health scale-brief (BSHS-B): a tool to improve its value in routine clinical work. *Journal of Trauma* 2008;64(June (6)):1581–6.
- Yoder LH, Nayback AM, Gaylord K. The evolution and utility of the burn specific health scale: a systematic review. *Burns* 2010;36(December (8)):1143–56.
- Andrews G, Slade T. Interpreting scores on the Kessler Psychological Distress Scale (K10). *Australian and New Zealand Journal of Public Health* 2001;25:494–7.
- Altier N, Malenfant A, Forget R, Choinière M. Long-term adjustment in burn victims: a matched-control study. *Psychological Medicine* 2002;32(May (4)):677–85.
- Van Loey NE, van Beeck EF, Faber BW, van de Schoot R, Bremer M. Health-related quality of life after burns: a prospective multicentre cohort study with 18 months follow-up. *Journal of Trauma* 2011;October. [Epub ahead of print].
- Doctor JN, Patterson DR, Mann R. The 1997 Clinical Research Award Health outcome for burn survivors. *Journal of Burn Care and Rehabilitation* 1997;18(November–December (6)):490–5.
- Sheridan RL, Hinson MI, Liang MH, Nackel AF, Schoenfeld DA, Ryan CM, et al. Long-term outcome of children surviving massive burns. *JAMA Journal of the American Medical Association* 2000;283(January (1)):69–73.
- Anzarut A, Chen M, Shankowsky H, Tredget EE. Quality-of-life and outcome predictors following massive burn injury. *Plastic and Reconstructive Surgery* 2005;116(September (3)):791–7.
- Bergner M. Quality of life, health status, and clinical research. *Medical Care* 1989;27(March (3 Suppl.)):S148–56.
- Cromes GF, Holavanahalli R, Kowalske K, Helm P. Predictors of quality of life as measured by the Burn Specific Health Scale in persons with major burn injury. *Journal of Burn Care and Rehabilitation* 2002;23(May–June (3)):229–34.
- Slade T, Grove R, Burgess P. Kessler Psychological Distress Scale: normative data from the 2007 Australian National Survey of Mental Health and Wellbeing. *Australian and New Zealand Journal of Psychiatry* 2011;45(April (4)):308–16.
- Patterson DR, Ptacek JT, Cromes GF, Fauerbach JA, Engrav LE. The 2000 Clinical Research Award describing and predicting distress and satisfaction with life for burn survivors. *Journal of Burn Care and Rehabilitation* 2000;21:490–8.
- Van Loey NE, Maas CJ, Faber AW, Taal LA. Predictors of chronic posttraumatic stress symptoms following burn injury: results of a longitudinal study. *Journal of Traumatic Stress* 2003;16:361–9.
- Wiechman SA, Ptacek JT, Patterson DR, Gibran NS, Engrav LE, Heimbach DM. Rates, trends, and severity of depression after burn injuries. *Journal of Burn Care and Rehabilitation* 2001;22:417–24.
- Reeve J, James F, McNeill R, Brown P, Cameron L, Mills S. Functional and psychological outcomes following burn injury: reduced income and hidden emotions are predictors of greater distress. *Journal of Burn Care & Research* 2011;32(July–August (4)):468–74.
- Dauber A, Osgood PF, Breslau AJ, Vernon HL, Carr DB. Chronic persistent pain after severe burns: a survey of 358 burn survivors. *Pain Medicine* 2002;3(March (1)):6–17.
- Taal LA, Faber AW. Burn injuries, pain and distress: exploring the role of stress symptomatology. *Burns* 1997;23(4):288–90.
- McGill V, Kowal-Vern A, Fisher SG, Kahn S, Gamelli RL. The impact of substance use on mortality and morbidity from thermal injury. *Journal of Trauma* 1995;38:931–4.
- Swenson JR, Dimsdale JE, Rockwell E, Carroll W, Hansbrough J. Drug and alcohol abuse in patients with acute burn injuries. *Psychosomatics* 1991;32:287–93.
- Oster C, Willebrand M, Dyster-Aas J, Kildal M, Ekselius L. Validation of the EQ-5D questionnaire in burn injured adults. *Burns* 2009;35(August (5)):723–32.

### **6.3 Summary of findings**

This is the first study, to our knowledge, to examine the generic health and burn specific HRQoL and level of psychological distress of burns patients who were affected by the 2009 Black Saturday Wildfires. Reporting over a 12-month period, the main findings showed that in a population that had little or no disability prior to the catastrophic event, the burn injury had a large, negative and persistent impact on their physical activities, routine daily tasks, and vitality levels. In addition, most burn patients were less able to work. Hence, the findings indicated that 12 months after injury, there remained a significant level of ongoing disability.

### **6.4 Chapter summary**

This chapter showed that at 12 months after the 2009 Black Saturday Wildfires, burns patients displayed worsened physical and psychological health along with burn-specific HRQoL from baseline, as well as persistent pain, despite intensive multidisciplinary management efforts during hospital admission and outpatient follow-up appointments. Whilst this group of patients suffered significant associated losses in addition to a burn injury, it is possible that the degree of ongoing disability and distress identified also existed in burn patients injured in other circumstances. Irrespective, the data illustrates the crucial importance of routine assessment of generic health by specialist staff in the acute care setting alongside the urgent need for staff to capture burn-specific HRQoL post-hospital discharge.

## **Chapter 7: Identifying patient demographics and injury characteristics that predict general and burn-specific health 12 months after injury**

*Chapter 7* contains a manuscript that was accepted for publication in *Burns*, the international peer review journal of the International Society for Burn Injuries (ISBI), on January 22<sup>nd</sup> 2014. The citation is as follows:

**Wasiak J**, Lee SJ, Paul E, Mahar P, Pfitzer B, Spinks A, Cleland H, Gabbe B. Predictors of health status and health-related quality of life 12 months after severe burn. *Burns*. 2014; 40(4): 568-74.

### **7.1 Introduction**

*Chapter 2* reported on the frequency, pattern, and mechanisms of burn injury leading to death or hospital treatment across the state of Victoria. Whilst hospital admission rates remained static with no temporal changes to overall burn rates, specific burn populations (i.e. men, children less than 5 years of age and the elderly) still remained at high risk of injury. More so, *Chapter 5* described how patients with a moderate burn injury reported declines in generic and burn-specific HRQoL at 3 months, which persisted at 12-months post discharge from a statewide burn service. Together, these manuscripts clearly highlight ‘who’ is the burned injured patient and ‘what’ is the impact of burn injury on health outcomes, but not who is most at risk of poorer outcome. Therefore, the aim of this chapter was to identify the clinical and patient characteristic predictors of burn-specific HRQoL 12 months after burn injury.

## 7.2 Declaration of authorship for thesis Chapter 7

Wasiak J, Lee SJ, Paul E, Mahar P, Pfitzer B, Spinks A, Cleland H, Gabbe B. Predictors of health status and health-related quality of life 12 months after severe burn. *Burns* 2014; 40(4): 568-74

In the case of Chapter 7, the nature and extent of my contribution to the work was the following:

<b>Nature of contribution</b>	<b>of</b>	<b>Extent of contribution (%)</b>
Principal author responsible for the concept, design, analysis of literature, the interpretation of results and development of the writing up of the manuscript.		80

The following co-authors contributed to the work. If co-authors are students at Monash University, the extent of their contribution in percentage terms must be stated:

<b>Name</b>	<b>Nature of contribution</b>	<b>Extent of contribution (%) for student co-authors only</b>
<b>Lee SJ</b>		
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<b>Mahar P</b>		
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<b>Gabbe B</b>		

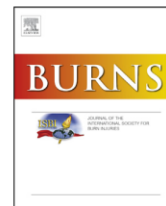
The undersigned hereby certify that the above declaration correctly reflects the nature and extent of the candidate's and co-authors' contributions to this work\*.

<b>Candidate's Signature</b>		<b>Date</b>
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<b>Main Supervisor's Signature</b>		<b>Date</b>
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## Predictors of health status and health-related quality of life 12 months after severe burn



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### ABSTRACT

**Introduction:** Sustaining a moderate to severe burn injury is associated with the potential for substantial impairments to long-term physical and psychosocial health, including health related quality of life (HRQoL). The objective of this study was to identify clinical and patient characteristics which predict HRQoL 12-months after injury.

**Methods:** A total of 125 patients were recruited over the study period, although only 99 were included in the final analysis representing all those who completed both the pre-burn and 12-months after burn injury Short Form 36 Medical Outcomes Survey (SF-36v2). These patients also completed the Burn Specific Health Scale-Brief (BSHS-B). Patient demographics and burn injury characteristics and treatment factors were collected to identify which factors predict 12-month health status outcomes. Multiple linear regression analyses were conducted to identify important predictors of outcomes. The SF36v2 models were adjusted for pre-injury measurements.

**Results:** Older age (regression coefficient  $-0.26$ , 95% confidence interval (95% CI)  $-0.38$ ,  $-0.13$ ), female gender ( $-8.08$ , 95% CI  $-12.8$ ,  $-3.34$ ) and increased percentage of full-thickness burns per body surface area ( $-0.51$ ; 95% CI  $-0.88$ ,  $-0.13$ ) were important predictors of poorer physical health status at 12 months. Older age ( $-0.15$ , 95% CI  $-0.26$ ,  $-0.04$ ) and increased percentage of full-thickness burns per body surface area ( $-0.36$ , 95% CI  $-0.69$ ,  $-0.03$ ) were important predictors of poorer mental health status at 12 months. Older age ( $-0.38$ ; 95% CI  $-0.66$ ,  $-0.11$ ) and female gender ( $-12.17$ ; 95% CI  $-22.76$ ,  $-1.57$ ) were important predictors of poorer BSHS-B total score at 12 months after injury.

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**Conclusions:** Given the complexity of burn care rehabilitation, physical and psychosocial screening and assessment within the first weeks after a burn injury along with adequate monitoring after discharge should be undertaken in burn injured patients. In this context, patients of specific demographics, such as female patients and older patients, and patients with a higher percentage of full thickness surface area burns are of greater risk for poorer physical and psychological outcomes and may benefit from additional monitoring and rehabilitation.

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## 1. Introduction

Sustaining a moderate to severe burn injury and undergoing consequent burn care therapies may result in long-term hospitalisation, repeated acute and reconstructive surgeries and multifaceted rehabilitation regimes. The potential physical stress from an extensive burn injury, as well as the subsequent complex and invasive treatment, often extends beyond the immediate acute phase of injury. This can result in months to years of complex rehabilitation, with significant impacts on the long-term physical and psychosocial health and well-being of patients [1,2].

