

Roads to recovery: Adult burn survivors' 'lived experience' of rehabilitation

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PUBLICATIONS AND PRESENTATIONS

Publications

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Successful applicant of 2010, Australian Postgraduate Award Scholarship (3 years).

DECLARATION

This work contains no material which has been accepted for the award of any other degree or diploma in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text. In addition, I certify that no part of this work will, in the future, be used in a submission for any other degree or diploma in any university or other tertiary institution without the prior approval of the University of Adelaide and where applicable, any partner institution responsible for the joint-award of this degree.

I give consent to this copy of my thesis when deposited in the University Library, being made available for loan and photocopying, subject to the provisions of the Copyright Act 1968. I also give permission for the digital version of my thesis to be made available on the web, via the University's digital research repository, the Library catalogue, the Australasian Digital Theses Program (ADTP) and also through web search engines, unless permission has been granted by the University to restrict access for a period of time.

Signed:

Dated: 23rd of April 2013

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ABSTRACT

Since antiquity, the trauma of a severe burn has beset humankind with poor outcomes and survival rates. However, over the last two decades there has been substantial progress in the management of acute burns that has resulted in life expectancy similar to the general population. Despite these advancements in the management of severe burns, the physical, psychosocial and economic implications following a severe burn injury are variable with a lack of substantial progress in the area of burn rehabilitation. Consequently, the rehabilitation of those with severe burns remains a lengthy process with significant associated physical and psychosocial problems. A crucial point raised by burn professionals internationally, is that burn rehabilitation needs to be recognised as a continuum of active care rather than a separate isolated phase, with rehabilitation commencing on the day of injury. The immediate commencement of therapy is a key factor in the management of burns with the initial focus directed towards life support, wound closure, infection control and aggressive metabolic support. However, at some point, patients' rehabilitation needs exceeds those that can be provided by burn units necessitating the transfer to a rehabilitation facility. Therefore, it is the experiences of these patients rehabilitating from severe burns that are the focus of this study.

This thesis reports on a research undertaking that explores patients' 'lived experience' of rehabilitation after a severe burn injury. The study utilised a descriptive phenomenological methodology approach. Purposeful sampling was utilised to select participants who sustained severe burns that required intensive rehabilitation across three Australian states. The researcher interviewed 21 burn survivors utilising semi structured interviews that were digitally audio recorded. The interviews were transcribed verbatim then analysed using Colaizzi's method of data analysis. From the data analysis, 25 cluster themes developed from the participants' experiences which were further merged into seven emergent themes that structured the 'lived experience' of burn survivors' rehabilitation journey forming the basis of the findings reported. The essence of these experiences is reflected in these themes: *Vital supports, Spatial environment, Endurance, Acceptance, Impact, Challenges and Progression*. These emergent themes incorporate both the physical and psychosocial impact after a severe burn injury.

Central to burn rehabilitation is the notion of social support that has a significant influence on burn survivors' psychosocial rehabilitation. Fundamental to burn rehabilitation are the development of coping strategies and the means of adjusting and adapting. Patient centred goals provided the necessary motivation and tenacity to progress through the lengthy rehabilitation journey that besets those with severe burns. Acceptance of an altered self-image and body image is a slow and challenging experience for those with severe burns. Key to burn rehabilitation is the appropriate timing and delivery of burn therapy and education that facilitates patients' adherence to burn care and therapy. The process of transition and reintegration after a severe burn injury is a significant event in the rehabilitation of burn survivors. Access to ongoing rehabilitation services remains a challenging experience because of the lack of burn expertise in the community setting.

This study has unearthed fundamental aspects of burn rehabilitation that span across a diverse and multidisciplinary sector of healthcare. In essence, these findings may provide for the further development of health policy in relation to management of severe burn injury; principles and guidelines for best practice; and both survivor and health professional education so as to improve outcomes for burn survivors, their families and the community .

CHAPTER ONE

INTRODUCTION

This chapter provides an overview of the statement of the research problem surrounding the rehabilitation of patients with severe burns, globally and within an Australian context. The purpose, research question, aims and objectives of the study are explained and the significance of and justification for the study are presented. A statement about the researcher's own assumptions related to patients' rehabilitation after a severe burn is disclosed. Finally, a definition of specific terms of reference is provided followed by an overview of how the thesis is structured and presented.

Background

Since the discovery of fire in the early Stone Age Period; 790,000 years ago, humans' attempts to control fire have resulted in injuries. One of the first documented texts of burn injuries was found in the London Medical Papyrus from the Bronze Age which described the treatment for burns after the volcanic eruptions in Santorini between 1603 – 1601 BCE (Trevisanato, 2007). The texts described the management of burn blisters with alkali-based mixtures such as breast milk and honey (Trevisanato, 2006; Trevisanato, 2007). Furthermore, the Ebers' Papyrus (1500 BCE) contained the first documented treatment for contractures after a burn injury with a description of the use of splints made from copper (Robotti, 1990).

It has only been in the last century with the advent of specialised burn centres, that healthcare professionals have laid down the foundations for the multidisciplinary care for those who have sustained severe burn injuries (Brigham & Dimick, 2008). Since the formalised approach to multidisciplinary care implemented over 40 years ago, rehabilitation has been an integral part of burn management (Richard et al., 2008). Burn rehabilitation is a complex process involving a multidisciplinary team aimed at minimising loss of function from complications such as skin contractures and maximising healing to promote, as much as possible independent return to family life and the greater community (Al-Mousawi, Mecott-Rivera, & Herndon, 2009; Jarrett, McMahon, & Stiller, 2008; Richard et al., 2009). Essentially, rehabilitation should focus on the restoration of patients' pre-injury level of independence, function and productivity (Hetherington & Earlam, 1994). Accordingly,

identification of specific rehabilitation needs is a key priority for those with severe burns to facilitate the restoration of their independence.

Despite the enormity of progress seen in the field of burn care, burns remain a tragic event with profound effects both physically and psychologically on individuals and their families, experiencing long periods of hospitalisation and rehabilitation. The loss of both function and independence can be physically limiting, requiring aggressive rehabilitation to improve functionality and quality of life. Consequently, rehabilitation is a critical element in the recovery of those who sustain severe burns. Unfortunately, the progression to a rehabilitation facility is often delayed due to the rehabilitation facility's inability to manage burn wounds (DeSanti, Lincoln, Egan, & Demling, 1998). Moreover, there are increasing concerns related to complications with burn wound care requiring unplanned readmissions to burn units (Mamolen & Brenner, 2000; Schneider et al., 2012) and suboptimal quality of care during transition that represents an interruption to the patients' rehabilitation (Schneider, et al., 2012). Patients with severe burns require careful consideration concerning rehabilitative needs to maximise their recovery (Farrell, Gamelli, & Sinacore, 2006). With the reduction in the length of stay in burn units, patients require a relatively high and intensive level of care and therefore burn units must provide comprehensive care that optimises patient outcomes that not only utilises the resources of the burn unit, but external resources to optimise the return to independent living (Farrell, et al., 2006).

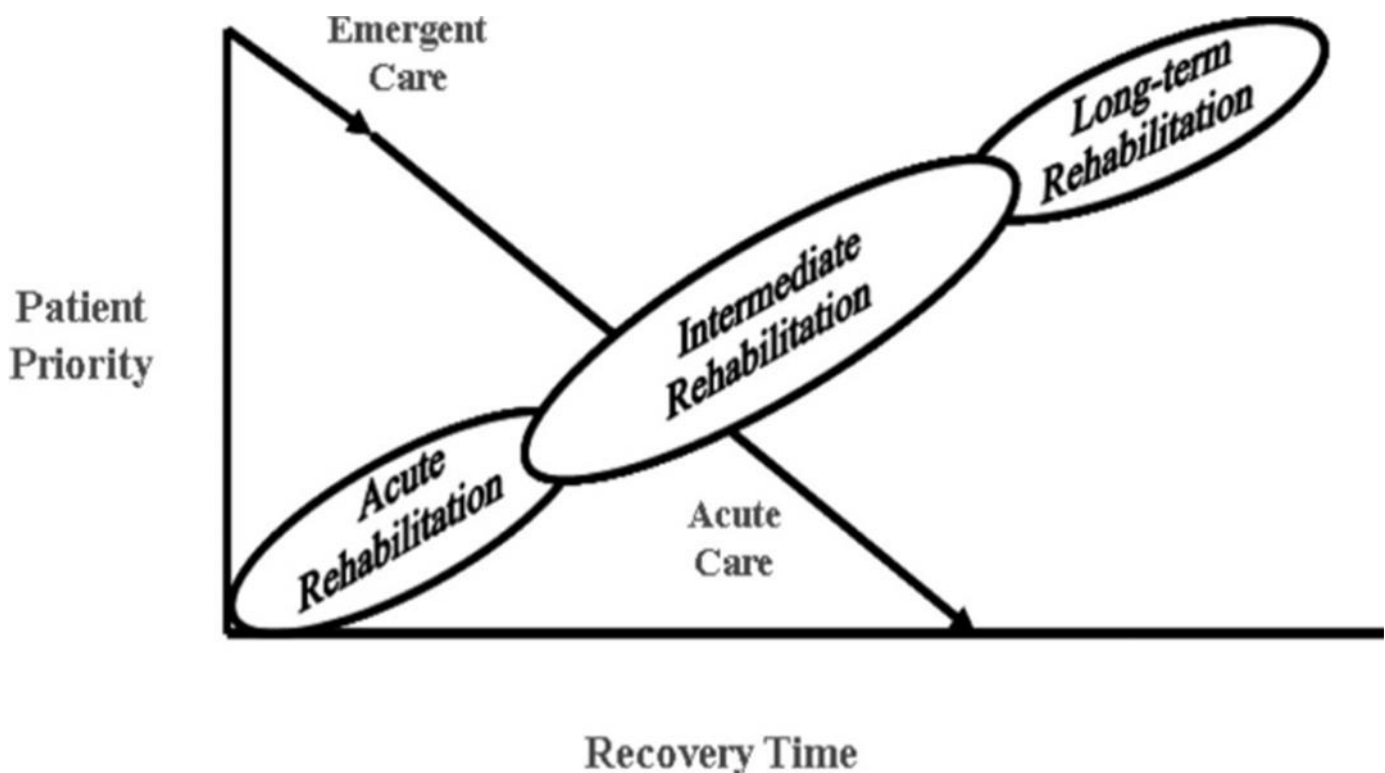
Statement of research problem

The goals of burn care rehabilitation include optimal restoration of function, an acceptable appearance, reintegration into society and the return to gainful employment (Klein et al., 2007; Kucan et al., 2010). With increasing survival rates over the last decade (Palmieri, London, O'Mara, & Greenhalgh, 2008; Richard, et al., 2009; Tan et al., 2012) the rehabilitation of those with severe burns poses significant challenges for patients experiencing long term physical and psychological complications (Esselman, Thombs, Magyar-Russell, & Fauerbach, 2006). Consequently, there has been a paradigm shift focusing on the rehabilitation process and the person's quality of life (Pereira, Murphy, & Herndon, 2004). Those who survive with major burns, experience significant functional and cosmetic impairments (Pereira, et al., 2004) and have complex rehabilitation requirements (Richard, et al., 2009; Sheridan, 2003). Recognition and understanding of the issues experienced by people with severe burns is imperative for providing long term rehabilitation (Holavanahalli,

Helm, & Kowalske, 2010). A heightened awareness is required as to the needs for advancements in burn rehabilitation pending a fundamental question of “when is burn rehabilitation going to advance the physical outcome of burn survivors?” (Richard, et al., 2008, p. 426). Richard, et al. (2008) in their paper ascribing to commitment and affirmation in the pursuit of burn rehabilitation, claimed that burn rehabilitation has become stagnated and viewed as an accompaniment to patient care with some physicians referring to rehabilitation as a “secondary resource” (p. 427). Subsequently, the increasing number of people surviving with severe burns, has resulted in research being directed at the outcome of burn injury (Richard, et al., 2009). However, as there has been a lack of substantial progress in the area of burn rehabilitation, advancements in the production and utilisation of rigorous scientific evidence that specifically relates to burn rehabilitation are necessary. Furthermore, without a consensus on the knowledge and skills required of burn clinicians, inconsistencies in the training and implementation of burn care practices concerning rehabilitation will persist (Parry, Esselman, & Rehabilitation Committee of the American Burn Association, 2011).

There is a growing body of evidence suggesting that those who sustain traumatic injuries do not always return to their pre-injury status physically, emotionally, socially or financially (DePalma, Fedorka, & Simko, 2003; Lundgaard Soberg, Bautz-Holter, Roise, & Finset, 2007; Sluys, Haggmark, & Iselius, 2005). The continuing financial costs are amplified if an immediate family member has to leave their place of employment to care for the burn survivor. The treatment for a severe burn is not a one-off treatment intervention, but involves a lifelong commitment to ongoing treatment and rehabilitation. Consequently, there is a need to focus on the rehabilitation process. A crucial point raised by burn professionals internationally, is that burn rehabilitation needs to be recognised as a continuum of active care rather than a separate isolated phase (Richard, et al., 2008) (figure 1) with rehabilitation commencing on the day of injury (Edgar, 2009; Edgar & Brereton, 2004; Richard, et al., 2008) with early and intensive rehabilitation required (Richard, et al., 2008). However within the burn literature, the rehabilitative phase is often associated with wound closure (Richard, Staley, Miller & Warden in Richard, et al., 2008). Furthermore, during the acute stage, rehabilitation has been acknowledged as a lesser priority than medical treatment although rehabilitation can be performed safely at this stage (Richard & Miller, 1995; Richard, Miller, & Staley, 1990). In fact, burn rehabilitation actually surpasses other forms of treatment concerning the quantity and duration of care (Richard, et al., 2008). The immediate commencement of therapy is a key factor in the management of burns with the initial focus

directed towards life support, wound closure, infection control and aggressive metabolic support (DeSanti, et al., 1998). However, at some point during the recovery phase, the rehabilitation needs of patients' with severe burns exceed those that can be provided in burn units necessitating transfer to a rehabilitation facility (DeSanti, et al., 1998). The ability for burn clinicians to commence a focused rehabilitation program early in recovery is perceived by those with severe burns and their families as a positive element (DeSanti, et al., 1998). It is therefore essential that there is a rehabilitation programme designed for those with severe burns that identifies specific goals that meets patients' needs throughout their rehabilitation (American Burn Association, 2010). In fact, the emphasis requires a shift from survival to rehabilitation with the end point being the restoration of independence through early and intensive rehabilitation instead of focusing on patient survival (Richard, et al., 2008).



(Richard, et al., 2008)

Figure 1: Phases of burn rehabilitation

Caring for those with severe burns is not commonplace in rehabilitation facilities and therefore creates many challenges for clinicians within those facilities (Hall, 2005; Hall, 2012). For example, due to educational preparation, rehabilitation nurses have limited knowledge and skills required for treating and managing burns. Additionally, medical staff in rehabilitation facilities may not necessarily have the knowledge and skills required to meet the high needs of hypermetabolic patients (DeSanti, et al., 1998). Skilled clinicians in the field of burn care are therefore imperative to ensure that patients' rehabilitation needs are met. The National Institute on Disability Rehabilitation Research recognised that the rehabilitation of patients with severe burn injuries is under-addressed (Patterson, 2007). Furthermore, a survey conducted by the American Burn Association (ABA) of burn facilities in the United States of America, revealed a significant lack of burn personnel, complexity of care and commitment to the rehabilitation of burn patients (Richard, et al., 2008). Similarly, a study addressing return to work after a burn injury, identified barriers to rehabilitation which included a lack of psychological assistance, no rehabilitation plan and no individualised training programme (Oster, Kildal, & Ekselius, 2010). In fact, Dimick, Cope, Barillo, Gillespie, and Mozingo (2005) state that anecdotal evidence supports the notion that variations in the acute care burn setting exist including a lack of reliable coordinated long term follow up that contribute to significant variations in outcomes. Finally, due to the National Burn Care Review (NBCR), recent reforms to burn care in the United Kingdom, it was recommended that a continuing model of care for burn patients should be adopted with psychological and intensive multi-specialty trauma rehabilitation services for patients and families (British Burn Association, 2010).

In Australia, although each state provides rehabilitation services for adult patients with severe burns, they are provided for differently. The rehabilitation of patients with severe burn injuries is conducted within burn units and generic rehabilitation facilities according to the individual state with the majority of states utilising the services of a generic rehabilitation facility. There is currently only one state which provides burn specific rehabilitation within a severe burn injury unit. Of the individual burn units across Australia (Table 1), each burn unit functions within its own specific environment and each unit has different practices in relation to discharge planning that include differences in the utilisation of inpatient rehabilitation (Cameron, Gabbe, Watterson, Picton, & Hannaford, 2011).

Table 1: Rehabilitation facilities for patients with severe burns in Australia

Australian State	Rehabilitation Facility	Specificity of Unit
New South Wales	The Royal Rehabilitation Centre	Generic
Queensland	The Geriatric and Rehabilitation Unit (GARU)	Generic
Victoria	Caulfield Hospital	Generic
Western Australia	Adult Burns Unit and Telstra Reconstruction and Rehabilitation Unit.	Burn specific
Tasmania	Dwyer Rehabilitation Unit	Generic
South Australia	Hampstead Rehabilitation Centre	Generic

Burn care is recognised as challenging for both the patient and those involved with the rehabilitation process (Kornhaber & Wilson, 2011). Inherent issues are related to the level of specialist clinical knowledge and expertise of staff at the receiving rehabilitation facility (Hall, 2012). The resources available, and management of burn wounds and associated complications, has led to unplanned re-admissions to the burn unit and an extended length of stay that has psychosocial implications for the patient and their family (Mamolen & Brenner, 2000). Exploring and addressing these issues surrounding burn rehabilitation is imperative for the development of policies and guidelines that could inform and shape future care for those who have endured a severe burn injury.

Purpose of study

Whilst minor burns are a common injury in the community and the majority of burn injuries heal with no or minimal medical interventions, there is a relatively small proportion consisting of 1% of the Australian population, who sustain burns each year (Wasiak et al., 2009). Of the 1% burned, 0.5% have a burn that affects their activities of daily living, 0.1% require hospitalisation and 0.01% have life threatening injuries (Wasiak, et al., 2009) Nevertheless, these injuries require intensive and long-term rehabilitation to assist in

achieving as close as possible pre-injury level of independence, function and productivity. Kramer (1997) states that the different encounters of rehabilitation have been shown to influence the patients' experience within the clinical area. Therefore, the purpose of the current study is to describe the 'lived experience' of adults' rehabilitation after a severe burn injury.

Research question

What is the 'lived experience' of patients' rehabilitation after a severe burn injury?

Aim

To explore the patients' experiences of rehabilitation after a severe burn injury and potentially inform future research efforts to contribute to influencing policy and burn care utilised to improve patient experiences and health outcomes.

Objectives

1. To describe patients' experiences of rehabilitation after a severe burn injury
2. To discover the meanings embedded in patients' experiences of rehabilitation after a severe burn injury
3. To articulate the difficulties encountered by patients with severe burns during the rehabilitation journey
4. To identify elements that enhance the rehabilitation experience of patients with severe burns.

Significance of the current study

The practices implemented to rehabilitate patients with severe burns vary greatly among institutions. Accordingly, clinicians believe that the rehabilitation of patients with severe burns, needs to be guided by practice guidelines based on sound clinical research (Richard, et al., 2009). However, there remains a paucity of literature that explores the patients' 'lived experience' of rehabilitation after a severe burn injury. Improvements in the rehabilitation of patients with severe burns has primarily occurred at an institutional level (Richard, et al., 2009) and questions that address patients' experiences of rehabilitation remain largely unanswered. Patients' perspectives are critical in helping focus the priorities for burn research and care (Acton, Mounsey, & Gilyard, 2007). Therefore, it is necessary to explore the patients' experiences during the rehabilitation journey.

The understanding of the ‘lived experience’ of patients’ rehabilitation after a severe burn injury would be enriched through a qualitative study assessing patients own encounters. This could facilitate further development of burn specific rehabilitation programmes and positively impact upon the health outcomes of patients, while addressing burn specific complications that impede patients’ recovery. As yet, only a small number of qualitative studies have investigated the experience of patients with severe burns (Badger & Royse, 2010a; Ciofi-Silva et al., 2010; Costa, Rossi, Lopes, & Cioffi, 2008; Moi & Gjengedal, 2008; Moi, Vindenes, & Gjengedal, 2008; Williams, Davey, & Klock-Powell, 2003). Although these studies have provided valuable insight and knowledge on how patients have experienced their lives after a severe burn, they do not address the complications embedded in the rehabilitation process within an Australian context. The exploration and understanding of peoples’ experiences of rehabilitation in Australia is essential in order to identify and address issues that arise from or during rehabilitation that contributes knowledge influencing health policy and informing care aimed at improving patient experiences and health outcomes.

Assumptions

Objectivity in a Husserlian phenomenological study requires the researcher to remain faithful to the phenomenon. Doing so enables the researcher to identify preconceived notions and let the text reveal the phenomenon in its pure form (Gadamer, Weinsheimer, & Marshall, 2004). Consequently, prior to the commencement of the study, it was essential that the researcher identified biases, assumptions and preconceptions related to patients’ rehabilitation after sustaining a severe burn. Declaring these views provided the researcher with the means of reducing the chance of imposing or sullyng existing preconceptions on the study and therefore influencing the outcome.

Biases, assumptions and preconceptions listed below are derived from the researcher’s own experience as a burn clinician:

1. A severe burn is a debilitating injury that will have a considerable impact on the quality of life of those with severe burns.
2. There is a great need to review the manner in which patients with severe burns are rehabilitated.
3. Those who sustain a severe burn injury have unique needs.

Definition of Terms

Contracture: An area of skin that has experienced excessive scarring resulting from a severe burn injury that restricts joint mobility and function (Schneider, Holavanahalli, Helm, Goldstein, & Kowalske, 2006).

Heterotrophic ossification: Commonly seen in patients with severe burns, heterotopic ossification is the abnormal formation of bone in soft tissues. (Pape, Marsh, Morley, Krettek, & Giannoudis, 2004).

Hypertrophic scars: Contracted hard, raised, red, itchy and painful scar tissue found in those with severe burns. These disfiguring scars can have a negative impact on rehabilitation with patients experiencing a loss of function and independence (Engrav, Garner, & Tredget, 2007).

Severe burn injury: Defined as being 20% or greater of the total body surface area in adults that requires admission to a tertiary referral hospital with specialist burn expertise and resources (NSW Department of Health, 2003).

Thesis outline

The thesis presented within provides a comprehensive report of the research inquiry in eight chapters. The introduction, literature review and methodology chapters frame the research providing the background and design. The research analysis, the backstories and findings are presented in chapters four, five and six as a descriptive phenomenological account of the 'lived experience' of patients' rehabilitation after a severe burn injury. Chapter seven provides an in depth discussion of the findings and the significance to clinical practice. The final chapter presents the conclusion and recommendations arising from this thesis, limitations of the study and recommendations for further research.

Chapter one: The introduction to the thesis contains a detailed statement of the research problem, the purpose and the research question, with specific aims and objectives of the study stated. The global context of burn rehabilitation is presented and the significance of burn rehabilitation from an Australian perspective is addressed and a definition of terms provided.