Highlighting the extent of ongoing difficulties experienced by discharged burn patients, a number of cross-sectional or retrospective studies have been conducted with a mean follow-up of up to eight years after burn. A study by Liang et al. [2] with 93 adult patients with a mean total burn surface area (TBSA) of 45% found that the level of physiological care needs had reduced over time whereas psychosocial needs (reported as being more extensive than physiological care needs) had not changed. More extensive burned areas and visible scarred areas were in particular predictive of greater physiological and psychosocial needs at follow-up. A second study that conducted a follow-up on average five years after burn injury for 50 patients (>10% TBSA) found that 70% of patients reported “good” to “very good” ratings of general quality of life, although on average patients reported “moderate” difficulties in heat sensitivity and body image and approximately one-quarter of patients reported elevated levels of trauma or depression symptoms [3]. A further study that conducted a matched-comparison of 49 burn patients (mean TBSA = 35%) on average five years after burn and a control group found that the groups did not significantly differ on any health status domains of the Short-Form 36 (SF36), whereas twice as many burn patients reported clinically-significant psychological distress [4]. A consistent pattern of findings across these cross-sectional studies was therefore better recovery in physical functioning and global quality of life whereas ongoing psychosocial difficulties were seen for many burn patients.

Further longitudinal and cross-sectional studies have, however, highlighted sub-samples of burn patients that failed to show similar levels of physical health improvement. A retrospective study interviewing 69 patients on average eight years after burn with more significant burn injury found that 49% of the interviewed sample had current healthcare contact

due to their burn injury [5]. Significantly greater difficulties with simple abilities, work and hand function were reported by patients receiving current healthcare contact. A prospective study in which 162 burn patients were assessed at hospital discharge and at 6 and 12 months after burn, also found that patients with more extensive burns (>30% TBSA) and greater in-hospital psychological distress had more impaired physical recovery [6]. The strength of this study was that pre-burn health status was estimated using the SF36 to enable changes from pre-burn functioning to be assessed over time.

A number of other prospective studies have similarly looked to assess broader clinical factors that can be used to identify burn patients at greater risk for poorer recovery. Less emotional distress and pain, and improved community re-entry were found to contribute significantly to better burn specific QoL scores at two and six months in one study [7]. Furthermore, a multi-centre study found that having received psychological treatment in the year prior to the burn-injury, not being married, more days spent in intensive care and treatment involving amputation were multivariate predictors of poorer life satisfaction at 6 months after burn [8]. More extensive full thickness burns and poorer hand function has also been found to be related to poorer physical health status following massive burn injury (TBSA > 50%) with poorer mental health status found to be related to older age at time of burn and less social support following burn injury [9].

Highlighted within the previous literature is that long-term physical and psychosocial recovery and health-related quality of life (HRQoL) is influenced by an array of pre-injury (e.g. pre-morbid psychological health and age), peri-traumatic (e.g. depth and site of burn and nature of intervention during admission) and after burn (e.g. presence of scars, impaired physical performance) factors. Complicating the assessment of the consistency of the findings, however, is that few have used a prospective design (with the result that patients at different points after burn are included) and few apart from Fauerbach et al. [6] have adjusted for pre-burn functioning or health status. Few studies have also focused on the demographic, injury and treatment-related variables that are available to the hospital treating team to illustrate acute care factors that may impact on longer-term HRQoL.

To address the identified research gaps, the current study had the aim of prospectively assessing which demographic, injury and acute care treatment variables were multivariate predictors of 12-month after burn outcomes to help identify patients with potentially poor HRQoL outcomes who could benefit from early intervention.

## 2. Methods

### 2.1. Setting

The state of Victoria, Australia, has a population of 5.62 million people. Over two thirds of the population (73%) live in the city of Melbourne. The Victorian Adult Burns Service (VABS) is the state-wide adult burns service at The Alfred Hospital, one of two designated major trauma services for adults in the state. The VABS admits approximately 250 patients with acute burns each year.

### 2.2. Ethics

Approval was obtained from the Alfred Health and Monash University Human Research Ethics Committees.

### 2.3. Study design and inclusion criteria

Patients meeting the following criteria were eligible for participation in this prospective cohort study: They include patients who were age  $\geq 18$  years, admitted to VABS between February 2008 and October 2009 and had a burn involving  $>10\%$  TBSA or site specific burns to areas like the face receiving skin grafting or hands and/or feet resulting in potential functional impairment.

A number of patients were excluded, which included those that had insufficient proficiency in English to complete the assessments, readmission due to pre-existing burns or those with complex psychosocial impairment (i.e. any loss or abnormality of psychological or social function) or documented diagnosis of pre-existing psychiatric illness as described by a medical officer in the patient's medical record. In particular, we looked for background information from the patient, collateral information from family or other relevant parties, previous psychological or medical reports, treatment background, activities of daily living review from social or occupational therapy experts or formulation of a DSM-IV diagnosis. It was anticipated that these patients would be difficult to follow-up not only as an outpatient, but also in the context of long-term outcomes research, therefore were excluded.

### 2.4. Patient data collection

A prospective chart review of medical records was also undertaken, in which we gathered the following demographic and clinical variables: age, gender, burn aetiology, %TBSA, percentage partial and full thickness burn, number of surgical procedures, hospital length of stay (LOS), proportion undergoing admission to intensive care unit (ICU) and mechanical ventilation.

### 2.5. Dependent variables

#### 2.5.1. General health measurement tool

The Short Form 36 Medical Outcomes Survey v2 (SF-36v2) is a 36-point item measure of quality of life/health status that includes composite or summary scales reflecting perceived physical and psychosocial health and functioning [11]. Individual responses are used to calculate a score for each of the two-summary

scales: Mental Component Summary (MCS) and the Physical Component Summary (PCS). The subscales incorporated in the PCS are physical functioning, role-physical, bodily pain and general health. The MCS subscales are vitality, social functioning, role-emotional and general mental health. Sub-scale scores are expressed as a percentage from 0 (poorest health status) to 100 (best health status).

#### 2.5.2. Burn specific health scale measurement tool

The Burn Specific Health Scale-Brief (BSHS-B) is the only condition-specific health status instruments to be employed in adult patients with burns. It is a measure consisting of 40 items covering nine well-defined domains (simple abilities, heat sensitivity, hand function, treatment regimens, work, body image, affect, interpersonal relationships and sexuality) [10]. Responses were rated on a 5-point scale from 0 (extremely) to 4 (none/not at all) for each of the 40 items. The total score used for the study analysis consisted of the sum of the item scores. The total score therefore had a range of 0–160, with higher scores indicating better burn-specific quality of life.

#### 2.5.3. Potential predictor variables

Demographic, injury-specific and acute treatment variables collected from time of burn injury as potential predictors of outcome included age, gender, %TBSA including percentage of full-thickness burn per body surface area (FTB) and number of surgical procedures performed. Inclusion of these variables as potential predictors was informed by previous studies exploring factors that influence recovery and functioning following burn injury such as the study undertaken by van Loey et al. [11].

#### 2.5.4. Statistical analysis

Physical and mental component scores of SF-36v2 and total BSHS-B score at 12 months after injury were the main outcome measures. Demographic, burn injury and acute treatment variables were assessed for the extent to which they were univariate and multivariate predictors of each outcome. In conducting the analyses, analysis of covariance (ANCOVA) adjusting for baseline pre-burn scores was used to predict SF-36v2 PCS and MCS. With no pre-burn injury BSHS-B score to adjust for, linear regression was used to predict BSHS-B score at 12 months post-burn injury. Variables with a level of significance defined as  $p < 0.05$  on univariate analyses and those judged to be clinically important were entered into multivariate regression models to identify which clinical factors were independently associated with the outcomes. The results from regression analyses were reported as regression coefficients with 95% confidence intervals (95% CI) and an  $R^2$  statistic to indicate the amount of variation in the outcomes explained by the predictor variables. A two-sided  $p$  value of less than 0.05 was considered to indicate statistical significance. All analyses were performed with the use of SPSS version 20.0 and SAS version 9.2 (SAS Institute, Cary, NC, USA).

## 3. Results

During the study period, of 125 patients who were eligible for the 12-month follow-up, 114 consented to participating in the



**Table 1 – Clinical and demographic characteristics (n = 99).**

Clinical and demographic variables	
Age: mean years (SE)	41.7 (1.7)
Gender: n (%)	
Male	74 (75)
Female	25 (25)
Burn aetiology: n (%)	
Thermal	78 (79)
Scalds	9 (9)
Electrical	7 (7)
Radiant	5 (5)
Hospital length of stay: median (IQR) days	17 (12–27)
Proportion with ICU stay: n (%)	25 (25)
Proportion on a ventilator: n (%)	24 (24)
%TBSA: mean (SE)	19.0 (1.3)
%Full burn thickness: mean (SE)	4.9 (0.7)
%Partial burn thickness: mean (SE)	11.2 (0.9)
Proportion undergoing surgery: n (%)	96 (97)
Number of surgical procedures: median (IQR)	1 (1–2)
Outcomes measures	
Change pre-burn to 12 month after burn	–3.7 (1.4)
SF36-PCS: mean (SE)	
Change pre-burn to 12 month after burn	0.01 (1.2)
SF36-MCS: mean (SE)	
BSHS-B total score at 12mth after burn: mean (SE) (n = 96)	131.1 (2.6)

BSHS-B = burns specific health scale-brief; ICU = intensive care unit; SF36-PCS = short form 36v2 – physical component scale; TBSA = total body surface area.

study. The SF-36v2 was not completed by 15 patients at both times of measurement (before burn and 12 months after burn injury), leaving us with 99 patients for final analysis. A comparison of the patients with or without complete data found no significant differences in age, gender, full thickness burn, and number of surgeries, although a significantly higher TBSA ( $p = 0.01$ ) was observed for patients without complete data.

Demographic and clinical burn injury and hospital admission characteristics are shown in Table 1. The majority of participants were male, had suffered a thermal burn and one quarter of these patients were treated in the ICU. At a group level, SF-36v2 PCS scores were significantly lower at 12 months post-injury (mean = 51.8; SD = 12.6) compared with pre-injury (mean = 55.6; SD = 9.2;  $p = 0.01$ ) scores, whereas there was no difference in SF-36v2 MCS scores between pre-injury (mean = 52.4; SD = 11.7) and 12 months after injury (mean = 52.4; SD = 10.6;  $p = 0.99$ ). Despite the relative reduction from pre-burn level of physical functioning, when compared with the Australian population mean PCS score (50.3) and MCS score (52.9), the mean scores for the current sample at 12 months post-injury were consistent with the Australian population mean score [12].

### 3.1. Univariate predictors of 12 months post-burn SF-36v2 PCS and MCS and BSHS-B scores

Table 2 shows the univariate relationships between each identified demographic, injury-related or acute treatment variable and either SF-36v2 PCS or MCS, adjusted for pre-injury

**Table 2 – Univariate predictors of 12 months post-burn SF-36v2 PCS and MCS scores adjusted for pre-burn PCS or MCS score.**

Variable	Regression coefficient	95% Confidence interval	p value
PCS			
Full thickness burn	–0.71	–1.03 to –0.38	<0.001
Ventilator hours	–0.06	–0.09 to –0.03	<0.001
Length of stay (days)	–0.24	–0.37 to –0.11	0.001
ICU stay (days)	–0.73	–1.17 to –0.28	0.001
Female gender	–9.01	–14.53 to –3.49	0.002
Age	–0.23	–0.38 to –0.09	0.002
%TBSA	–0.26	–0.45 to –0.08	0.006
Number of surgical procedures	–1.82	–3.13 to –0.52	0.006
MCS			
Full thickness burn	–0.32	–0.58 to –0.05	0.019
Female gender	–4.88	–9.31 to –0.44	0.030
Age	–0.15	–0.26 to –0.04	0.010
Length of stay (days)	–0.05	–0.16 to 0.06	0.365
ICU stay (days)	–0.15	–0.51 to 0.20	0.391
%TBSA	–0.05	–0.20 to 0.10	0.504
Number of surgical procedures	–0.62	–1.65 to 0.40	0.227

score. All identified variables were significant predictors of 12 month post-burn PCS scores. Higher physical health status was predicted by lower full thickness burn severity or %TBSA, shorter hospital or ICU length of stay, fewer ventilator hours and surgical procedures, younger age and being male. Only three variables were significant univariate predictors of 12 month post-injury MCS scores, with being male, younger age and having lower full thickness burn severity predictive of higher mental health status.

All identified variables were found to be significant univariate predictors of 12-month post-burn BSHS-B total score (see Table 3). Better burn-specific quality of life was predicted by lower full thickness burn or %TBSA, shorter hospital or ICU length of stay, fewer ventilator hours and surgical procedures, younger age and being male.

### 3.2. Multivariate predictors of 12 months post-burn SF-36v2 PCS and MCS and BSHS-B scores

Prior to conducting multivariate analysis, intercorrelations between predictor variables were calculated as a measure of

**Table 3 – Univariate predictors of 12 months post-burn BSHS-B total score.**

Variable	Regression coefficient	95% Confidence interval	p value
Full thickness burn	–1.22	–1.77 to –0.67	<0.001
Ventilator hours	–0.12	–0.18 to –0.07	<0.001
Length of stay (days)	–0.43	–0.67 to –0.18	0.001
ICU stay (days)	–1.51	–2.37 to –0.66	0.001
Female gender	–12.97	–24.90 to –1.04	0.032
Age	–0.36	–0.67 to –0.05	0.021
%TBSA	–0.58	–0.95 to –0.22	0.002
Number of surgical procedures	–4.30	–6.71 to –1.88	0.001



**Table 4 – Multivariate predictors of 12 months post-burn in SF-36v2 PCS and MCS.**

Variable	Regression coefficient	95% Confidence interval	p value
<b>PCS<sup>a</sup></b>			
Pre-burn PCS	0.12	–0.11 to 0.35	0.305
Age	–0.26	–0.38 to –0.13	<0.001
Female gender	–8.08	–12.83 to –3.34	0.001
%TBSA	–0.09	–0.28 to 0.11	0.360
Full thickness burn	–0.51	–0.88 to –0.13	0.009
Number of surgical procedures	–0.98	–2.26 to 0.29	0.127
<b>MCS<sup>b</sup></b>			
Pre-burn MCS	0.35	0.20 to 0.51	<0.001
Age	–0.15	–0.26 to –0.04	0.006
Female gender	–4.02	–8.29 to 0.25	0.063
%TBSA	0.05	–0.12 to 0.22	0.542
Full thickness burn	–0.36	–0.69 to –0.03	0.033
Number of surgical procedures	–0.28	–1.39 to 0.84	0.620

<sup>a</sup> 12 months post-burn PCS model  $R^2 = 0.401$ .

<sup>b</sup> 12 months post-burn MCS model  $R^2 = 0.342$ .

the potential for multicollinearity to bias regression coefficient estimation. The maximum intercorrelation was  $r = 0.58$  between TBSA and full thickness burn severity, suggesting that multicollinearity was not a problem for the sample. Tables 4 and 5 show the results of the multivariate models fitted to identify independent predictors of SF-36v2 PCS or MCS and BSHS-B total score at 12 months after injury respectively. Younger age and lower full thickness burn severity were important predictors of higher physical and mental health status. Being male was also an important predictor of higher physical health status after adjusting for other factors. Of further interest was that pre-burn PCS scores were not predictive of 12 month PCS scores whereas pre-burn MCS scores did predict 12 month MCS scores. This suggested that patients displaying lower mental health status 12 months post-burn injury were also experiencing lower mental health status prior to their burn injury. Only younger age and being male were important predictors of better BSHS-B total scores 12 months post-injury.

#### 4. Discussion

This study explores the relationship between health status, demographic, injury and treatment factors in a large

Australian sample of moderate to severely injured burns patients. Understanding predictors of physical and psychosocial recovery is crucial given that participant mean SF-36v2 scores were 3.7 points lower 12 months after their injury as compared to their pre-burn scores. While these findings are consistent with outcomes from other studies who have also reported a reduction in physical health status at 12 months [6] and 47 months [13] post-burn, they suggest a variation in physical limitations in most burn patients relative to their pre-injury levels of functioning.

The results of our study identified age, gender and the severity of full-thickness burns as the strongest predictors of SF-36v2 PCS and BSHS-B total scores at 12 months after injury. This is in line with results from other studies who had described similar relationships between age, the presence and localisation of full-thickness burns and their impact on long-term physical and psychosocial health [4,8,12,13].

The issue of age as an independent predictor of increased SF-36v2 scores was noted by Reeves [3] who examined the functional and psychosocial outcomes of older adults after burn injury. Stratified according to various age brackets, all patients showed a decrease in both PCS and MCS components of the SF-36 from pre-injury to discharge, with PCS scores not returning to baseline levels until two years post injury. Similarly, Edgar [14] showed that age negatively influenced the recovery in the SF-36 PCS subscales scores of physical functioning, role physical and MCS subscales of vitality and role emotional. McGill [15] also noted that lower age, along with other clinical variables such as shorter hospitalisation period, correlated with better functional outcomes and higher return to a pre-injury living situation. In line with our findings, this would suggest that it may be beneficial to develop rehabilitation programs tailored to the needs of older patients. Most of what has been written about rehabilitation following a burn injury has involved prolonged and focused intervention at different levels of care. In other non-burn wound injuries, there is often a period of time focused on acute care/surgical treatment followed by a focus on rehabilitation, but the ideal treatment of an individual with a burn, regardless of age, %TBSA, or premorbid psychopathology includes rehabilitation as part of the acute management and long-term rehabilitation coordinated with surgical reconstruction [16]. An article by Richard 2008 [17] discusses the continuum of rehabilitation care of burns, in which he describes an early rehabilitation phase starting at the time of admission to the burn unit and continuing until the patient's wounds are 50% closed or skin grafting has begun. This is a period of time in which rehabilitation has a focus on proper positioning, splinting, range of motion, and mobilisation that aim to prevent long-term complications. The next phase according to the same authorship team is the intermediate phase, which aims for complete wound closure. In this phase, the rehabilitation team is more involved but works closely with the acute care team to promote wound healing while focusing on positioning and functional mobility and preventing contractures. Lastly, Richard [17] points out that the long-term phase is the rehabilitation intensive phase leading up to discharge from the acute care hospital and admission to inpatient rehabilitation or transition to an outpatient rehabilitation program. In this phase the primary focus is on

**Table 5 – Multivariate predictors of 12 months post-burn BSHS-B total score.**

Variable <sup>a</sup>	Regression coefficient	95% Confidence interval	p value
Age	–0.38	–0.66 to –0.11	0.007
Female gender	–12.17	–22.76 to –1.57	0.024
%TBSA	–0.23	–0.65 to 0.20	0.292
Full thickness burn	–0.73	–1.47 to 0.01	0.053
Number of surgical procedures	–2.14	–4.92 to 0.64	0.127

<sup>a</sup> 12 months post-burn BSHS-B total score model  $R^2 = 0.298$ .

maximizing function with therapy intervention or reconstructive surgery.

Similarly, the relationship between gender and SF-36v2 and BSHS-B scores at 12 months was not easily explained. Recent evidence suggests that other study populations (i.e. trauma) also showed that women experienced poorer risk adjusted functional outcomes [18,19]. In particular, Holbrook et al. [19] found as early as hospital discharge, functional outcomes and quality of life were markedly lower in women than in men, although the explanations for the marked gender differences was considered unclear and somewhat puzzling since no factors in their study accounted for the strength of the association. It is possible that the location of the burn injury and the visibility of scarring had more adverse effects on women [20,21], however this was speculative at best. Previous research has found a two-fold increase in the mortality rate of female burn patients aged 30–59 years; however, the authors were unclear as to the potential mechanism for increased risk [22,23]. In a more recent study by Ying et al. [24], which investigated gender differences in quality of life and coping patterns after discharge following a burn injury in China, there was no difference in general quality of life. However, gender differences existed in a series of select BSHS sub domains, which included interpersonal relationships, affect and sexuality. Hence, more research is needed to better understand why female burn patients are at greater risk of poorer outcomes following burn injury.

In contrast to some other studies [11] more objective hospital demographics such as such as length of hospital stay, proportion of patients treated in the ICU and number of surgical procedures did not emerge as important predictors of higher SF-36v2 or BSHS-B scores. After adjusting for demographic and severity of full thickness burn, no additional impact on HRQoL or psychosocial adjustment was detected. It is interesting to explore the discrepancy in results between our study and other findings from the literature. van Loey et al. [11] described that the number of surgical procedures was the best predictor of initial health loss and health status after burn injury using the Euro-QoL-5 Dimensions tool. More precisely, patients who underwent one surgical procedure reached normative levels between three and nine months, whilst patients undergoing two or more procedures needed 18 months after burn injury to approximate normative levels. One possible explanation is that the different measurement tools used account for the differences in results. In addition, our patient sample underwent fewer repeated surgical procedures (i.e. one) which may be reflective of a lesser degree of severity as compared to other sample populations.

It is important to acknowledge the limitations in the present study. Firstly, it may be the case that some of our patients had pre-existing physical or poorly reported or undocumented psychosocial problems which may have led to a greater physical and psychological vulnerability. More so, we did not track the number of participants who were seeking mental health support prior to, or after enrolment in the study. Also related to the generalisability of study findings was that the 15 consenting patients who did not complete the SF36 v2 at pre-burn and 12 months had significantly higher TBSA severity. Secondly, we did not assess coping strategies

which may have helped to determine coping styles over the course of recovery as well as patients' subjective perceptions of their injury. Moreover, there are other factors contributing to HRQoL such as chronic pain, community re-integration, and return to work, which may have the potential to impact on the complex relationship between burns and HRQoL. Our unit attempts to minimise these immediate complications by providing occupational therapy and psychological support services in the outpatient setting, but there is an urgent need for the development of burn-specific multi-disciplinary after-care clinic that moves upon beyond the hospital setting and focuses on the long-term rehabilitation treatment goals with input from a variety of burn, pain, rehabilitation and psychological specialists. Finally, this study was conducted at one particular site only which limits the generalisability of the results.