Chapter two: This chapter is presented as an integrative literature review referring to the personal perceptions and experiences of adult rehabilitation following severe burn injuries. Factors that influence the patients' rehabilitation are identified. The review highlights the

gaps in research and demonstrates how the current study can add new knowledge to the area of rehabilitation of people with severe burn injuries.

Chapter three: This chapter introduces phenomenology as a methodology used in qualitative research within the interpretive research paradigm. An overview of phenomenology and the two main fields of phenomenological research Husserlian (descriptive) and Heideggerian (interpretive) are presented. The philosophical assumptions of descriptive (Husserlian) phenomenology provides the philosophical and methodological framework for this study aimed at describing and gaining a rich understanding of the rehabilitation of patients with severe burns.

Chapter four: The methods chapter provides the research strategies utilised in the current study. Chapter four discusses the study design, including the sample population, recruitment strategies, ethical considerations, data collection and the process of data analysis. In addition, the issues of methodological rigour and trustworthiness are discussed.

Chapter five: The backstories give an overview of each participant. Provided is a brief descriptive biography of each participant encompassing their age, percentage of total body surface area burnt, the length of hospitalisation, their current work status and family support.

Chapter six: The findings which describe the ‘lived experience’ of rehabilitation for patients with severe burn injuries are presented. An in-depth analysis of cluster and emergent themes that developed from the data is provided. The focus of this chapter is the exploration of how each emergent theme is supported by the participants’ experiences. The emergent themes developed from the data were: Spatial environment, endurance, acceptance, impact, vital supports, progression and challenges.

Chapter seven: This chapter provides an in-depth discussion of the study’s findings in relation to the relevant literature and the presentation of new knowledge that emerges from the study.

Chapter eight: The eighth and final chapter presents the recommendations and conclusion of the thesis. This chapter considers the significance of the research undertaken and makes recommendations for practice and education that aims to influence health policy and inform care so as to provide for the further development of health policy in relation to management of severe burn injury; principles and guidelines for best practice; and both survivor and health professional education so as to improve outcomes for burn survivors, their families and the

community. The limitations of the study are addressed and recommendations are made for further inquiry into the domain of burn rehabilitation.

Appendices: The appendices contains the search strategy for the integrative review, key personnel information sheet, participant information sheet and consent form, semi structured interview questions, ethical approval documentation, endorsement letters and demographic data.

Summary

Chapter one introduces the focus of the research reported within this thesis. It provides a clear statement of the research problem, followed by the purpose, aims and objectives of the study and addresses the significance of the research. A statement about the researcher's own assumptions related to the rehabilitation of severe burn injury patients is disclosed. Finally, a definition of specific terms relating to the research is presented. The chapter concludes with a concise summary of all chapters that are presented in this thesis.

CHAPTER TWO

INTEGRATIVE REVIEW

Introduction

This chapter reports on an integrative review of the personal perspectives and experiences of rehabilitation as experienced by adults with severe burn injuries. The rationale for choosing an integrative literature review is discussed, and the methodological process is explained. The findings report on and discuss the key areas of how burn survivors perceive and experience rehabilitation with the inclusion of key characteristics of burn injury found within the reviewed papers. The significance of the findings to the field of burn rehabilitation and the limitations and strength of evidence are presented.

Background

Since antiquity, the trauma of a severe burn has beset humankind with poor outcomes and survival rates. However, survival has improved significantly over the last two decades with life expectancy similar to the general population (Ryan et al., 1998). Consequently, the rehabilitation of those with severe burns has become a lengthy process with significant associated physical and psychosocial problems (Greenwood, Tee, & Jackson, 2007) that relies on physiotherapy and occupational therapy to reintegrate patients into society (Yohannan, Ronda-Velez, et al., 2012). Despite the advancements in the management of severe burns, the physical, psychosocial and economic implications following burn rehabilitation are variable (Hulbert-Williams, Hulbert-Williams, McIlroy, & Bunting, 2008).

The primary goal of burn rehabilitation is the optimal restoration of function, an acceptable appearance, reintegration into society and the return to gainful employment (Kucan, et al., 2010; Schneider, Bassi, & Ryan, 2009). Although having attained the short term goal of survival, the burn survivor is confronted with the challenges of a long and complex rehabilitation often continuing for many months and often years after the initial injury (Edgar, 2009; Procter, 2010). Primarily, the importance of an early and rigorous focus on regaining physical and emotional independence remains critical.

Globally, the incidence of severe burns is estimated at six million people annually (Brusselaers, Monstrey, Vogelaers, Hoste, & Blot, 2010). Within the Australian context, the

number of adult burn cases recorded for the population of Australia and New Zealand for the period from the 1st July 2009 to 30th June 2010 was 1550 cases with 12 per cent of adult cases requiring an ICU admission for a burn greater than 20% TBSA (Cameron, Gabbe, Watterson, Picton, & Hannaford, 2011). Additionally, 50% of those who sustain a burn injury experience a disruption to their daily life (Education Committee of the Australian and New Zealand Burn Association, 2012). Despite the physical and psychological trauma endured during rehabilitation, the growing body of literature concerning burn rehabilitation is based mainly on research relating to complications of severe burns and largely of a quantitative nature. However, there remains a dearth of literature that explores the personal perceptions and experiences of adults' rehabilitation after a severe burn. Of the literature that investigates the views of those with burns injuries, the majority of studies utilise surveys, questionnaires and scales employing statistical analysis to interpret the data with limited research of a qualitative nature. Therefore this integrative review aims to illuminate the personal perceptions and experiences of rehabilitation as experienced by adult burn survivors through voice and narrative and to understand the factors that influence burn rehabilitation. The perspectives of burn survivors offers a unique and influential insight in assessing the efficacy of burns rehabilitation with patients perspectives' representing an available source of constructive information (Yohannan, Ronda-Velez, et al., 2012).

The review

Aim

The aim of this integrative review is to systematically synthesis the literature focussing on research into the personal perceptions and experiences of adult burn survivors' rehabilitation and gain an insight into factors that influence the survivors' experiences.

Design

An integrative review methodology was selected to review the literature concerning burn survivors' perspectives and experiences of rehabilitation on the premise that it is a logical and systematic process for reviewing the literature. An integrative review has the ability to influence evidence based practice by means of the synthesis of knowledge and the application of findings from significant studies into practice (Tavares de Souza, Dias da Silva, & de Carvalho, 2010; Whitemore & Knafel, 2005). This allows for a comprehensive understanding of the phenomenon and healthcare issue that informs research, practice and policy initiatives

(Tavares de Souza, et al., 2010; Whittmore & Knafl, 2005). Integrative reviews are broader in the description and understanding of an area of research compared to a systematic review that addresses a specific clinical question (Oermann & Hays, 2010; Tavares de Souza, et al., 2010). An integrative review therefore has the potential to build knowledge presenting various perspectives on the phenomenon of interest (Whittmore & Knafl, 2005). However, combining different research methodologies and data poses inherent risks that can lead to a lack of rigour, inaccuracies and bias (Whittmore & Knafl, 2005). To limit these issues concerning bias, rigour and validity of findings, it is recommended that an integrative review requires the same methodological scholarly standing as primary research (Russell, 2005). Therefore, the framework for guiding this integrative review is based on Whittmore and Knafl's (2005) five stages: problem identification, literature search, data evaluation, data analysis and presentation.

Search methods

An initial search of PubMed, CINAHL and EMBASE was undertaken to establish the index terms used to describe the papers and the text words that were found in both the title and abstracts. Following the initial search, the search strategy was reviewed by a research librarian to ensure that the search was logical, comprehensive and inclusive. The search strategy was developed to reflect all facets of burn rehabilitation in relation to the perceptions and experiences of those with severe burns.

After determining the index terms and text words, a comprehensive and systematic literature search was conducted on the 6th of August 2012 utilising the following electronic databases:

- PubMed (United States National Institutes of Health).
- Cumulative Index to Nursing and Allied Health Literature (CINAHL) on the EltonBStephens Company (EBSCO) platform.
- ExcerptaMedica database (EMBASE).
- Scopus on the SciVerse platform.
- Psychological Information Database (PsycINFO) on the EBSCO platform.
- Trove – National Library of Australia (digital theses of both international and Australian theses).

The advanced search feature was utilised for all databases with truncation symbols and Boolean connectors AND, OR and NOT used to combine search terms in order to broaden or focus the search. A complete list of the search strategy for each database is provided in

Appendix 1. In addition to the search strategy, the references of potential papers retrieved were examined to identify any additional papers. All searches were limited to papers in the English language published between 2002 and 2012 that focused on the adult burn survivors' personal perceptions and experiences of rehabilitation. It was noted that there was a discrepancy between databases concerning the adult population. CINAHL and PubMed classify adults as 19 years and over however, PsycInfo and EMBASE classify adults as 18 years and over. Yet, Scopus and Trove do not have filters to limit age. This discrepancy had no bearing on the overall literature search.

Inclusion criteria

Peer reviewed reports of original research, reviews of literature and dissertations published in the English language within the last 10 years were included in the integrative review. The 10 year range between 2002 and 2012 was chosen due to the advancements made in the area of burn care in the last decade resulting in an increased need for inpatient rehabilitation (Tan, et al., 2012). In order to focus on the phenomenon of interest, papers that illuminated or described, through the means of voice and narrative, personal perspectives or experience of adults' rehabilitation following severe burn injuries were included.

Exclusion criteria

Papers published prior to 2002 or which did not describe original research were excluded as were abstracts or unpublished manuscripts. Those papers that utilised scales and surveys to measure outcomes measures for burn rehabilitation were excluded, as these papers are limited in providing the personal perceptions or experiences of adult burn rehabilitation. Papers that focused on either paediatric or adolescent burn rehabilitation or adults burned as children were excluded as the needs and care provided for such children are different to those of an adult (Berman, Viera, Amini, Huo, & Jones, 2008; Birchenough, Gampper, & Morgan, 2008). Additionally, papers that addressed self-immolation or focused on psychiatric disorder in burn rehabilitation were excluded as the requirements of this cohort of patients necessitate specific needs (Ahmadi, 2007).

Search outcome

The papers identified from the search strategy were imported into Endnote Version X5 bibliographic software and the duplicate references were removed. The search method identified a total of 378 papers in which the titles and abstracts were reviewed to determine their relevance to the aim of the integrative review. Through this process, 143 papers were

found to be related to rehabilitation, however not specifically burn rehabilitation. Ninety one papers focused on the surgical aspect and management of burn injuries, 24 papers discussed the epidemiology of burn injury, 10 papers concentrated on the management and effects of burn pain, 29 papers addressed the psychological aspects of burn injury, nine papers focused on the reliability and validation of different surveys and scales in the assessment of burn injury, six papers were not original research and two reported on the relatives' perception and experiences of burn rehabilitation. Despite placing filters designed to capture studies containing the adult population in the English language, nine papers referred to paediatric burns or adults burnt as children and seven papers were published in Chinese. Forty eight papers were retrieved for detailed evaluation, however after a full review, a further 31 papers were excluded for not meeting the inclusion criteria. A total of 17 papers appeared to meet the inclusion criteria (Figure 2).

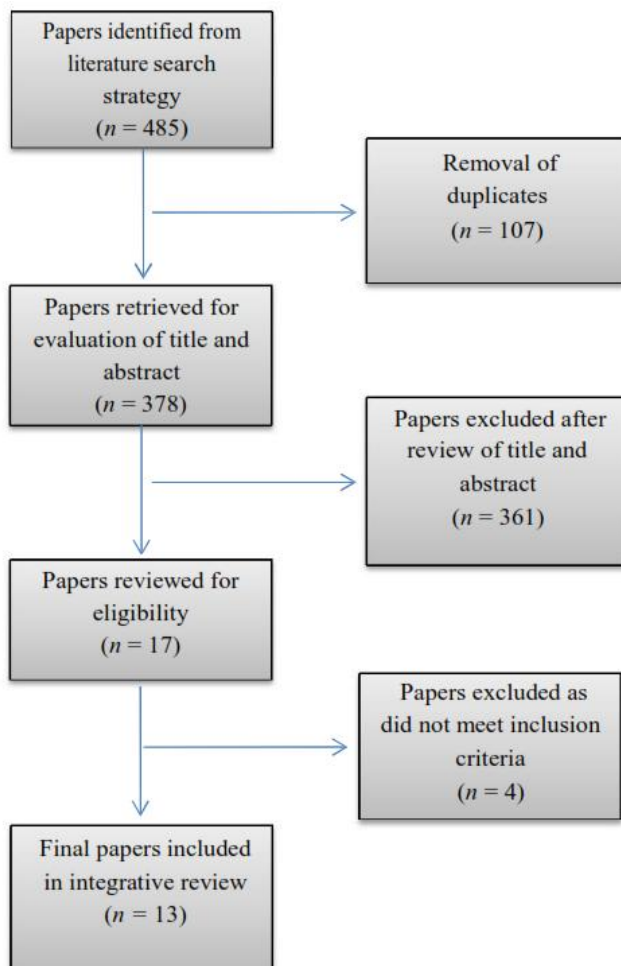


Figure 2: Flow diagram: Literature review

Data extraction and evaluation

The sample of 17 papers was summarised. The researcher extracted data from each of the 17 papers including the author, country of origin, research design, purpose, sample and study population, data collection method, method of analysis, significant finding/s and outcomes and the significance to burn rehabilitation. During the data extraction process, four papers were further excluded because the full review found that they did not focus on the rehabilitation process. On completion of the full review, 13 papers met the final criteria for inclusion (Table 2). Papers reviewed for inclusion were not assessed for methodological quality because the purpose was to integrate all findings describing adult burn survivors' personal perceptions and experiences of rehabilitation therefore no studies meeting the inclusion criteria were excluded. Data were presented, with the majority of studies reporting the number of participants, age, percentage of TBSA burned, and the time period after the initial burn injury occurred and gender. Findings describing burn survivors' personal perspectives and experiences of rehabilitation were compiled then arranged to identify themes and relationships. During the literature review process, it was observed that despite many papers addressing burn rehabilitation, the number of papers relevant to the personal perspectives and experiences of adult burn rehabilitation were few. This resulted in the small number of papers that are included in this integrative review.

Table 2: Summary of included studies

Author/s, year and country	Design	Purpose	Sample and study population	Data collection method	Method of analysis	Significant finding/s and outcome	Significance to burn rehabilitation
Badger and Royse (2010) (USA)	Qualitative descriptive study.	To explore burn survivors' perceptions of the value of peer support in participants' psychosocial rehabilitation.	Purposive sample of 30 adult burn survivors; M/F 19/11; mean age 41, range 19 to 71 years; mean TBSA 60%, range 25% to 93%; 17 reported facial burns. Sustained burn on average 14 years prior with a range of 2 to fifty years.	Face to face Semi structured interviews.	Thematic analysis.	Burn peer support provided a sense of belonging, affiliation and gave hope and confidence to burn survivors.	The importance of the development of peer support resources in coordination with burn professionals to facilitate psychological rehabilitation.
Ciofi-Silva, Rossi, Dantas, Costa, Echevarria-Guanilo and Ciol (2010) (Brazil)	Qualitative descriptive study.	To describe the changes experienced by Brazilian burn survivors during their rehabilitation and to investigate associations between changes in work and the percentage of TBSA and the anatomy burned.	Purposive sample of 44 adult burn survivors; M/F 24/20; mean age 38, range 18 to 71 years; 50 % (22) < 20% TBSA and 50% (22) >20% TBSA. Discharged from hospital between 6 months to 1 year prior. Marital status: 65.2 % were married. 59% reported changes in their work status.	Face to face semi structured interviews.	Thematic analysis	Burn injury had a high impact on participants' lives in particular in relation to their work status and financial status.	Relatives and health professionals are key components in the rehabilitation process.
Costa, Rossi, Lopes and Cioffi (2008) (Brazil)	Ethnographic study based on modern hermeneutics.	To interpret the meanings of quality of life of people undergoing burn rehabilitation based on participants' own experiences, conceptions and values.	Purposive sample of 19 adults who had sustained burns; M/F 12/7; age range 18 to 50 years. (11 relatives of the participants present at the time of the data collection also took part).	Direct observation and semi structured interviews.	Thematic analysis.	Quality of life altered due to physical and psychological limitations experience by a severe burn injury.	Family support, work, independence and social integration are key concepts in the rehabilitation journey.

Author/s, year and country	Design	Purpose	Sample and study population	Data collection method	Method of analysis	Significant finding/s and outcome	Significance to burn rehabilitation
Dahl, Wickman and Wengstrom (2012) (Sweden)	Qualitative descriptive study.	To explore burn patients' experiences of adapting to life after a burn injury in order to acquire a deeper understanding of important issues for patients during and after a burn injury.	Purposive sample of 12 adult who had sustained burns; M/F 8/4; mean age 50, range 19 to 74 years; mean TBSA 11%, range 2% to 40%, mean LOS 16.4 days, range 8 to 45 days. Sustained burn between 6 to 12 months prior.	Face to face interviews	Qualitative content analysis using Kvale's three step method for structuring analysis.	Patients with severe burns require more information about and involvement with their rehabilitation plan.	Necessity of support to assist burn survivors to cope with altered bodily sensations and appearance early in the burn rehabilitation period.
Mackey, Diba, McKeown, Booth, Gilbert and Dheansa (2008) (UK)	Qualitative descriptive study	To explore burn survivors experiences and perceptions of returning to work after discharge.	Purposive sample of 23 adults of working age; TBSA range of 10% to 25%. Excluded self-inflicted burns.	Face to face semi structured interviews	Matrix analysis methodology developed by the Qualitative Research Unit at the National Centre for Social research (not described).	Employment prospects after a severe burn is related to their pre injury status, employment factors, physical and psychological issues related to the burn injury, treatment and therapies and the patients' socio-economic background.	The rehabilitation of burn survivors' back into the workforce has benefits for burn survivors, their families and the community.

Author/s, year and country	Design	Purpose	Sample and study population	Data collection method	Method of analysis	Significant finding/s and outcome	Significance to burn rehabilitation
Moi and Gjengedal (2008) (Norway)	Husserlian phenomenological study.	To explore and describe the experience of quality of life after a major burn injury.	Purposive sample of 14 adults who survived a major burn injury; M/F 11/3; mean age 46, range 19 to 74 years; mean TBSA 33%, range 7.5% to 62%, mean full thickness burn 27%, range 3% to 62%. Burn sustained on average 14 months after injury with a range of 5 to 35 months.	20 Open, unstructured, in-depth interviews.	Thematic analysis using Giorgi's phenomenological method using data analysis software NVivo.	Accidental burn injuries and the subsequent hospitalisation were life changing events that altered participants' perception of life with the necessity to accept what could not be changed and make efforts to change what was changeable.	Education and information is critical in preparing burn survivors and their families for the long rehabilitation journey ahead.
Moi, Vindenes and Gjengedal (2008) (Norway)	Husserlian phenomenological study.	To describe the body of people who had survived a severe burn injury and understand the essence of participants 'lived experience'.	Purposive sample of 14 adults who survived a major burn injury; M/F 11/3; mean age 46.2; mean TBSA 32.6%, mean full thickness burn 26.8%; mean LOS 50.6 days. Burn sustained on average 14 months prior. 50% participants unemployed.	20 face to face open, in-depth interviews (9 participants were interviewed once, 4 participants interviewed twice and 1 participant interviewed 3 times).	Thematic analysis using Giorgi's phenomenological method using data analysis software NVivo.	An altered and demanding bodily awareness that revealed both limitations and potentials for burn survivors.	The facilitation of social support is critical in the rehabilitation after a severe burn injury.

Author/s, year and country	Design	Purpose	Sample and study population	Data collection method	Method of analysis	Significant finding/s and outcome	Significance to burn rehabilitation
Na (2008) (Australia)	Hermeneutic inquiry: Dissertation	To understand how burn survivors view their participation and re-engagement in activities after a burn injury.	Purposive sample of 5 adults rehabilitating from burn injuries; M/F 2/3; mean age 47, range 32 – 61 years; mean TBSA 16.4%, range 6% - 30%; 2 reported facial burns. Burns sustained on average 16 months prior with a range of 2 to 54 months. Marital status: 4 married and 1 divorced.	The Occupational Performance History Interview-II (OPHI-II) utilised as a guide in conducting face to face interviews.	Thematic analysis.	The use of cognitive behavioural therapy during burn rehabilitation to assist patients in reframing their experiences and modifying misconception in relation to pain and social stigma	The importance of social and professional support to facilitate adjustment and adaption in burn survivors' everyday lives.

Author/s, year and country	Design	Purpose	Sample and study population	Data collection method	Method of analysis	Significant finding/s and outcome	Significance to burn rehabilitation
Oster, Kildal and Ekselius (2010) (Sweden)	Qualitative descriptive study.	To explore the burn injured persons' perception of facilitators or barriers to returning to work after a severe burn injury.	Purposive sample of 39 who had previously sustained a burn injury; M/F 29/10, mean age at time of injury 39.7 years, range 19-61 years; mean TBSA 29%, range 1.5% to 80%, mean full thickness burn 19.9%, range 0% to 64%; mean LOS 29 days, range 1 to 230 days. Sustained burn on average 4.6 years prior.	Face to face semi structured interviews.	Qualitative content analysis.	Barriers returning to work were perceived as: cessation of pain medication, primary healthcare facility's lack of knowledge, a lack of psychological support and a lack of individualised rehabilitation plans. Facilitators returning to work were perceived as: the individual characteristics of own ability to take action, goals for rehabilitation, determination and ability to adjust. Assistance with modified work or change of work place was also perceived as a facilitator.	The importance of a return to work coordinator early in the rehabilitation process focusing on capabilities not impairments.

Author/s, year and country	Design	Purpose	Sample and study population	Data collection method	Method of analysis	Significant finding/s and outcome	Significance to burn rehabilitation
Ripper, Renneberg, Landmann, Weigel and Germann (2009) (Germany)	Qualitative descriptive study.	To investigate the specific problems and impairments that patients wearing pressure garments confront, and the supportive aspects or resources that help patients to continue with therapy.	Randomised selection 21 participants (method of randomisation not described); M/F 13/8, mean age 42 years, mean TBSA 19.8%; average time since injury 17 months, range 5 months to 50 months; marital status: 71% in relationship, 19% single and 10% widowed.	Face to face semi structured interviews.	Content analysis using MAX _{QDA} .	Adherence to pressure garment therapy was related to education and available resources.	Education and social support facilitates with adherence to burn therapy.
Rossi, Costa, Dantas, Ciofi-Silva and Lopes (2009) (Brazil)	Qualitative descriptive study.	To explore the cultural meaning and dimensions of the quality of life of Brazilian burn patients.	Purposive sample of 19 burn survivors and 11 relatives (7 wives, 1 husband, 2 mothers and 1 sister-in-law); M/F 12/7; age range 20 to 50 years; mean TBSA 33%, range 1% to 68%; 8 reported facial burns; Sustained burn approximately 6 months prior.	Direct observation and face to face semi structured interviews.	Thematic analysis.	The importance of returning to their pre injury status including independence, mobility, employment resuming interpersonal relations and leisure activities.	The importance of socio-cultural dimensions for burn survivors undergoing rehabilitation.