Despite the limitations, the emergence of increased age and female gender as strong and independent predictors of changes in SF-36v2 PCS and BSHS-B total scores are important in light of intervention-planning. Knowledge about critical demographic factors could be used to assess risk factors to recovery early rather than referring patients on a case by case basis once the problems have become evident. However, further research into other factors impacting on HRQoL may be warranted. In conclusion, the current study found significant reductions in pre-injury physical and psychosocial health status 12 months after the burn injury, with being female, older and experiencing more extensive full thickness burns predictive of poorer outcomes. The results warrant for an early screening and detection of risk factors and the development of targeted interventions

## REFERENCES

- [1] Van Loey NE, Van Son MJ. Psychopathology and psychological problems in patients with burns scars: epidemiology and management. *Am J Clin Dermatol* 2003;4(4):245–72.
- [2] Liang CY, Wang HJ, Yao KP, Pan HH, Wang KY. Predictors of health-care needs in discharged burn patients. *Burns* 2012;38(March (2)):172–9.
- [3] Reeve J, James F, McNeill R, Brown P, Cameron L, Mills S. Functional and psychological outcomes following burn injury: reduced income and hidden emotions are predictors of greater distress. *J Burn Care Res* 2011;32:468–74.
- [4] Altier N, Malenfant A, Forget R, Choinière M. Long-term adjustment in burn victims: a matched-control study. *Psychol Med* 2002;32(May (4)):677–85.
- [5] Wikehult B, Willebrand M, Kildal M, Lannerstam K, Fugl-Meyer AR, Ekselius L, et al. Use of healthcare a long time after severe burn injury; relation to perceived health and personality characteristics. *Disabil Rehabil* 2005;27(August (15)):863–70.
- [6] Fauerbach JA, Lezotte D, Hills RA, Cromes GF, Kowalske K, de Lateur BJ, et al. Burden of burn: a norm-based inquiry into the influence of burn size and distress on recovery of physical and psychosocial function. *J Burn Care Rehabil* 2005;26(January–February (1)):21–32.
- [7] Cromes GF, Holavanahalli R, Kowalske K, Helm P. Predictors of quality of life as measured by the Burn Specific Health Scale in persons with major burn injury. *J Burn Care Rehabil* 2002;23:229–34.

- [8] Patterson DR, Pracek JT, Cromes F, Fauerbach JA, Engrav L. The 2000 Clinical Research Award. Describing and predicting distress and satisfaction with life for burn survivors. *J Burn Care Rehabil* 2000; 21:490–8.
- [9] Anzarut A, Chen M, Shankowsky H, Tredget EE. Quality-of-life and outcome predictors following massive burn injury. *Plast Reconstr Surg* 2005;116(3):791–7.
- [10] Kildal M, Andersson G, Fugl-Meyer AR, Lannerstam K, Gerdin B. Development of a brief version of the Burn Specific Health Scale (BSHS-B). *J Trauma* 2001;51(October (4)):740–6.
- [11] van Loey NE, van Beeck EF, Faber BW, van de Schoot R, Bremer M. Health-related quality of life after burns: a prospective multicentre cohort study with 18 months follow-up. *J Trauma Acute Care Surg* 2012;72(February (2)):513–20.
- [12] Hawthorne G, Osborne RH, Taylor A, Sansoni J. The SF36 Version 2: critical analyses of population weights, scoring algorithms and population norms. *Qual Life Res* 2007;16(May (4)):661–73. Epub 2007 February 1.
- [13] Moi AL, Wentzel-Larsen T, Salemark L, Wahl AK, Hanestad BR. Impaired generic health status but perception of good quality of life in survivors of burn injury. *J Trauma* 2006;61(October (4)):961–8.
- [14] Edgar DW, Homer L, Phillips M, Gurfinkel R, Rea S, Wood FM. The influence of advancing age on quality of life and rate of recovery after treatment for burn. *Burns* 2013;39(September (6)):1067–72.
- [15] McGill V, Kowal-Vern A, Gamelli RL. Outcomes for older burns patients. *Arch Surg* 2000;135(March (3)):320–5.
- [16] Sliwa JA, Heinemann A, Semik P. Inpatient rehabilitation following burn injury: patient demographics and functional outcomes. *Arch Phys Med Rehabil* 2005;86(October (10)):1920–3.
- [17] Richard R, Baryza MJ, Carr JA, Dewey WS, Dougherty ME, Forbes-Duchart L, et al. Burn rehabilitation and research: proceedings of a consensus summit. *J Burn Care Res* 2009;30(July–August (4)):543–73.
- [18] Gabbe BJ, Simpson PM, Sutherland AM, Wolfe R, Fitzgerald MC, Judson R, et al. Improved functional outcomes for major trauma patients in a regionalized, inclusive trauma system. *Ann Surg* 2012;255(June (6)):1009–15.
- [19] Holbrook T, Hoyt D, Anderson J. The importance of gender on outcomes after major trauma: functional and psychologic outcomes in women versus men. *J Trauma* 2001;50:270–3.
- [20] Kleve L, Robinson E. A survey of psychological need amongst adult burn-injured patients. *Burns* 1999;25(November (7)):575–9.
- [21] Thombs BD, Notes LD, Lawrence JW, Magyar-Russell G, Bresnick MG, Fauerbach JA. From survival to socialization: a longitudinal study of body image in survivors of severe burn injury. *J Psychosom Res* 2008;64(February 2):205–12.
- [22] Kerby JDMG, George RL, Cross JA, Chaudry AH, Rue LW. Sex differences in mortality after burn injury: results of analysis of the National Burn Repository of the American Burn Association. *J Burn Care Res* 2006;27:452–6.
- [23] O'Keefe GEHJ, Purdue GF. An evaluation of risk factors for mortality after burn trauma and the identification of gender-dependent differences in outcomes. *J Am Coll Surg* 2001;192:153–60.
- [24] Ying WL, Petrini MA, Liao LX. Gender differences in the quality of life and coping patterns after discharge in patients recovering from burns in China. *J Res Nurs* 2013;18(May (3)):247–62.

### **7.3 Summary of findings**

This study described the association between demographic, injury and treatment factors and SF-36 v.2 and the BSHS-B scores 12 months following severe burn injury. The study showed that age, gender, and the presence and severity of full-thickness burns were the strongest predictors of SF-36 v.2 and BSHS-B scores. In contrast to overseas studies, clinical demographics such as hospital length of stay, proportion of patients treated in ICU and number of surgical procedures were not important predictors of these outcomes.

### **7.4 Chapter summary**

The emergence of risk factors and independent predictors of changes in SF-36 v.2, PCS and BSHS-B total scores are important to help tailor burn care rehabilitation planning and delivery of services. Knowledge about critical demographic factors could be used to assess risk factors for poorer recovery early rather than referring patients on a case-by-case basis once the problems have become evident. However, further research into other factors impacting on generic and burn-specific factors (i.e. return to work rates level of support from families and friends etc.) is required. The results warrant for an early screening and detection of risk factors at the beginning of hospital admission and the delivery of patient-focused rehabilitative interventions.

## Chapter 8: Conclusion

The research conducted in this thesis aimed to improve understanding of the physical and psychosocial health outcomes following a moderate to severe burn injury. The burden of burn injury was assessed using data from statewide and hospital administrative datasets, and prospective, longitudinal study of patient outcomes. Recognising that there was limited local and national data, the research reduced evidence gaps by describing the incidence of burn injury over time in a defined population, and reporting on the impact of injury on generic and burn-specific HRQoL outcomes.

### 8.1 Key findings in relation to the aims of the thesis

*Aim number one: Determine the epidemiology, trends and outcomes associated with burn injury in the state of Victoria, Australia.*

The published paper in *Chapter 2* examined patient demographic and injury-specific patterns, rates and trends in patients with burn injury using accumulated data from multiple statewide and hospital administrative datasets in Victoria, Australia. During the study period, there were 178 fatal burns and 36,430 patients who received treatment for non-fatal burns, of whom 21% were admitted to hospitals. Children below the age of 5 years and the elderly of 65 years and over had the highest incidence rates of burn injury. Almost 65% of hospital admissions were for treatment of burns caused by contact with hot objects and fluids. Although we did not report on any significant changes over time, the importance of these findings showcased how successful routine monitoring of a unique burn dataset can map the burden of burn injury.

*Aim number two: Evaluate patient-reported outcome measures used to measure the long-term consequences of burn-related injuries, in regards to their suitability for burn populations, using the international classification of functioning, disability and health (ICF).*

The published paper in *Chapter 3* used the Cochrane systematic review methodology to provide an overview of the concepts contained in outcome measures that were

frequently used to assess the progress of recovery following a burn injury, by using the ICF as a framework. A total of 132 papers reporting on 151 outcome instruments were included in the review after screening more than 10,000 abstract citations. Of the 151 outcome measures, the items of the 14 most commonly used outcome instruments were then mapped to the ICF domains. Whilst these high mapping rates were encouraging, our paper could not establish from the instruments available a single measure that covered all concepts of the ICF. It was proposed that a combination of instruments be identified to measure the impact of burn injury and health, whilst also covering the core set of functions considered important through the ICF. Subsequently, the findings were then used to inform the choice of outcome measures used in the main cohort study of this thesis.

***Aim number three: Quantify the 12-month general and burn-specific HRQoL in generalised hospitalised burns patients presenting to a burns unit.***

The published papers in *Chapter 5* and *Chapter 6* used the proposed cohort methodology (see *Chapter 4*) that was specifically designed to provide a comprehensive picture of the general and burn-specific health outcomes of patients with moderate to severe burn injury presenting to a statewide burns service. As outlined in *Chapter 1* of this thesis, the use of a specific research methodology would quantify the 12-month general and burn-specific health status in generalised hospitalised burns patients, along with a subset of patients injured following the 2009 ‘Black Saturday’ bushfires. Both publications revealed that patients were experiencing significant reductions in overall generic and burn health, and those patients affected by the 2009 ‘Black Saturday’ bushfires were still feeling heightened levels of psychological distress and pain. It was proposed that the need for early and ongoing identification of physical and psychosocial impairments during hospital admission and upon discharge would be helpful in the development of long-term rehabilitation after moderate to severe burn injury.

***Aim number four: Identify potential key variables (e.g. demographic, injury and clinical factors) that will facilitate the identification of individuals at risk of developing chronic poor outcomes post burn injury.***

The published paper in *Chapter 7* was the last in a suite of three papers from the

prospective cohort study that focused on identifying specific patient demographic or burn-specific characteristics that could predict generic and burn-specific health 12 months after injury. The results showed that SF-36 v.2 and BSHS-B scores were affected by age and gender. These results also suggest that knowledge about critical demographic factors should be used to assess risk factors to early recovery rather than referring patients on a case-by-case basis once the problem has become clinically evident.

## **8.2 Limitations**

The specific limitations associated with each individual study have been outlined in the relevant chapters. This section focuses on the general limitations of this thesis.

Firstly, the generic and disease-specific outcome measures were administered at arbitrary time points post-burn injury because of the restrictions placed around the PhD candidature. Restricting data collection to 3, 6 and 12-months post-injury may not have reflected the dynamic changes seen in a patient's physical and psychosocial parameters. Given the natural fluctuations in health over time, the 12-month mark may not have reflected the final stage of burns recovery. Further research, encompassing a longer time frame to investigate may be helpful.