Author/s, year and country	Design	Purpose	Sample and study population	Data collection method	Method of analysis	Significant finding/s and outcome	Significance to burn rehabilitation
Williams, Davey and Klock-Powell (2003) (USA)	Qualitative descriptive study.	To explore burn survivors' adaption to a severe burn injury. Research questions: 1. How did the participants in this study experience the process of recovery from a severe burn injury? 2. What personal and environmental factors appeared to influence the survivors' recovery process?	Purposive sample of 8 adult burn survivors; M/F 4/4; mean age at time of injury 29.6 years; mean age at time of interview 41.75 years; mean age at time of injury 29.63 years; 2 of the participants were African American, 3 Latino heritage and 3 Caucasian. Marital status: 3 married, 1 widow 4 single.	Face to face semi structured interviews.	Thematic analysis.	The primary themes that emerged encompassed losses, gains, adaption and coping with change and relationships with others.	The importance of burn professionals' role in facilitating burn survivors' adjustment and the transition to regain their lives.
Wu, Zhai and Liu (2009) (China)	Descriptive phenomenological study.	To describe the differences in coping strategies that affect psychological and physical rehabilitation in Chinese burn patients.	Purposive sample of 8 adult burn survivors; M/F 6/2; mean age 39, range 22 to 54 years; mean TBSA 67%, range 30% to 98%. LOS ranged from 4 to 68 months.	Face to face Semi structured interviews.	Case study analysis.	Optimistic personality, positive coping styles and social support were vital to the rehabilitation process.	Social support is a critical element to the burn rehabilitation process.

Results

Study characteristics

There were 13 primary research papers that incorporated 184 participants conducted across eight different countries. One study was conducted in Australia (Na, 2008), three studies were conducted in Brazil (Ciofi-Silva, et al., 2010; Costa, et al., 2008; Rossi, Silva Costa, Dantas, Ciofi-Silva, & Lopes, 2009), one study utilised a Chinese setting (Wu, Zhai, & Liu, 2009), two originated from the United States of America (Badger & Royse, 2010a; Williams, et al., 2003), two studies were conducted in Norway by the same primary author (Moi & Gjengedal, 2008; Moi, et al., 2008), two were from settings within Sweden (Dahl, Wickman, & Wengstrom, 2012; Oster, et al., 2010), another was conducted in Germany (Ripper, Renneberg, Landmann, Weigel, & Germann, 2009) and one in the United Kingdom (Mackey et al., 2009). Among the studies that reported the participants' age and TBSA, the mean age was 41 years with a mean TBSA of 34%. The ages ranged from 18 to 74 years of age. Only one study did not specify the ages only stating that participants were of working age (Mackey, et al., 2009). Most studies specified the time period after the initial burn injury with participants interviewed after discharge ranging from five months to 50 years. Of the studies that reported the TBSA, the range was wide ranging from 1% to 98%. Three studies reported if participants had a significant facial burn (Badger & Royse, 2010a; Ciofi-Silva, et al., 2010; Na, 2008). All but one study (Mackey, et al., 2009) stated the number of males to females with men sustaining significantly more burns than women. Only four studies reported the length of stay during hospitalisation (Dahl, et al., 2012; Moi & Gjengedal, 2008; Oster, et al., 2010; Wu, et al., 2009) ranging from one day to 68 months (5 years). Surprisingly, only five studies reported the marital status of participants (Ciofi-Silva, et al., 2010; Na, 2008; Oster, et al., 2010; Ripper, et al., 2009; Williams, et al., 2003) and only five addressed the issue of return to work (Ciofi-Silva, et al., 2010; Mackey, et al., 2009; Na, 2008; Oster, et al., 2010; Williams, et al., 2003).

The review incorporated a broad perspective on burn survivors' perceptions and experiences of burn rehabilitation addressing burn survivor peer support (Badger & Royse, 2010a), adherence to therapy (Ripper, et al., 2009), the return to work (Ciofi-Silva, et al., 2010; Mackey, et al., 2009; Na, 2008; Oster, et al., 2010; Williams, et al., 2003), quality of life (Costa, et al., 2008; Rossi, et al., 2009), adaption and coping (Dahl, et al., 2012; Moi, et al.,

2008; Wu, et al., 2009) and regaining independence and the reintegration into society (Ciofi-Silva, et al., 2010; Moi & Gjengedal, 2008; Na, 2008; Williams, et al., 2003).

Four themes were identified in this integrative review: The influence of support, coping and acceptance, the importance of work and physical changes and limitations.

The influence of support

Support was identified in all 14 papers reviewed and organised into three categories: Support provided by family and friends, professional support and peer support.

Family and friends

Social and physical support from family, friends and significant others was a significant factor found in this review of the literature. Rossi, et al. (2009) indicate that family support provides a better quality of life and facilitates coping strategies:

I think that my strong will to continue comes from my family. I think that this support from my family, my husband, the companionship, everything helps me (p. 717).

Moi, et al. (2008) also found that family and friends gave burn survivors the motivation necessary to recover:

I just feel, she [his wife] had belief in me all the time, always saying: 'Oh no, you're so stubborn, you'll get going again.' From day 1 she said that; she had belief in me all the time, and she was right (p. 283).

Badger and Royse (2010a) plus Ciofi-Silva, et al. (2010), despite reporting that the participants experienced positive and uplifting relationships that facilitated their recovery, also noted that they encountered difficult and insensitive experiences with family members and friends after their burn injury. Ciofi-Silva, et al. (2010) state that several participants experienced adverse changes in their relationships:

I do not like that my husband look at my body. He always remembers my condition (burnt person) and says that he will try to find a new woman (p. 435).

Badger and Royse (2010a) described a shift and a loss of relationships particularly with friends:

A great many of people that I spent a lot of time with before I was burned have since disappeared...I knew that if I talked about it, it would help me understand. I needed somebody to stop long enough to listen. And people didn't want to hear it (p. 70).

Na's (2008) study highlighted negative experiences with relatives and friends of burn survivors and also describes in contrast how total strangers assisted:

People, (a) couple of strangers ... put on meals and pick up the kids and do things ... people we barely know ... just come in and helped. (Na, 2008, p. 69)

Professional support

Identified in the literature, was the lack of or limited knowledge and education afforded to burn survivors by healthcare professionals concerning therapy and wound care during their rehabilitation (Dahl, et al., 2012; Oster, et al., 2010; Ripper, et al., 2009). Dahl (2012) demonstrated the lack of education, information and assistance:

Information is important about treatment and medication and what is going to happen, I did not get any information...there is always a lack of information...for those who work here everything is self-evident (p. 6).

The transition from the burns unit to a district hospital or home created insecurities and negative experiences as the primary responsibility for care was handed over to the burn survivor and their families. Participants in Moi et al.'s (2008) study revealed that after discharge from the burns centre, participants experienced wound breakdown and a restriction in their mobility that were a significant source of stress. Na (2008) highlighted the importance of feeling secure and familiar with the treating health professionals. In the absence of familiarity, the perception of a potential threat was evident:

I didn't really feel like he understood me or what I've been through ... I sort of broke down ... 'cause he just sort of put a couple of dressings on me and sent me on my way (p. 83).

Others were emotionally unprepared with a lack of professional support:

When I came home I suddenly felt unsafe, I was sad and I was close to tears and felt confused because I did not recognise my own feelings (Dahl, et al., 2012, p. 7).

A lack of educational support from burns personnel facilitated non-compliant behaviours as demonstrated in Ripper et al.'s (2009) study with participants displaying little knowledge of why they should adhere to burn therapies:

It hurt terribly and I had no idea why I should wear it – they just told me that I should (p. 660).

For example I didn't know in the summer: "Do I need to put sun protection underneath?" [underneath burn compression garments](p. 660)

In fact, 57% of participants in Ripper et al.'s (2009) study identified that a lack of education concerning the purpose and aim of pressure garment therapy contributed to non-adherent behaviours.

Peer support

The significance of peer support during rehabilitation that empowered burn survivors was reported in half of the papers reviewed. One paper in particular focussed on burn survivors' perception of peer support (Badger & Royse, 2010a). Participants from Badger and Royse's (2010a) study reported that their lives had changed by the acquisition of hope for the future and gaining a perspective as a result of burn survivor peer support:

Visualize a future. Seeing someone who is happy, doing things allows burn survivors to rebuild lives. People can tell you [that you can rebuild your life] but you can't see it without a real example (p. 306).

A participant from Oster et al.'s (2010) study highlighted the power of peer support for burn survivors:

When you meet someone who really knows what you're going through, you can discuss things in a different way (p. 545).

Badger and Royse's (2010a) study also echoed Oster et al.'s (2010) findings demonstrating how speaking with other burn survivors was an empowering action:

Amazing to have someone know what it [recovery] is about...the itching, emotional/hormonal roller coaster...Other support systems don't have a road map like burn survivors do. (p. 305)

Evident in several papers reviewed was the credibility that peer support brought to burn rehabilitation. Health professionals have the knowledge and expertise to treat and manage burn injuries however; they lack actual experiences that can only come from those who have experienced being burnt:

Credibility that comes from burn survivors. It is okay to ask questions. There is trust because the information comes from someone other than a health professional (Badger & Royse, 2010a, p. 307).

Peer support was a means for burn survivors to not only receive support but also, to give support to other burn survivors. Williams, et al. (2003) found that survivors engaging in peer support experienced a significant positive change in their attitude providing comfort from reaching out to others:

That was my emotional healing, that I wanted to go help someone (p. 69).

Additionally, Badger and Royse (2010a) also found that burn survivors providing peer support helped themselves:

It made me address my issues. Helping others forces one to grow and heal. (p. 308)

Coping and acceptance

Much of the literature reviewed focused on the psychological impact of a burn injury. However, a common theme found among the literature reviewed was the notion of coping and acceptance. Coping strategies were identified as influential in the rehabilitation journey. Accepting the unchangeable was often difficult as portrayed by a participant in Moi and Gjengedal's (2008) research:

I take one day at the time. I keep to the time horizon they [the burn unit staff] have given me, one and a half to two years, and this I can manage. But if next year they tell me that I have to continue [treatment], I do not know how I will react (p. 1626).

Another approach to coping found in the literature was to adopt a pragmatic attitude enabling patients to progress through their rehabilitation. Pain was addressed by all papers reviewed as a reality of burn rehabilitation. However, coping often required a specific mind set as a participant in Dahl et al.'s (2012) demonstrated:

You learn to live with the pain...you can't do anything about pain...the body has to heal and there is no other way out...you support and adapt to pain...and you say to yourself that this is going to be good...not expect the pain to disappear completely (p. 5).

As a result of sustaining a severe burn injury, depression and anxiety were found to negatively influence a patients' ability to cope. Wu, et al. (2009) found that a prolonged hospitalisation facilitated 'endless negative thoughts'(p. 891) that affected patients' physical and psychological well-being. While Williams, et al. (2003) found depression and feelings of intense anger were universal among the participants of their study:

I would say my first year there was a lot of anger, emotionally, a lot of "what ifs" (p. 68).

Dahl, et al. (2012) found that even patients with minor burns also experienced psychological issues six to eight months after discharge from the burns unit. In fact, patients with minor burns and short hospital admissions seemed to experience traumatic memories of the injury making coping difficult (Dahl, et al., 2012).

Four papers (Ciofi-Silva, et al., 2010; Costa, et al., 2008; Rossi, et al., 2009; Williams, et al., 2003) focused on spirituality and religion as a coping mechanism that provided strength and support:

I think He, God, gave me the strength to get through it (Williams, et al., 2003, p. 68).

However, religion and spirituality was also used as a form of rationalising and questioning the reason for the burn that made the process of acceptance difficult:

I think that it was a punishment because I abandoned my religion (Rossi, et al., 2009, p. 716).

Before the accident I always felt that it was every man's obligation to be compassionate... that we were, indeed, responsible for our brothers. Immediately after the accident, it was almost like, "God I've given you everything and you've taken everything away from me" (Williams, et al., 2003, p. 69).

Common to six papers (Costa, et al., 2008; Dahl, et al., 2012; Moi & Gjengedal, 2008; Na, 2008; Rossi, et al., 2009; Wu, et al., 2009) was to employ the coping strategy of comparing

oneself with others who they perceive were in worse situations or to reframe the experience claiming that it could have been worse. This coping strategy offered burn survivors a form of comfort and compensation (Costa, et al., 2008) that assisted with coping and acceptance of their burn injury:

I'm lucky that I did not get any hot water in my face...and then it could be much worse...when I see other people who have cancer and everything with that...I'm grateful... (Dahl, et al., 2012, p. 6).

A participant from Williams, et al.'s (2003) study also illuminated rationalising behaviour:

I know it was fortunate and that I survived this tragic event. So it wasn't my time and I think I was lucky because I didn't lose my eyesight (Williams, et al., 2003, p. 67).

The importance of work

From the studies reviewed, participants in five out of 14 papers reported returning to work as an important rehabilitation goal (Ciofi-Silva, et al., 2010; Dahl, et al., 2012; Mackey, et al., 2009; Oster, et al., 2010; Rossi, et al., 2009). These authors have clearly demonstrated how the participants' have experienced disruptions, difficulties and financial implications concerning limitations that encompassed: a leave of absence, forced retirement, difficulties with adapting to the work environment, poor performance, loss of job, change of employment and difficulties in attaining new employment. The following narratives illustrate the experiences of vocational changes as reported by participants:

I used to do other activities at work but, after the accident, my arms ache; my hands are good, but I do not have strength in them and my fingers ache (Ciofi-Silva, et al., 2010, p. 434).

I had an extra job working as an electrician. I have already resumed this activity at home, fixing things to test my limits and preparing myself to resume activities at the sugar cane mill. I know that it will not be possible to resume the activities I had before the accident happened, because I can't stay in the sun for a long time, my skin is very sensitive to sun exposure, hot weather and also to air conditioning (Rossi, et al., 2009, p. 715).

The limitations experienced when returning to work included burns to the hands and upper limbs, hypertrophic scarring and contractures, pain, skin hypersensitivity, ongoing

psychological issues, difficulties with reintegration into the work force and the reaction of others (Ciofi-Silva, et al., 2010; Oster, et al., 2010; Rossi, et al., 2009). Additionally, Ciofi-Silva, et al. (2010) state that 68.7% of participants that sustained burns to upper limbs reported some form of change in their vocation compared to those who sustained burns on other areas of anatomy. However, some participants in Mackey, et al.'s (2009) study experienced no change in their work as a consequence of their burn injury and returned to the same employment having made a full recovery both physically and psychologically. Both Mackey, et al. (2009) and Oster, et al. (2010) in particular, focus on the participants' perception of barriers and facilitators of returning to work after a significant burn injury. The individual characteristics of burn survivors such as a positive outlook, adapting, motivation and having set rehabilitation goals, social, employer and health professionals' support, were influential in facilitating the return to work process (Mackey, et al., 2009; Oster, et al., 2010).

It's not like I remember having any problems with training, I had goals and once I've made up my mind about it, then I can also do it, it doesn't matter how much outside influence there is... You can get care and support and everything but if you don't have the will yourself you don't get any further (Oster, et al., 2010, p. 543).

But health care personnel are enormously professional; I've experienced that as very positive. It was a lot more than a burn injury and everyone was affected by it, you could say...(Oster, et al., 2010, p. 545).

Oster, et al.'s (2010) study demonstrates that a supportive and compassionate employer providing flexibility was perceived as important:

The company agreed that I could shuffle along in ordinary slippers and with crutches and do lighter work, paperwork and that kind of thing (p. 546).

However, significant barriers experienced in returning to work were reported as a lack of psychological assistance, fear of the workplace coupled with physical impairments, no specific rehabilitation plan or individualised training and the wait for reconstructive surgery (Mackey, et al., 2009; Oster, et al., 2010). In addition, Oster (2010) found that a lack of primary care regarding limited knowledge of wound care impacted on poor wound healing and infections that unduly delayed the return to work:

The first district nurse I saw, she was like this, I mean, almost just standing there with her mouth hanging open and saying, "My god, it's really a lot," and so on... Yes, it

was strange; you don't feel secure, because it was as if she (district nurse) was unsure, she'd had more education than I have...if she didn't know what to do then, well, it would be difficult. So I had to explain what she should do. Well you can't put it on tight, you have to use Vaseline first and then put the dressing on, otherwise they'll stick.(p. 545)

One point that should be considered concerning Oster's (2010) study that focused on burn survivors' perception of facilitators and barriers in returning to work, is that not all the illustrations provided in Oster's study are necessarily specific to returning to work and at times address issues that concern burn injury in general.

Physical changes and limitations

Evident in each article reviewed was the physical and emotional trauma experienced. Most of the papers reviewed addressed the physical changes and limitations experienced from the burn injury. Identified as problematic areas were; pain, altered physical appearance, burn wound and scarring and physical limitations that were commonly experienced by burn survivors.

Pain

The ongoing physical pain was identified as a significant factor that negatively affected burn survivors' rehabilitation in 10 of the papers reviewed. Williams, et al. (2003) highlighted that participants experienced and perceived pain in different ways. Pain was a difficult bodily sensation to cope with which according to Moi and Gjengedal (2008) has the potential to alter burn survivors' perspectives on life. One participant in Mackey et al.'s (2009) study stated that pain was a primary reason for not returning to work. While participants in Dahl et al.'s (2012) study stated that they were still experiencing pain and altered sensations that include heat, itching, smarting pain, cold and pricking pain. Moi et al.'s (2008) findings also concur with Dahl et al.'s (2012) that participants often experiencing smarting and pain.

Ripper et al.'s (2009) study revealed that pain was a significant factor in non-adherence to pressure garment therapy with almost half of the participants referring to the pain as a difficulty while wearing the pressure garment. Furthermore, half of the participants experienced altered sensations with more than a third, mentioning burn itch as a major concern.

Issues with pain medications and withdrawal were reported by Dahl, et al. (2012), Na (2008) and Oster, et al. (2010). Difficulties experienced included withdrawal symptoms and the reduction and cessation of pain medications. Four participants in Oster, et al.'s (2010) study experienced withdrawal symptoms with participants stating that it was essential to cease taking pain killers prior to returning to work, however were ill equipped to do so. These participants experienced increased pain upon a reduction of medication and felt unprepared, emphasising the importance of education and support. A participant in Na's (2008) study revealed that pain medication although suppressing the pain, interfered with rehabilitation limiting their functioning more so than the burn injury itself claiming "I feel that those tablets had actually dragged me down probably for lot longer than what I even really realised" (Na, 2008, p. 58). Another participant experienced difficulties with taking strong pain killers for an extended period and endured the pain to be able to live a normal life:

I don't want to be on strong pain killers all my life ... I'd much rather endure the pain and try and function as normal as possible (Na, 2008, p. 70).

Coping and managing the physical pain is a challenge for burn survivors. Williams, et al. (2003) and Oster, et al. (2010) both report on the difficulties with coping and managing burn pain. A participant from Williams, et al.'s (2003) study was made to debride devitalised skin off their body after premature discharge from hospital:

The physical therapist had said you have to debride yourself so uh...but I didn't know what to really debride with, so I finally took a razor blade and I would just cut the adhesions that would start...looking back, I don't know how I did it (Williams, et al., 2003, p. 64).

While others realised that pain was an inevitability and part of the rehabilitation journey in which "you learn to live with pain" (Dahl, et al., 2012, p. 5).

Altered physical appearance

The literature reviewed described an altered physical appearance as variations in colouring of grafted skin and donor sites in an assortment of colours, shades and textures with thick, raised scars with some burn survivors experiencing facial disfigurement. Participants of Moi, et al.'s (2008) study perceived their bodies as unfamiliar. Looking at oneself was a difficult experience that was a constant reminder of the trauma experienced: "this body, this thing with the arm, it is like I am reminded of it a hundred, 200, 300 times a day" (Moi, et al.,

2008, p. 282). Moi, et al. (2008) also conveyed an altered body image by this powerful statement:

I was not very pretty before [the accident], but I was a normal person and suddenly you see a person in the mirror, without hair and with an ugly face, and you think, ‘That is not me!’ Even though I knew it was me I saw in the mirror, I refused to admit it was me. It was painful, indescribable. Me, like that (p. 281).

Experiencing an altered physical appearance had a significant impact on burn survivors’ body image which was evident throughout the papers reviewed that triggered feelings of isolation as demonstrated by a participants in Dahl et al.’s (2012) study:

I’m more depressed now than before...anyway in a mental aspect...I look different and I’m trying to cover my body with a sweater even when it’s warm outside... I’m not such an open person anymore...I’m hiding more today (p. 4).

Reintegration back into the community was difficult with an altered appearance that engendered feelings of stigmatisation. A participant in Rossi et al.’s (2009) study felt like an attraction stating “I am a tourist attraction. I need to stop in the street to tell people about the accident” (p. 716). Moi, et al.’s (2008) study also highlighted thoughts of what people might be thinking

“so to be in public areas, and look as normal, that was difficult” (p. 281).

Na’s (2008) study identified participants that reported feeling afraid in public areas due to their altered appearance and the potential for interaction with strangers. However other studies reviewed portrayed a positive light on an altered appearance, stating that the visible scars were “a bit like tattoos...they just tell a better story” (Mackey, et al., 2009, p. 340) and “Friends tell me it is not that bad after all and that the glove I am wearing is really cool” (Ripper, et al., 2009, p. 661).

Physical limitations

A primary goal of burn rehabilitation is the optimal restoration of function. The review of literature demonstrates the physical limitations and challenges experienced. Barriers and challenges experience by burn survivors encompassed loss of physical functioning, scarring, amputations, difficulty with walking and performing activities of daily living (Costa, et al., 2008; Dahl, et al., 2012; Mackey, et al., 2009; Moi & Gjengedal, 2008; Na, 2008; Williams,

et al., 2003) issues with pain (Dahl, et al., 2012; Mackey, et al., 2009; Moi, et al., 2008; Na, 2008; Oster, et al., 2010; Williams, et al., 2003) adherence to pressure garment therapy (Ripper, et al., 2009) challenges experienced with employment and returning to work (Ciofi-Silva, et al., 2010; Dahl, et al., 2012; Mackey, et al., 2009; Oster, et al., 2010; Rossi, et al., 2009) burn wounds and infections (Moi & Gjengedal, 2008; Na, 2008; Oster, et al., 2010).

Physical limitations encountered by burn survivors triggered such emotions as frustration, anger and grief as expressed by a participant in Moi, et al.'s (2008) study:

In the beginning it was hard – (it would have been) almost peculiar if it hadn't been so. After having woken up realizing that all muscles were on vacation, everything was an effort. I just couldn't see any light at the end of the tunnel by then (p. 282).

Simple tasks such as getting dressed became a significant problem as this burn survivor stated that “until I found out how to dress and close that zipper – that was a real battle” (Ripper, et al., 2009, p. 661). The scars that developed as a result of the burn created physical limitations by means of restricting movement:

I feel that they [the scars] will pull me even more downwards. Yes, the strings go all the way down, and on this side they are very thick and tight (Moi, et al., 2008, p. 282).

However, despite the physical limitations experienced, studies illuminated how some burn survivors perceived small steps as a significant turning point in their rehabilitation:

My best moment was when I managed some steps with the walking frame from the bed – I moved! That's when I started to see things in a brighter perspective (Moi, et al., 2008, p. 283).

Even the smallest achievement gave some form of accomplishment as with this participants perception stating “there were times when if they moved it one micrometer that was cause for celebration” (Williams, et al., 2003, p. 66).