Secondly, we were limited by a relatively small sample size ( $n=114$ ) because of the small number of patients presenting with moderate to severe burn injury to VABS in any given year. The potential to increase overall study numbers could be possible by pooling data from multiple burn unit sites around Australia. However, the heterogeneous burn population (i.e. considerable variations in age, mechanism of injury, depth and size of burn) along with significant difference seen in the delivery of acute burn care practices, the outcomes for this cohort may not have necessarily reflected the outcomes for patients treated at other burn care facilities.

Thirdly, we did not capture pre-existing physical or poorly reported or undocumented psychosocial problems that may have led to a greater physical and psychological vulnerability. Due to time and financial constraints, we did not track the number of participants who were seeking mental health support prior to, or after enrolment into the

cohort study. In addition we did not assess coping strategies that may have helped to determine coping styles over the course of recovery as well as patients' subjective perceptions of their injury. Moreover, there were many other noted factors contributing to overall general health and well-being such as chronic pain, community re-integration, and return to work, which may have had some potential to impact on the complex relationship that existed between burn injury and quality of life.

### **8.3 Recommendations**

Monitoring the incidence of burn injuries and their long-term consequences is an important public health care issue, the findings within this thesis suggesting patients still report levels of physical functioning that are significantly below their pre-injury level of functioning. Reliable incidence and outcome information, including generic health and burn-specific HRQoL outcomes is needed to identify priority areas for injury prevention, to measure the effectiveness of injury prevention and treatment strategies during hospital admission and post-hospital discharge. Therefore, the following recommendations are put forward:

Firstly, although it is important to consider the ongoing use of various datasets to report on the incidence of burn injury, patient demographics, and burn injury characteristics, equal consideration should be placed on collecting generalised and burn-specific health outcome data post-hospital discharge. These additional data points could not only map the long-term efficacy of acute burn care treatments, but also describe the patterns of recovery and quality of survival in this patient population.

Secondly, there is a need to develop consensus with routine data collection points to help burn experts with achieving clinical agreement when measuring the impact of injury on physical and psychosocial outcomes. Using established tools that share a common language could help mitigate clinician concerns with 'what to measure' and 'how to measure it' in those with burn injury.

Thirdly, data now illustrates the crucial importance and relevance of identifying risk factors for burn injury along with routine patient physical and psychological assessments, to burn clinicians who can provide expert care following hospital discharge. The delivery of appropriate services could be closely monitored in a goal-



directed, patient-centered after-care clinic and be linked to a burns unit. In this way, the long-term efficacy of acute burn care treatments could be determined, whilst the negative long-term impact on psychosocial and physical health could be reduced.

#### **8.4 Conclusions**

Significant advances in the delivery of burn care treatments over the last few decades have shown that patients may experience an array of diverse health outcomes extending from the very poor to the fully recovered. Reporting on health and burn-specific HRQoL outcomes has largely been done using statewide and hospital datasets along with direct patient contact. The findings contained in this thesis have improved our understanding of the trends and burden of moderate to severe burn injuries in terms of long-term outcomes, in particular, general and burn-specific health outcomes, in a series of 114 patients presenting to a burns centre.

## References

1. Pruitt BA Jr. Reflection: evolution of the field over seven decades. *Surg Clin North Am.* 2014; 94(4): 721-40.
2. Peck MD. Epidemiology of burns throughout the world: Part 1: distribution and risk factors *Burns.* 2011; 37(3): 1087-1100.
3. Atiyeh BS, Costagliola M, Hayek SN. Burn prevention mechanisms and outcomes: pitfalls, failures and successes. *Burns.* 2009; 35(2): 181-93.
4. Herndon D (ed.). "Chapter 3: Epidemiological, Demographic, and Outcome Characteristics of Burn Injury" and "Chapter 47: Comprehensive rehabilitation of the burn patient". *Total burn care* (4th ed.). 2012 Edinburgh: Saunders.
5. Rice PL, Orgil DP. Classification of burns In: UpToDate, Post TW (Ed), UpToDate, Waltham, MA. (Accessed on November 6th 2015)
6. Hettiaratchy S, Papini R. ABC of burns Initial management of a major burn: II—assessment and resuscitation. *BMJ.* 2004; 329: 101.
7. Klein MB, Gorman J, Hayden DL, Fagan SP, McDonald-Smith GP, Alexander AK, et al. Benchmarking outcomes in the critically injured burn patient. *Ann Surg.* 2014 May; 259(5): 833-41.
8. Forjuoh SN. Burns in low- and middle-income countries: a review of available literature on descriptive epidemiology, risk factors, treatment, and prevention. *Burns.* 2006; 32(5): 529-37.
9. Peck M. Epidemiology of burn injuries globally In: UpToDate, Post TW (Ed), UpToDate, Waltham, MA. (Accessed on November 6th 2015)
10. Stylianou N, Buchan I, Dunn K. A review of the international Burn Injury Database (iBID) for England and Wales: descriptive analyses of burn injuries 2003–2011 *BMJ Open* 2015 5:e006184
11. IHW, Begg S, Vos T, Barker B, Stevenson C, Stanley L & Lopez A 2007 The burden of disease and injury in Australia 2003. Cat. no. PHE 82. Canberra: AIHW.
12. Harrison J & Steel D 2006 Burns and scalds National Injury Surveillance Unit

- (NISU) briefing no. 7 Cat. no. INJ 92. Canberra: AIHW.
13. Wolf SE, Tompkins RG, Herndon DN. On the horizon: research priorities in burns for the next decade. *Surg Clin North Am.* 2014 Aug; 94(4): 917-30.
  14. Gabbe, B. J., Cleland, H. J. and Cameron, P. A. Profile, transport and outcomes of severe burns patients within an inclusive, regionalized trauma system. *ANZ Journal of Surgery.* 2011; 81: 725–730.
  15. Van Loey NE, Van Son MJ. Psychopathology and psychological problems in patients with burn scars: epidemiology and management. *Am J Clin Dermatol* 2003; 4: 245–72.
  16. WHO. ICF-International Classification of Functioning, Disability and Health. Geneva: WHO Library; 2001.
  17. Falder S, Browne A, Edgar D, Staples E, Fong J, Rea S, et al. Core outcomes for adult burn survivors: a clinical overview. *Burns.* 2009; 35(5): 618–41.
  18. Yoder LH, Nayback AM, Gaylord K. The evolution and utility of the burn specific health scale: a systematic review. *Burns.* 2010; 36(8): 1143–56.
  19. Ware Jr JE, Kosinski M, Bjorner JB, Turner-Bowker DM, Gandek B, Maruish ME. *User's manual for the SF-36v2TM health survey.* 2nd ed. Lincoln, RI: Quality Metric Incorporated; 2007.
  20. Willebrand M, Kildal M. Burn Specific Health up to 24 months after the Burn-A prospective validation of the simplified model of the Burn Specific Health Scale-Brief. *J Trauma.* 2011; 71(1): 78-84.
  21. Liang CY, Wang HJ, Yao KP, Pan HH, Wang KY. Predictors of health-care needs in discharged burn patients. *Burns.* 2012; 38(2): 172-9.
  22. Reeve J, James F, McNeill R, Brown P, Cameron L, Mills S. Functional and psychological outcomes following burn injury: reduced income and hidden emotions are predictors of greater distress. *J Burn Care Res.* 2011; 32: 468-74.
  23. Altier N, Malenfant A, Forget R, Choiniere M. Long-term adjustment in burn victims: a matched-control study. *Psychol Med.* 2002; 32(4): 677-85.
  24. Anzarut A, Chen M, Shankowsky H, Tredget EE. Quality-of-life and outcome predictors following massive burn injury. *Plast Reconstr Surg.* 2005; 116(3):

- 791-7.
25. Cromes GF, Holavanahalli R, Kowalske K, Helm P. Predictors of quality of life as measured by the Burn Specific Health Scale in persons with major burn injury. *J Burn Care Rehabil.* 2002; 23(3): 229-34.
  26. McGill V, Kowal-Vern A, Gamelli RL. Outcomes for older burns patients. *Arch Surg.* 2000; 135(3): 320-5.
  27. van Loey NE, van Beeck EF, Faber BW, van de Schoot R, Bremer M. Health-related quality of life after burns: a prospective multicentre cohort study with 18 months follow-up. *J Trauma Acute Care Surg.* 2012; 72(2): 513-20.
  28. Health Data Acquisition Unit. VAED Manual 20th Edition 2010-11 Melbourne: Victorian State Government; 2011 [updated 2011 7 September 2011; cited November 2011]; <http://www.health.vic.gov.au/hdss/vaed/vaed-manual.htm>
  29. Duke J, Wood F, Semmens J, Spilsbury K, Edgar DW, Hendrie D, Rea S. A 26-year population-based study of burn injury hospital admissions in Western Australia. *J Burn Care Res.* 2011; 32(3): 379-86.
  30. Duke J, Wood F, Semmens J, Edgar DW, Spilsbury K, Hendrie D, Rea SA study of burn hospitalizations for children younger than 5 years of age: 1983-2008. *Pediatrics.* 2011; 127(4): e971-7.
  31. Duke J, Wood F, Semmens J, Edgar DW, Spilsbury K, Rea S. An assessment of burn injury hospitalisations of adolescents and young adults in Western Australia, 1983-2008. *Burns.* 2012; 38(1): 128-35.
  32. Duke J, Rea S, Semmens J, Wood F. Urban compared with rural and remote burn hospitalisations in Western Australia. *Burns.* 2012 Jun; 38(4): 591-8.
  33. Duke J, Rea S, Semmens J, Edgar DW, Wood F. Burn and cancer risk: a statewide longitudinal analysis. *Burns.* 2012; 38(3): 340-7.
  34. Duke J, Wood F, Semmens J, Edgar DW, Rea S. Trends in hospital admissions for sunburn in Western Australia, 1988 to 2008. *Asia Pac J Public Health.* 2013; 25(1): 102-9
  35. Grisbrook TL, Stearne SM, Reid SL, Wood FM, Rea SM, Elliott CM. Demonstration of the use of the ICF framework in detailing complex functional

- deficits after major burn. *Burns*. 2012; 38(1): 32-43.
36. Meirte J, van Loey NE, Maertens K, Moortgat P, Hubens G, Van Daele U. Classification of quality of life subscales within the ICF framework in burn research: identifying overlaps and gaps. *Burns*. 2014; 40(7): 1353-9.
  37. Wasiak J, McMahon M, Danilla S, Spinks A, Cleland H, Gabbe B. Measuring common burn outcome measures and their concepts using the International Classification of Functioning, Disability and Health (ICF): a systematic review. *Burns*. 2011; 37(6): 913-24.
  38. Hawthorne G, Osborne RH, Taylor A, Sansoni J. The SF36 Version 2: critical analyses of population weights, scoring algorithms and population norms. *Qual Life Res*. 2007; 16(4): 661-73.
  39. Edgar D, Dawson A, Hankey G, Phillips M, Wood F. Demonstration of the validity of the SF-36 for measurement of the temporal recovery of quality of life outcomes in burns survivors. *Burns*. 2010; 36(7): 1013-20.
  40. Moi AL, Wentzel-Larsen T, Salemark L, Wahl AK, Hanestad BR. Impaired generic health status but perception of good quality of life in survivors of burn injury. *J Trauma*. 2006; 61(4): 961-8.
  41. Xie B, Xiao SC, Zhu SH, Xia ZF. Evaluation of long-term health-related quality of life in extensive burns: a 12-year experience in a burn center. *Burns*. 2012; 38(3): 348-55.
  42. Kildal M, Andersson G, Fugl-Meyer AR, Lannerstam K, Gerdin B. Development of a brief version of the Burn Specific Health Scale (BSHS-B). *J Trauma*. 2001; 51(4): 740-6.
  43. Willebrand M, Kildal M. A simplified domain structure of the burn-specific health scale-brief (BSHS-B): a tool to improve its value in routine clinical work. *J Trauma*. 2008; 64 (6): 1581-6.
  44. Andrews G, Slade T. Interpreting scores on the Kessler Psychological Distress Scale (K10). *Australian and New Zealand Journal of Public Health*. 2001; 25(6): 494-7.