Discussion

Limitations and strength of evidence

This integrative review presented in the current study is limited by the small number of original papers identified for review. The review primarily integrates qualitative studies

concerning burn rehabilitation. Subsequently, the incorporation of quantitative data although contributing to the body of knowledge for the management of burn injuries, does little to illuminate the subjective perspectives and experiences of those rehabilitating from a severe burn injury. Furthermore, the importance of methodological congruence within the review requires consideration. The incorporation of quantitative research could have been construed as incongruent threatening the trustworthiness and rigour and furthermore not reflecting the qualitative philosophy underlying the current study. The participants incorporated into the integrative review consisted mainly of men. However, this is consistent with other findings that report men to have a higher incidence of burn injury than women due to occupational risk factors leaving them prone to industrial accidents (Kara, Gok, Horsanli, & Zencir, 2008; Wasiak, et al., 2009). There is a wide range of ages from 18 to 74 years and a varied TBSA burned from 1% to 98%. The diversity of age and TBSA found in the studies demonstrates the limited amount of literature that incorporates the subjective perspectives and experiences of rehabilitation of adults with severe burns further limiting the results found in this review. Despite this diversity in burn injury and age, the papers reviewed did describe subjective perceptions and experiences that were comparable with each other. Whilst informative, the issues raised may limit the applicability and transferability of the synthesised results to other fields of rehabilitation. Additionally, the transferability is also limited by the inclusion of papers mainly from developed countries while the incidence and occurrence of severe burns is considerably higher in underdeveloped countries (Dissanaike & Rahimi, 2009). Several studies included in the review were conducted in languages other than English. The narratives have been translated into English that allowed the authors of the original papers to publish in an English speaking journal. However, this process may have led to the meaning and context of the narratives being lost.

The other limitation that needs consideration is that in reviewing the primary research the reader is restricted to the illustrations as reported in the studies. In some cases the reporting of the findings and the illustration presented in this literature review may not quite fit the case in point. This then raises the question of the validity and credibility of the findings. However, no formal critical appraisal was conducted as the aim was to be inclusive of the reported findings therefore the reader must then determine the credibility of the findings. Notwithstanding these limitations, conclusions can be made about the perceptions and experiences that influence burn rehabilitation.

Significance to burn rehabilitation

With significant long term physical and psychological morbidity associated with a severe burn injury, the complexity of care involved in the rehabilitation of patients with severe burns requires a multidisciplinary approach. The diverse problems associated with severe burn injury encompassing physical and psychological functioning, activities of daily living, socialisation and returning to work highlight the importance of a solid social support structure incorporating both family and friends, health professionals and more recently the involvement of peer support.

Ongoing educative support to the health professionals, burn survivors and their family is an important element in burn rehabilitation. There is a necessity for appropriate knowledge and education based programmes for burn survivors with consideration given to the timing and delivery of education to facilitate the rehabilitation journey. Research that explores the broad understanding of burn survivors' experiences and perceptions of both the physical and psychological rehabilitation following a burn injury in the Australian context is essential in that it suggests and informs a multidisciplinary approach leading to possible education and research development.

Conclusion

This chapter has systematically synthesised research selected through an integrative review process relating to burn survivors' experiences and perceptions of rehabilitation. The findings of this integrative review enabled the exploration of voice and narrative of those who have experienced a severe burn and the subsequent rehabilitation. These included primarily qualitative research enabling a comprehensive representation of data available about the perspectives of rehabilitation for those with severe burn injuries. The review highlights that burn survivors encounter significant factors that influence experiences and perceptions of rehabilitation incorporating social support, in particular the significance of peer support, coping and acceptance, issues concerning returning to work and the physical changes and limitations experienced. Despite these factors being cornerstones in the rehabilitation of burn survivors, the Australian experiences that burn survivors attribute to their rehabilitation after a severe burn injury have not been explored in the studies reviewed. This gap in the literature is the focus of the current research. The next chapter is a discussion of the research methodology, which is situated in the qualitative framework of descriptive phenomenology which underpins the research presented in this thesis.

CHAPTER THREE

METHODOLOGY

Introduction

Chapter three describes the methodology that underpins the research presented in this thesis and which is grounded in descriptive phenomenology as described by Edmund Husserl. Therefore the focus of the chapter is to explore the philosophical foundations of phenomenology and phenomenology as a research methodology. The chapter commences with an overview of phenomenology and its historical roots and perspectives which then leads into a discussion concerning the two distinct schools of Husserlian and Heideggerian phenomenology. Descriptive phenomenology as a research methodology is examined and the relevance to healthcare discussed. The utilisation of a Husserlian phenomenological approach to investigate the exploration of burn survivors ‘lived experience’ of rehabilitation is justified.

Phenomenology

Deriving from the Greek verb *phainómenon*, phenomenology consists of two words *phainómenon* and *logos* (Moran, 2000). Its origins date back to ancient Greek philosophy with Aristotle known to have used the word *lógos* to denote discourse (Hartford, 2010). The word phenomenology roughly translates to ‘*that which shows itself, and discourse*’ (Hartford, 2010, p. 17). However, the true meaning of the English term *phenomenon* has little to do with appearance; rather it “describes the showing of itself, in itself, of an entity” (Hartford, 2010, p. 32). The suffix –logy, comes from the ancient Greek word, *logos* (Hartford, 2010) meaning ‘study’ or ‘concept’ (Kruger, 2011; Moran, 2000). Consequently, phenomenology can be broadly described as the body of discourse or the study of phenomena (Hartford, 2010).

Phenomenology is an arm of philosophy that involves the study of phenomena with the goal of describing the ‘lived experience’ (Streubert & Carpenter, 2007). The object of phenomenological research are the participants’ experiences (Mortari & Tarozzi, 2010). Phenomenology evolved as an alternative to quantitative scientific methods utilised within the field of social sciences (Pascal, 2010). Herbert Spiegelberg, an American philosopher who was a prominent figure in the advancement of the phenomenological movement, defined phenomenology as:

...the name for a philosophical movement whose primary objective is the direct investigation and description of phenomena as consciously experienced, without theories about causal explanation and as free as possible from unexamined preconceptions and presuppositions (Spiegelberg, 1975, p. 3).

Phenomenology seeks the truth and logic via critical and intuitive thinking of human existence (Jones, 2001b). However, it is important to note that phenomenology refers to a philosophy and a research approach frequently used by qualitative researchers (Dowling, 2004). As a philosophy, phenomenology is the “search for a real beginning of all philosophical thinking” (Schutz, 1962, p. 101).

As a methodology, phenomenology has become widely held within the domain of qualitative research (Dowling, 2007) with contemporary researchers embracing the phenomenological methodology as a means to explore and describe human experience (Barkway, 2001; Caelli, 2000). Centred on the exploration, the ‘lived experience’ is the process of constructing meaning of human experience through the discourse of those that are living the experience (Streubert & Carpenter, 2007). It is a way of seeing “the unprejudiced, descriptive study of whatever appears to consciousness, precisely in the manner in which it so appears” (Moran, 2002, p. 1). Phenomenology endeavours to view the phenomenon with fresh eyes, uncontaminated by prior knowledge or scientific impositions (McNamara, 2005). Fundamentally, phenomenology seeks to understand the essence of the individuals’ experiences. Merleau-Ponty (1956), a French phenomenological philosopher, considered that a phenomenological approach provided greater insight into understanding human experiences with perception being pivotal to experiences:

Perception is not a science of the world, nor even an act, a deliberate taking up of a position. It is the basis from which every act issues and it is presupposed by them. The world is not an object the law of whose constitution I possess. It is the natural milieu and the field of all my thoughts and of all my explicit perceptions. Truth does not “dwell” only in the “interior man” for there is no interior man. Man is before himself in the world and it is in the world that he knows himself. When I turn upon myself from the dogmatism of common sense or the dogmatism of science, I find, not the dwelling place of intrinsic truth, but a subject committed to the world (p. 62).

Phenomenology has and continues to be a fundamental methodology in the field of social and health sciences. There are numerous schools of phenomenology and although all share a common thread, they all have distinct characteristics. In the main, there are four distinct perspectives of phenomenology. These are the positivist (Husserl), interpretivist (Heidegger), constructivist (Gadamer) and post-positivist (Merleau-Ponty) (Dowling, 2007). Although these philosophers did not develop methods of research per se, their philosophy is often

utilised as a framework for qualitative research methodologies (Fleming, Gaidys, & Robb, 2003). For the reported study, phenomenology is an appropriate methodology to explore the 'lived experience' of rehabilitation after a severe burn injury as it is a valuable and effectual methodology in the exploration and description, of the way the phenomenon appears. As such, it is expected that the participants in the reported study recount their perceptions when describing the 'lived experience' of rehabilitation after a severe burn injury. It is these lived experiences that are not open to an empirical interpretation, and therefore a descriptive phenomenological framework would capture and unearth how humans experience the world in which they live (Rapport & Wainwright, 2006).

The historical, philosophical and methodological perspectives of phenomenology are of importance as they allow researchers to gain an insight into the development and transformation of phenomenology. Therefore the next part of this chapter will present the historical development of phenomenology that has spanned across several centuries.

Overview of the historical perspective of phenomenology

Historically, the roots of phenomenology emerged during the first decade of the 20th century. Phenomenology as a philosophy arose out of Germany prior to World War I and during this period "remained by and large a German affair" (Spiegelberg, 1982, p. 20). Although, prior to this, 18th century philosophers such as Immanuel Kant and Georg Hegel used the term phenomenology leaving an enduring mark on philosophy today (Moran, 2000). In fact, Hegel's first major comprehensive philosophical work, 'Phenomenology of Spirit' published in 1807, is a detailed account of the development of consciousness and self-consciousness in the context of fundamental epistemological, anthropological and cultural themes of history (Duquette, 2005). Phenomenology has emerged as a dominant philosophical movement (Dowling, 2007) and greatly influenced social psychology, sociology and anthropology (Jones, 2001b). There has been a clear movement away from empirical methods within the social sciences with phenomenology emerging as a rigorous qualitative method having a legitimate standing amongst the scientific community (Giorgi, 2005). However, the rigour of phenomenology involves exploring the historical foundations to clearly understand its fundamental concepts and true meaning (Cohen, 1987).

Describing the historical development of the phenomenological movement can be demonstrated with the emergence of three separate phases as described by Spiegelberg (1982). Spiegelberg used the term 'movement' to demonstrate that phenomenology is not a

stationary philosophy but is dynamic changing significantly across differing philosophers and in addition, within each philosopher (Cohen, 1987). The preparatory phase incorporated the pioneers of phenomenology with the contributions from Franz Brentano (1838-1917) and Carl Stumpf (1848-1936) (Jones, 2001a; Streubert & Carpenter, 2007). The German phase encompassed Edmund Husserl (1857-1938) and Martin Heidegger (1889-1976) as prominent and influential figures during the German phenomenological movement (Streubert & Carpenter, 2007). Finally the French phase, was a uniting of Husserl's phenomenology to existentialism that saw the likes of Gabriel Marcel (1889-1973), Jean-Paul Sartre (1905-1980) and Maurice Merleau-Ponty (1908-1961) become prominent figures of the phenomenological movement (Jones, 2001a). A description of the three phases of phenomenological development is further described below.

Preparatory phase

The preparatory phase commenced in Vienna during the 19th century, with Franz Brentano and Carl Stumpf. A prominent student of Brentano's, Stumpf was strongly influenced by Brentano, who developed the idea of experimental phenomenology involving the analysis of data by means of empirical methods and it was Stumpf who named phenomenology a foreknowledge (Jones, 2001a). Brentano's goal was to transform philosophy to provide answers that religion could not provide (Cohen, 1987). His book 'Psychology from an Empirical Standpoint' first introduced the concept of intentionality. A significant contribution to phenomenology was Brentano's idea of intentionality, a concept that became fundamental to all phenomenological analyses (Cohen, 1987) with the notion 'that the mind is directed toward objects' (Koch, 1995, p. 829). Brentano used the phrase 'descriptive phenomenology' which was to motivate a student of Brentano's, Edmund Husserl, who developed the form of phenomenology (Dowling, 2007) which led into the German phase.