45. Mahar, P, Wasiak J, O'Loughlin CJ, Christelis N, Arnold C, Spinks A, Danilla S. Frequency and use of pain assessment tools implemented in randomised controlled trials in the adult burns population. *Burns*. 2012; 38(2): 47-54.
46. Hawker GA, Mian S, Kendzerska T, French M. Measures of adult pain: Visual Analog Scale for Pain (VAS Pain), Numeric Rating Scale for Pain (NRS Pain), McGill Pain Questionnaire (MPQ), Short-Form McGill Pain Questionnaire (SF-MPQ), Chronic Pain Grade Scale (CPGS), Short Form-36 Bodily Pain Scale (SF-36 BPS), and Measure of Intermittent and Constant Osteoarthritis Pain (ICOAP). *Arthritis Care Res (Hoboken)*. 2011; 63(S11): S240-52.
47. Babor T, Higgins-Biddle JC, Saunders J, Monteiro MG: AUDIT. *The Alcohol Use Disorders Identification Test World Health Organization: Geneva*. 2001.
48. Cleland HJ, Proud D, Spinks S and Wasiak J. Multidisciplinary team response to a mass burn casualty event: outcomes and implications. *Med J Aust*. 2011; 194 (11): 589-593.
49. Pfitzer B, Katona LJ, Lee SJ, O'Donnell M, Cleland H, Wasiak J, Ellen S. Three Years After Black Saturday: Long-Term Psychosocial Adjustment of Burns Patients As a Result of a Major Bushfire. *J Burn Care Res*. 2014 Dec 10. [Epub ahead of print].
50. Bryant RA, Waters E, Gibbs L, Gallagher HC, Pattison P, Lusher D et al. Psychological outcomes following the Victorian Black Saturday bushfires. *Aust N Z J Psychiatry* 2014 Jul; 48(7): 634-43

## Appendices

### Appendix 1: Ethics Approvals



#### **ETHICS COMMITTEE CERTIFICATE OF APPROVAL EXTENSION**

*This is to certify that*

**Project No:** 8/05

**Project Title** The physical and psychosocial outcomes following burn injury: A 12 month follow-up study.

**Principal Researcher:** Dr Heather Cleland

*has been given an extension of approval by the Ethics Committee from*

**Approval date:** 31-Mar-2007 **Expiry date:** 31-Mar-2009

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It is the Principal Researcher's responsibility to ensure that all researchers associated with this project are aware of the conditions of approval and which documents have been approved.

***The Principal Researcher is required to notify the Secretary of the Ethics Committee, via amendment or progress report, of***

- Any significant change to the project and the reason for that change, including an indication of ethical implications (if any);
- Serious adverse effects on participants and the action taken to address those effects;
- Any other unforeseen events or unexpected developments that merit notification;
- The inability of the Principal Researcher to continue in that role, or any other change in research personnel involved in the project;
- Any expiry of the insurance coverage provided with respect to sponsored clinical trials and proof of re-insurance;
- A delay of more than 12 months in the commencement of the project; and,
- Termination or closure of the project.

***Additionally, the Principal Researcher is required to submit***

- A Progress Report every 12 months for the duration of the project (*forms to be provided*);
- A Request for Extension of the project prior to the expiry date, if applicable; and,
- A detailed Final Report at the conclusion of the project.

The Ethics Committee may conduct an audit at any time.

All research subject to the Alfred Hospital Ethics Committee review must be conducted in accordance with the National Statement on Ethical Conduct in Research Involving Humans (1999).

The Alfred Hospital Ethics Committee is a properly constituted Human Research Ethics Committee in accordance with the National Statement on Ethical Conduct in Research Involving Humans (1999).

#### **SPECIAL CONDITIONS**

*None*

**SIGNED:** \_\_\_\_\_

*Chair, Ethics Committee (or delegate)*

***Please quote Project No and Title in all correspondence***

## Appendix 2: Participant information and consent form

### **PARTICIPANT INFORMATION AND CONSENT FORM:**

#### **THE BURNS OUTCOME STUDY**

**Version 2: Dated 2nd January 2008**

**Site: The Alfred Hospital**

#### **Full Project Title:**

Full Project Title: The physical and psychosocial outcomes following burn injury: A 12 month follow-up study

Principal Researcher: Dr Heather Cleland

Associate Researcher(s): Mr Jason Wasiak, Dr Belinda Gabbe

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This Participant Information and Consent Form are 5 pages long. Please make sure you have all the pages.

#### **1. Your Consent**

You are invited to take part in this research project.

This Participant Information contains detailed information about the research project. Its purpose is to explain to you as openly and clearly as possible all the procedures involved in this project before you decide whether or not to take part in it.

Please read this Participant Information carefully. Feel free to ask questions about any information in the document. You may also wish to discuss the project with a relative or friend or your local health worker. Feel free to do this.

Once you understand what the project is about and if you agree to take part in it, you will be asked to sign the Consent Form. By signing the Consent Form, you indicate that you understand the information and that you give your consent to participate in the research project.

You will be given a copy of the Participant Information and Consent Form to keep as a record.

#### **2. Purpose and Background**

Patients who are burnt by accidents may have a number of factors which complicate treatment and delay rehabilitation. These are either pre-existing, or may even develop during time spent in hospital. They include psychological problems such as anxiety and depression, drug dependence, or chronic pain. At present, the nature of these problems and the way they impact on daily life are poorly documented.

Treatment for burns is often poorly co-ordinated between the local GP clinic and treating hospital. General practitioners may be ill-equipped to deal with these complex patients, and doctors in the treating hospital may not be aware of these challenges until they are discharged from hospital.

The aim of the project is to look at the physical and psychological aspects of patients who have been burnt as a result of an accident for up to 2 years. With this follow up, we hope to identify factors associated with hospital readmission and delayed rehabilitation.



Follow up will involve being asked to fill in a number of simple questionnaires. More so, a number of physical tests such as measuring weight and arm movements will be recorded. It is hoped that the information gained from these simple tests will enable hospital programs to be developed to improve the delivery of care. It is also hoped that organising this type of care will help with decreasing hospital re-admissions, improve the chances of returning to work and/or school, and improve the rehabilitation process.

A total of 120 people will participate in this project.

You are invited to participate in this research project because all burns patients with complex physical and psychological needs requiring health advice and support potentially may be at risk of an unplanned readmission or struggle with the rehabilitation process.

This trial has been initiated by the investigator, Dr Heather Cleland, Director of the Victorian Adult Burns Service Unit, The Alfred Hospital.

### **3. Procedures**

Participation in this project will require you to fill in a number of simple questionnaires and undergo a number of pain-free physical tests at one month, three, six, and twelve months.

The simple questionnaires in which you fill in yourself are expected to take up to 45 minutes. They include:

*Psychological interviews* – up to 5 questionnaires in which you fill in yourself will examine specific burn injury matters such as body image (Burn Specific Health Scale), depression and anxiety (Kessler 10 Scale) quality of life (Short-Form 36 Quality of Life Scale, levels of pain (the McGill Pain Questionnaire), and alcohol consumption (Australian AUDIT Questionnaire).

The four interviews at three, six, and twelve months will take up to 45 minutes and will be conducted face-to-face at an out-patients clinic appointment you have with your doctor. None of the tests requires a psychologist because they are very simple, and if necessary can be conducted the day prior to review at the out-patients clinic by telephone. An additional survey of open-ended items questions will be asked that detail work or study habits and perception of your health before and after the injury. More so, access to current and anticipated health care services will also be recorded.

### **5. Possible Benefits**

It is anticipated that the information and understanding gained will enable hospital programs to be developed to improve the delivery of care to all burn patients and improve the relationship and partnership between hospital and community based doctors and nurses. Improving the services will help decrease hospital re-admission rates, reduce the possible feelings of isolation you may experience from family and friends, encourage the return to work and/or school, and increase your physical functioning and overall, improve the rehabilitation process.

### **6. Possible Risks**

The recall of your injury and thoughts, feelings and emotions surrounding the event and subsequent recovery may arouse adverse emotional feelings. If your reaction of is severe the interview will be terminated immediately. Following all interviews, we will ask you if they felt upset at any point in the interview process and if you like, follow this up with the principle researcher or the hospitals social work department. Permission will be sought from the social work department to deal with any potential contingencies should they arise.

## **7. Other Treatments Whilst on Study**

It is important to tell your doctor and the research staff about any treatments or medications you may be taking, including non-prescription medications, vitamins or herbal remedies and any changes to these during your participation in the study.

## **8. Alternatives to Participation**

All therapeutic interventions will be provided regardless of you consenting to this study or not.

## **9. Privacy, Confidentiality and Disclosure of Information**

Any information obtained in connection with this research project that can identify you will remain confidential and will only be used for the purpose of this research project. It will only be disclosed with your permission, except as required by law. If you give us your permission by signing the Consent Form, we plan to publish the results de-identifying your personal details.

## **10. New Information Arising During the Project**

During the research project, new information about the risks and benefits of the project may become known to the researchers. If this occurs, you will be told about this new information. This new information may mean that you can no longer participate in this research. If this occurs, the person(s) supervising the research will stop your participation. In all cases, you will be offered all available care to suit your needs and medical condition.

## **11. Results of Project**

It is expected that an English summary of the burns outcome study will be freely available using a wide variety of educational materials (i.e. pamphlets or brochures, CD-ROM, stickers, teaching sessions, lecture materials, posters, internet). More so, community support centres involved in improving the burns rehabilitation process will serve as the meeting point between the clinician and patient.

## **12. Further Information or Any Problems**

If you require further information or if you have any problems concerning this project (for example, any side effects), you can contact the principal researcher. The researchers responsible for this project are:

Dr Heather Cleland, MB BS FRACS, Director, Burns Unit, The Alfred Hospital Commercial Rd Melbourne 3004. [REDACTED]

Mr. Jason Wasiak, MPH, Research Officer Burns Unit, The Alfred Hospital Commercial Rd Melbourne 3004. [REDACTED]

Dr Belinda Gabbe, PhD, Research Fellow, Department of Epidemiology and Preventative Medicine, The Alfred Hospital Commercial Rd Melbourne 3004. [REDACTED] [REDACTED] [REDACTED] [REDACTED]  
[REDACTED]

## **13. Other Issues**

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about your rights as a research participant, then you may contact

Name: Rowan Frew

Position: Ethics Manager  
[REDACTED]

You will need to tell Rowan Frew the name of one of the researchers given in section 12 above.

#### **14. Participation is Voluntary**

Participation in any research project is voluntary. If you do not wish to take part you are not obliged to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage.

Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect your routine treatment, your relationship with those treating you or your relationship with The Alfred Hospital.

Before you make your decision, a member of the research team will be available so that you can ask any questions you have about the research project. You can ask for any information you want. Sign the Consent Form only after you have had a chance to ask your questions and have received satisfactory answers.

If you decide to withdraw from this project, please notify a member of the research team before you withdraw. This notice will allow that person or the research supervisor to inform you if there are any health risks or special requirements linked to withdrawing.

#### **15. Reimbursement for your costs**

You will not be paid for your participation in this trial. However, you will be reimbursed for any of the following costs that you incur as a result of participating in this trial.

#### **16. Ethical Guidelines**

This project will be carried out according to the *National Statement on Ethical Conduct in Research Involving Humans* (March 2007) produced by the National Health and Medical Research Council of Australia. This statement has been developed to protect the interests of people who agree to participate in human research studies.

The ethical aspects of this research project have been approved by the Human Research Ethics Committee of The Alfred Hospital.

## CONSENT FORM

THE ALFRED HOSPITAL
---------------------

**Version**                      **2:**                      **Dated**                      **2<sup>nd</sup>**                      **January**                      **2008**  
**Site: The Alfred Hospital**

Full Project Title: The physical and psychosocial outcomes following burn injury: A 12 month follow-up study

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I have read, or have had read to me in my first language and I understand the Participant Information version 2 dated 2<sup>nd</sup> January 2008.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to participate in this project according to the conditions in the Participant Information.

I will be given a copy of the Participant Information and Consent Form to keep.

I understand that the researcher has agreed not to reveal my identity and personal details if information about this project is published or presented in any public form.

Participant's Name (printed) .....

Signature \_\_\_\_\_ Date \_\_\_\_\_

Name of Witness to Participant's Signature (printed) .....

Signature \_\_\_\_\_ Date \_\_\_\_\_

Declaration by researcher\*: I have given a verbal explanation of the research project, its procedures and risks and I believe that the participant has understood that explanation.

Researcher's Name (printed) .....

Signature \_\_\_\_\_ Date \_\_\_\_\_

\* A senior member of the research team must provide the explanation and provision of information concerning the research project.

*Note:* All parties signing the Consent Form must date their own signature.

## REVOCATION OF CONSENT FORM

*(To be used for participants who wish to withdraw from the project.)*

**(Attach to Participant Information)**

On Institution's Letterhead
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### Revocation of Consent Form

Full Project Title: The physical and psychosocial outcomes following burn injury: A 12 month follow-up study

**I hereby wish to WITHDRAW my consent to participate in the research proposal named above and understand that such withdrawal WILL NOT jeopardise any treatment or my relationship with *Name of Institution*.**

Participant's Name (printed) .....

Signature

Date

## Appendix 3: Outcome measures

### Appendix 3.1: Form 36 Medical Outcomes Survey v.2 (SF-36 v.2)



MONASH University



# Your Health and Well-Being

This questionnaire asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities. *Thank you for completing this survey!*

For each of the following questions, please mark an ☐ in the one box that best describes your answer.

1. In general, would you say your health is:

Excellent	Very good	Good	Fair	Poor
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
1	2	3	4	5

2. Compared to one week ago, how would you rate your health in general now?

Much better now than one week ago	Somewhat better now than one week ago	About the same as one week ago	Somewhat worse now than one week ago	Much worse now than one week ago
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
1	2	3	4	5

3. The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

	Yes, limited a lot ▼	Yes, limited a little ▼	No, not limited at all ▼
a <u>Vigorous activities</u> , such as running, lifting heavy objects, participating in strenuous sports .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
b <u>Moderate activities</u> , such as moving a table, pushing a vacuum cleaner, bowling, or playing golf.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
c Lifting or carrying groceries .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
d Climbing <u>several</u> flights of stairs .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
e Climbing <u>one</u> flight of stairs .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
f Bending, kneeling, or stooping .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
g Walking <u>more than a kilometre</u> .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
h Walking <u>several hundred metres</u> .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
i Walking <u>one hundred metres</u> .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
j Bathing or dressing yourself .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3

4. During the past week, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a Cut down on the <u>amount of time</u> you spent on work or other activities.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
b <u>Accomplished less</u> than you would like .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
c Were limited in the <u>kind</u> of work or other activities .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
d Had <u>difficulty</u> performing the work or other activities (for example, it took extra effort) .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

5. During the past week, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a Cut down on the <u>amount of time</u> you spent on work or other activities.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
b <u>Accomplished less</u> than you would like .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
c Did work or other activities <u>less carefully than usual</u> .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5



6. During the past week, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours, or groups?

Not at all	Slightly	Moderately	Quite a bit	Extremely
▼	▼	▼	▼	▼
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

7. How much bodily pain have you had during the past week?

None	Very mild	Mild	Moderate	Severe	Very severe
▼	▼	▼	▼	▼	▼
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6

8. During the past week, how much did pain interfere with your normal work (including both work outside the home and housework)?

Not at all	A little bit	Moderately	Quite a bit	Extremely
▼	▼	▼	▼	▼
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

9. These questions are about how you feel and how things have been with you during the past week. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past week...

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a Did you feel full of life? .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
b Have you been very nervous? .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
c Have you felt so down in the dumps that nothing could cheer you up? .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
d Have you felt calm and peaceful? .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
e Did you have a lot of energy? .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
f Have you felt downhearted and depressed? .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
g Did you feel worn out? .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
h Have you been happy? .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
i Did you feel tired? .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

10. During the past week, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

All of the time	Most of the time	Some of the time	A little of the time	None of the time
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

**11. How TRUE or FALSE is each of the following statements for you?**

	Definitely true ▼	Mostly true ▼	Don't know ▼	Mostly false ▼	Definitely false ▼
a I seem to get sick a little easier than other people .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
b I am as healthy as anybody I know .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
c I expect my health to get worse.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
d My health is excellent.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

***Thank you for completing these questions!***


## Burn-Specific Health Scale-Brief (BSHS-B)

Name: .....

Personal ID number: .....

Current date: 20– –

### INSTRUCTION

This form contains questions which in one way or another are related to problems or feelings that people may experience sometimes. A number of questions concern your previous burn in one way or another.

There are five possible answers for each question. The alternatives are given at the top of each page.

Read every question carefully. Your task is to identify which answer (only one!) that best describes you or how you feel in general, in other words not just now. Put one "cross" in the square which corresponds your answer. Don't skip any items. If you believe that any question is unclear, or this is unclear, contact the person who mailed you this inquiry.

The questions are written in the form of statements. We will start with an example (which is not found in the actual inquiry):

Extremely    Quite a bit    Moderately    A little bit    Not at all

My burn itches a lot.

☒☐☐☐☐

**Work quickly and do not consider each question too long!**

## How much difficulty do you have:

	Extreme	Quite a bit	Moderate	A little bit	None at all
1 bathing independently?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2 dressing by yourself?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3 getting in and out of a chair?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4 signing your name?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5 eating with utensils?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6 tying shoelaces, bows, etc?.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7 picking up coins from a flat surface?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8 unlocking a door?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9 working in your old job performing your old duties?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**To what extent does each of the following statements describe you?**

	Extremely	Quite a bit	Moderately	A little bit	Not at all
10 Sometimes, I would like to forget that my appearance has changed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11 I feel that my burn is unattractive to others.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12 I am troubled by feelings of loneliness.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13 I often feel sad or blue.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14 At times, I think I have had an emotional problem.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15 I am not interested in doing things with my friends.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16 I don't enjoy visiting people.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17 My injury has put me further away from my family.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18 I would rather be alone than with my family.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19 I don't like the way my family acts around me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20 My family would be better off without me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21 I have no one to talk to about my problems.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22 I feel frustrated because I cannot be sexually aroused as well as I used to.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23 I am simply not interested in sex any more.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24 I no longer hug, hold or kiss.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25 My general appearance really bothers me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

26	I have feelings of being trapped or caught.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
----	---	--------------------------	--------------------------	--------------------------	--------------------------	--------------------------

**Below you will find a number of questions about your injury.  
To what extent does each of the following statements describe you?**

	Extremely	Quite a bit	Moderately	A little bit	Not at all
27 Being out in the sun bothers me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28 Hot weather bothers me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29 I can't get out and do things in hot weather.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30 It bothers me that I can't get out in the sun.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
31 My skin is more sensitive than before.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32 Taking care of my skin is a bother.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
33 There are things that I've been told to do for my burn that I dislike doing.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
34 I wish that I didn't have to do so many things to take care of my burn.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
35 I have a hard time doing all the things I've been told to take care of my burn.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
36 Taking care of my burn makes it hard to do other things that are important to me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
37 My burn interferes with my work.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
38 Being burned has affected my ability to work.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
39 My burn has caused problems with my working.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

40 The appearance of my scars bothers me.

☐☐☐☐☐



## **Subscales**

<b>Simple Abilities (SA):</b>	<b>1, 2, 3</b>
<b>Hand Function (HF):</b>	<b>4, 5, 6, 7, 8</b>
<b>Work (W):</b>	<b>9, 37, 38, 39</b>
<b>Body Image (BI):</b>	<b>10, 11, 25, 40</b>
<b>Affect (A):</b>	<b>12, 13, 14, 15, 16,</b>
<b>21, 26</b>	
<b>Interpersonal Relationships (IR):</b>	<b>17, 18, 19, 20</b>
<b>Sexuality (S):</b>	<b>22, 23, 24</b>
<b>Heat Sensitivity (HS):</b>	<b>27, 28, 29, 30, 31</b>
<b>Treatment Regimens (TR):</b>	<b>32, 33, 34, 35, 36</b>

## **Scoring**

- 0 = Extreme/Extremely**
- 1 = Quite a bit**
- 2 = Moderate/Moderately**
- 3 = A little bit**
- 4 = None/not at all**

### Appendix 3.3: Kessler Psychological Distress Scale (K-10)



MONASH University



Please use sticker label if available

Patient Identifier: or Client

Surname:

Other names:

Date of Birth: Sex Male ☐ Female ☐

Address:

Date completed: \_\_\_\_ / \_\_\_\_ / \_\_\_\_

### Instructions

The following ten questions ask about how you have been feeling in the **last four weeks**. For each question, mark the circle under the option that best describes the amount of time you felt that way.

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
1. In the last four weeks, about how often did you feel tired out for no good reason?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. In the last four weeks, about how often did you feel nervous?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. In the last four weeks, about how often did you feel so nervous that nothing could calm you down?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. In the last four weeks, about how often did you feel hopeless?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

5.	In the last four weeks, about how often did you feel restless or fidgety?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6.	In the last four weeks, about how often did you feel so restless you could not sit still?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7.	In the last four weeks, about how often did you feel depressed?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8.	In the last four weeks, about how often did you feel that everything was an effort?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		None of the time	A little of the time	Some of the time	Most of the time	All of the time
9.	In the last four weeks, about how often did you feel so sad that nothing could cheer you up?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10.	In the last four weeks, about how often did you feel worthless?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

The next few questions are about how these feelings may have affected you in the **last four weeks**.

You need not answer these questions if you answered “None of the time” to **all** of the ten questions about your feelings.

11.	In the last four weeks, how many days were you TOTALLY UNABLE to work, study or manage your day to day activities because of these feelings?	_____ (number of days)
12.	[Aside from those days], in the last 4 weeks, HOW MANY DAYS were you able to work or study or manage your day to day activities, but had to CUT DOWN on what you did because of these feelings?	_____ (number of days)
13.	In the last 4 weeks, how many times have you seen a doctor or any other health professional about these feelings?	_____ (number of consultations)

**14.** In the last 4 weeks, how often have physical health problems been the main cause of these feelings?

- ☐ None of the time
- ☐ A little of the time
- ☐ Some of the time
- ☐ Most of the time
- ☐ All of the time

**Thankyou for completing this questionnaire.**

Please return it to the staff member who asked you to complete it.  
*Appendix 3.4: McGill Pain Questionnaire (MPQ)*

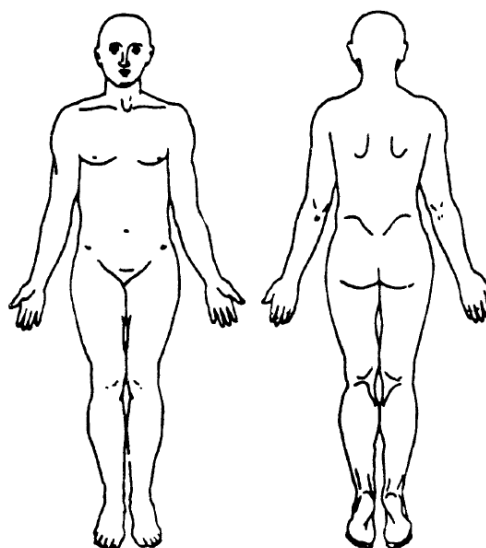
# McGill Pain Questionnaire

Patient's Name \_\_\_\_\_ Date \_\_\_\_\_ Time \_\_\_\_\_ am/pm

PRI: S \_\_\_\_\_ A \_\_\_\_\_ E \_\_\_\_\_ M \_\_\_\_\_ PRI(T) \_\_\_\_\_ PPI \_\_\_\_\_  
 (1-10) (11-15) (16) (17-20) (1-20)

1 FLICKERING	11 TIRING
QUIVERING	EXHAUSTING
PULSING	12 SICKENING
THROBBING	SUFFOCATING
BEATING	13 FEARFUL
POUNING	FRIGHTFUL
2 JUMPING	TERRIFYING
FLASHING	14 PUNISHING
SHOOTING	GRUELING
3 PRICKING	CRUEL
BORING	VICIOUS
DRILLING	KILLING
STABBING	15 WRETCHED
LANCINATING	BLINDING
4 SHARP	16 ANNOYING
CUTTING	TROUBLESOME
LACERATING	MISERABLE
5 PINCHING	INTENSE
PRESSING	UNBEARABLE
GNAWING	17 SPREADING
CRAMPING	RADIATING
CRUSHING	PENETRATING
6 TUGGING	PIERCING
PULLING	18 TIGHT
WRENCHING	NUMB
7 HOT	DRAWING
BURNING	SQUEEZING
SCALDING	TEARING
SEARING	19 COOL
8 TINGLING	COLD
ITCHY	FREEZING
SMARTING	20 NAGGING
STINGING	NAUSEATING
9 DULL	AGONIZING
SORE	DREADFUL
HURTING	TORTURING
ACHING	PPI
HEAVY	0 NO PAIN
10 TENDER	1 MILD
TAUT	2 DISCOMFORTING
RASPING	3 DISTRESSING
SPLITTING	4 HORRIBLE
	5 EXCRUCIATING

BRIEF	RHYTHMIC	CONTINUOUS
MOMENTARY	PERIODIC	STEADY
TRANSIENT	INTERMITTENT	CONSTANT



E = EXTERNAL  
I = INTERNAL

COMMENTS:

McGill Pain Questionnaire. The descriptors fall into four major groups: sensory, 1-10; affective, 11-15; evaluative, 16; and miscellaneous, 17-20. The rank value for each descriptor is based on its position in the word set. The sum of the rank values is the pain rating index (PRI). The present pain intensity (PPI) is based on a scale of 0 to 5.

*Appendix 3.5: Alcohol Use Disorders Identification Test (AUDIT)*

## AUDIT QUESTIONNAIRE

Please read the questions as written and record your answers carefully. Begin by saying "These questions are about your use of alcoholic beverages IN THE LAST SIX MONTHS."

Code answers in terms of "standard drinks", such as 1 pot of heavy beer, a glass of wine, a shot of spirits etc...

Please place the correct answer number in the box at the right.

<p><b>1. How often do you have a drink containing alcohol?</b></p> <p>(0) Never <b>[SKIP to Q9 &amp; 10]</b></p> <p>(1) Monthly or less</p> <p>(2) 2 to 4 times a month</p> <p>(3) 2 to 3 times a week</p> <p>(4) 4 or more times a week</p>	<p><b>6. How often during the last year have you needed a first drink in the morning to get yourself going after a heavy drinking session</b></p> <p>(0) Never</p> <p>(1) Less than monthly</p> <p>(2) Monthly</p> <p>(3) Weekly</p> <p>(4) Daily or almost daily</p>
<p><b>2. How many drinks containing alcohol do you have on a typical day when you are drinking?</b></p> <p>(0) 1 or 2</p> <p>(1) 3 or 4</p> <p>(2) 5 or 6</p> <p>(3) 7, 8, or 9</p> <p>(4) 10 or more</p>	<p><b>7. How often during the last year have you had a feeling of guilt or remorse after drinking?</b></p> <p>(0) Never</p> <p>(1) Less than monthly</p> <p>(2) Monthly</p> <p>(3) Weekly</p> <p>(4) Daily or almost daily</p>
<p><b>3. How often do you have six or more drinks on one occasion?</b></p> <p>(0) Never</p> <p>(1) Less than monthly</p> <p>(2) Monthly</p> <p>(3) Weekly</p> <p>(4) Daily or almost daily</p>	<p><b>8. How often during the last year have you been unable to remember what happened the night before because you had been drinking?</b></p> <p>(0) Never</p> <p>(1) Less than monthly</p> <p>(2) Monthly</p> <p>(3) Weekly</p> <p>(4) Daily or almost daily</p>
<p><b>SKIP TO Q9 &amp; Q10 if Answer to 2 and 3 adds up to 0 (zero)</b></p>	
<p><b>4. How often during the last year have you found that you were not able to stop drinking once you had started?</b></p> <p>(0) Never</p> <p>(1) Less than monthly</p> <p>(2) Monthly</p> <p>(3) Weekly</p> <p>(4) Daily or almost daily</p>	<p><b>9. Have you or someone else been injured as a result of your drinking?</b></p> <p>(0) No</p> <p>(2) Yes, but not in the last year</p> <p>(4) Yes, during the last year</p>
<p><b>5. How often during the last year have you failed to do what was normally expected from you because of drinking?</b></p> <p>(0) Never</p> <p>(1) Less than monthly</p> <p>(2) Monthly</p> <p>(3) Weekly</p> <p>(4) Daily or almost daily</p>	<p><b>10. Has a relative or friend or a doctor or another health worker been concerned about your drinking or suggested you cut down?</b></p> <p>(0) No</p> <p>(2) Yes, but not in the last year</p> <p>(4) Yes, during the last year</p>

Record total of specific items here	
-------------------------------------	--

#### Appendix 4: Demographic and burn-injury characteristics

##### Standardized demographic and burn injury characteristics:

##### Impact of Burn Injury Study (IBIS)

##### *Patient Demographic Information*

1. Age:
2. Gender:            O Male      O Female
3. Date of birth:
4. Date of injury:
5. Type of injury – intentional (yes/no) or unintentional (yes/no)
6. Patient's Surname:
7. Patient's First Name:
8. Contact Telephone Number (1):
9. Contact Telephone Number (2):
10. Data collected:   O face to face      O via telephone
11. Contact attempts: date and time –
12. Next of Kin details:

##### *Pre-injury information*

##### Work status (asked at baseline only)

11. Prior to your injury were you working or studying? ☐ Yes    ☐ No ☐  
Unknown    ☐ Not Applicable

What was your occupation?

.....

12) Did you <provide the options>? (Please mark ☒ **one** box only)

- |   |   |
|---|---|
| <input type="checkbox"/> Not applicable       | <input type="checkbox"/> Work full time                     |
| <input type="checkbox"/> Work part time       | <input type="checkbox"/> Study full time                    |
| <input type="checkbox"/> Study part time      | <input type="checkbox"/> Work part time and study part time |
| <input type="checkbox"/> Other (specify)..... |   |

If you were working or studying prior to your injury, have you returned to work or study?

☐ Yes      ☐ No      ☐ Unknown      ☐ Not Applicable

Is this with the same business, organisation or institution as prior to your injury?

☐ Yes      ☐ No      ☐ Unknown      ☐ Not Applicable

Is this in the same role? (i.e. same job)

☐ Yes      ☐ No      ☐ Unknown      ☐ Not Applicable

In the week prior to your injury, did you have any of the following (asked at baseline only)?

- ☐ No disability
- ☐ Mild disability
- ☐ Moderate disability
- ☐ Marked disability
- ☐ Severe disability

In general, over the last week have you have any of the following (asked at 3, 6 and 12 months)?

- ☐ No disability
- ☐ Mild disability
- ☐ Moderate disability
- ☐ Marked disability
- ☐ Severe disability

***Patient Injury Information***

**1. Aetiology of burns:**

O Thermal

O Radiation

O Chemical

O Electrical

O

Explosion

O Other – give details

**2. Location of burn: Yes/No to all that apply and give percentage affected**



- O Head or neck: \_\_\_\_\_
- O Trunk: \_\_\_\_\_
- O Arms: \_\_\_\_\_
- O Hands: \_\_\_\_\_
- O Legs: \_\_\_\_\_
- O Genitals and Buttocks: \_\_\_\_\_
3. Other Injuries? Please describe:
  4. Date of admission:
  5. Date of discharge:
  6. Total length of stay in hospital (days)
  7. Length of stay in ICU (days):
  8. Number of ventilator (if relevant) hours (hours):
  9. Weight (kg):
  10. Height (cm):
  11. Total Body Surface Area Injured in Burn (numerical %):
  12. Ratio of full thickness burns (numerical as %):
  13. Ratio of partial thickness burns (numerical as %):
  14. Past medical history:
  15. Compensable injury – yes/no
  16. Number of operative procedures (surgeries)
  17. Type of operative procedures (surgeries)