German phase

The second phase of the phenomenological movement is known as the German phase and was dominated by prominent philosophers Edmund Husserl and Martin Heidegger. Husserl is considered and still remains the central figure of the phenomenological movement (Cohen, 1987). Husserl's goals were of an epistemological nature that regarded experience as the basis of all knowledge (Racher & Robinson, 2003). Husserl believed that science required a philosophy that would connect with human concerns (Cohen, 1987). Three key phenomenological concepts that Husserl developed were 'intentionality', 'essences' and 'phenomenological reduction' (bracketing).

Heidegger, an established scholar and assistant of Husserl, considered phenomenology not to be integral to his philosophy (Cohen, 1987; Jones, 2001a). Heidegger linked phenomenology to existentialism where his main interests were concerned with ontology and temporal issues related to authenticity and the notion of 'being in the world' proposing the notion of hermeneutics (Jones, 2001a). Perhaps Heidegger's greatest contribution to the phenomenological movement was the motivation and inspiration that Heidegger gave to the philosophers of the French phase.

French phase

Out of the French phase came the development of existentialism. After the rise of the Nazism in Germany, the development of phenomenology moved from Germany to France with the conception of the French phase of the phenomenological movement. The prominent existential phenomenologists were Gabriel Marcel, Jean-Paul Sartre and Maurice Merleau-Ponty. Sartre expressed a belief in "individuals' total freedom and responsibility for their world" (Cohen, 1987, p. 33). However, Merleau-Ponty influenced by Marcel, was more concerned with science. He wanted to demonstrate that a science of human beings was achievable with perception being the basis for adding valuable insights to understanding (Cohen, 1987). Merleau-Ponty's most prominent published work 'The phenomenology of perception' was where he developed the notion for the importance of considering the individuals' experiences (Cohen, 1987). Merleau-Ponty proposed that the goal of phenomenology was to rediscover what he termed the 'primacy of perception' (Racher & Robinson, 2003), the essence of perception and of consciousness. Fundamental concepts developed during this phase were embodiment and the notion of 'being in the world' (Streubert & Carpenter, 2007). These concepts encompassed the belief that all acts are built on the foundations of perception (Streubert & Carpenter, 2007).

Descriptive and interpretive phenomenology

There are differing styles practiced under the banner of phenomenological research. However, there are two main approaches of phenomenological research being descriptive (eidetic) and interpretive phenomenology (hermeneutic) (Bradbury-Jones, Sambrook, & Irvine, 2008; Lopez & Willis, 2004). These methodologies are underpinned by the phenomenologists, Edmund Husserl (descriptive) and Martin Heidegger (interpretive) (Bradbury-Jones, et al., 2008; Rapport & Wainwright, 2006). Both Husserl and Heidegger provide the underlying philosophy for phenomenological research (Stubblefield & Murray,

2002). There is a distinct difference between Husserlian and Heideggerian phenomenological methodology. The Husserlian approach is of an epistemological nature based on the study of knowledge whereas Heideggerian phenomenology is ontological, concerned with the study of being. The epistemological perspective asks ‘*how do we know what we know?*’ and an ontological perspective asks ‘*what is reality?*’ (Mortari & Tarozzi, 2010). Both perspectives result in the development of knowledge enhancing understanding and insight into the investigated phenomenon, but their philosophical frameworks are different and how findings are generated have implications for the methodology utilised (Flood, 2010; Penner & McClement, 2008; Stubblefield & Murray, 2002). Interpretive phenomenology requires reinterpretation of the researcher’s prejudgements or preconceptions. However, a descriptive phenomenological methodology requires the suspension of the researcher’s own preconceptions in order to understand another’s experience (Stubblefield & Murray, 2002). In particular, a descriptive phenomenological approach aims to provide a description of phenomena as free as possible from presumptions with no causal explanation or theories considered (Spiegelberg, 1975). The next section of this chapter is a review of key concepts that underpin Husserl’s and Heidegger’s phenomenological methodologies.

Husserlian phenomenology

Edmund Husserl has been recognised as the founding father of the phenomenological movement that aimed to develop a discipline that described the world as it appeared with “absoluteness of conscious existence” (McCall, 1983, p. 56). Husserl believed that consciousness was the path to the material world in which all knowledge was a result of experience (Priest, 2002). Husserlian phenomenology is grounded in epistemology that utilises a rigorous scientific methodology in order to answer questions related to “how do we know it”? (Bradbury-Jones, et al., 2008, p. 664). It seeks to understand the participant’s *lebenswelt* that translates to lifeworld or ‘lived experience’. The emphasis is on illuminating and describing the essence of the phenomenon of interest perceived in everyday life experiences. Husserlian phenomenology is:

...in fact, a purely descriptive discipline, exploring the field of transcendently pure consciousness by pure intuition...pure or transcendental phenomenology will be established, not as a science of matters of fact, but as a science of essences (as an ‘eidetic’ science); it will be established as a science that seeks to ascertain exclusively ‘cognitions of essences (Kersten, 1989, p. 20).

As previously mentioned, three fundamental notions that are pivotal to Husserlian phenomenology are the concepts of ‘intentionality’, ‘essences’ and ‘phenomenological reduction’ (bracketing) (Racher & Robinson, 2003).

Intentionality

Intentionality is one of the core concepts of phenomenology. Husserl adopted his mentor, Brentano’s description of intentionality as the basis of understanding mental acts (Dowling, 2007). Intentionality can be defined in a narrow sense as “object-directedness” (Thompson & Zahavi, 2007, p. 71) however, in a broader sense, intentionality can be defined as an “openness towards otherness” (Thompson & Zahavi, 2007, p. 71).

Husserlian phenomenology proposes that consciousness is intentional in that its intent is for something that is beyond itself (Thompson & Zahavi, 2007). Husserl perceived intentionality as a process where the mind consciously directs thoughts towards objects (Lavery, 2003). Husserl believed that access to the structures of consciousness was a result of the grasping of phenomena (Lavery, 2003). It is the principle that every action is related to some object (Moran, 2000) and for Husserl, intentionality was the key to understanding human experience (Earle, 2010; Koch, 1995). Therefore, the construction of our understanding of reality should commence with conscious awareness (Koch, 1995) in which Husserl (1970) himself stated that:

Intentionality is the title which stands for the only actual and genuine way of explaining, making intelligible. To go back to the intentional origins and unities of the formation of meaning is to proceed towards a comprehension, which, once achieved would leave no meaningful question unanswered (p. 168).

For Husserl, the primary focus was the study of phenomena as it appeared through conscious awareness.

Essence

The word ‘essence’ is derived from the Greek “ousia”, which means the inner essential nature of a thing, “the true being of a thing” (van Manen, 1997, p. 177) and the Latin term ‘essentia’, from ‘esse’ means ‘to be’ (van Manen, 1997). Essence is the notion of what makes a thing what it is. Essentially, essence is the ‘whatness’ of things, as opposed to their ‘thatness’ that is their existence (van Manen, 1997). Husserlian phenomenology suggests that eidetic structures are common to all humans who have a ‘lived experience’ with the need to ‘return to the things themselves’ to the essence that constitutes the consciousness and perception of the phenomenon (Racher & Robinson, 2003). When the essence or essential

structure of a thing is put into words, those who have not experienced it can capture the essential characteristics in order to see what it is (Mortari & Tarozzi, 2010). Therefore, the essence of a phenomenon can be sequestered and analysed. Natanson (1973) emphasises that “essences are unities of meaning intended by different individuals in the same acts or by the same individuals in different acts”(p. 14). Essence is therefore the basic structure of understanding of a phenomenon (Streubert & Carpenter, 2007). It can be said that “phenomenology is the study of essences” (Merleau-Ponty, 1962, p. vii).

The current study explores the essence of the ‘lived experience’ of patients’ rehabilitation after a severe burn injury uncovering how they identified themselves within the world they live in order to understand their ‘lived experience’. Therefore this study seeks to identify the essence of the rehabilitation journey after a severe burn.

Phenomenological reduction

Phenomenological reduction is a key epistemological concept of Husserlian phenomenology (Dowling, 2007). Husserl (1970) described the process of phenomenological reduction as being above the ground and looking downwards and seeing things with great clarity:

It is from this very ground that I have freed myself through the epoché; I stand above the world, which has now become for me, in a quite peculiar sense, a phenomenon. (p. 152).

It is achieved through phenomenological reduction (bracketing) or otherwise known as epoché [εποχή], an ancient Greek word that dates back to Hellenistic philosophies, and in particular to scepticism, to neither accept nor refute (Mortari & Tarozzi, 2010). Phenomenological reduction describes the suspension of judgment, beliefs and preconceptions that allows the exploration of phenomena with a fresh perspective (Mortari & Tarozzi, 2010; Patton, 2000). It is the isolation of the pure phenomenon from what the researcher already knows, however, this is only possible when the researcher remains void of any preconceived ideas (Streubert & Carpenter, 2007). Bracketing can be thought of as a mathematical concept whereby the attitude of the researcher is placed in brackets so as to disconnect and therefore not influence the study but leave it exactly as it is. Phenomenological reduction requires the researcher to not only bracket the “outer world but also the individual consciousness” (Schutz, 1970, p. 6) abandoning cultural and social understanding which mask the essence of the phenomenon (McNamara, 2005). For it is the researcher and not the participants who engages in the act of bracketing, the participants’ natural attitude is what the researcher is attempting to understand (Giorgi, 2000). It is through

the process of bracketing, that the validity of the study is defended against the influences and self-interests of the researcher (Koch, 1995). However, Valle, King, and Halling (1989) clearly state that to enable the researcher to engage in the act of bracketing, it is necessary to overtly express all preconceptions clearly. It is then, and only then that it is possible to analyse the object as it naturally appears (Pascal, 2010).

Often misunderstood is the notion of phenomenological reduction. Researchers often associate bracketing with phenomenology in general, despite the underlying phenomenological philosophy to which it belongs (Walters, 1995). Bracketing an experience is not to change it but to leave it exactly as it is. However, despite the necessity to separate knowledge from experience, Heidegger believed that it was not tenable to bracket experiences, although through the process of reflection it is possible to become aware of assumptions without interpretation (Pascal, 2010). It is here that both Husserl and Heidegger developed differing stances regarding the pursuit of phenomenology.

Heideggerian phenomenology

Heidegger's phenomenology formed the basis of interpretive or hermeneutic phenomenological inquiry. Hermeneutics is an ontological approach that seeks the meanings of a phenomenon in order to understand the human experience (Crist & Tanner, 2003). In contrast to Husserl whose primary focus was epistemology, the study of knowing, the basis of Heideggerian phenomenology is ontological investigating the study of being. Heidegger aligned himself with ontology wanting to understand the meaning of being. While Husserl remained focused on understanding the pure phenomena, Heidegger focused on '*dasein*', a German verb meaning 'being-in-the-world' (Bradbury-Jones, et al., 2008). This term was used by Heidegger to refer to the way humans exist and act in the world (Van Manen, 1990) forming the basis of Heideggerian thinking. Heidegger moved away from the epistemological perspective with an emphasis on the ontological foundations of understanding accessed by 'being-in-the-world' (Racher & Robinson, 2003). Heidegger's primary interest was the meaning of 'being' as opposed to being there (Giorgi, 2007; Racher & Robinson, 2003). Heidegger articulated that suspending prior understanding was untenable rejecting Husserl's transcendental approach. In fact, Heidegger's concept of '*dasein*' conveyed that the person and their world are co-constituted, a binding unity as a person makes sense of their world from within it and not detached from it (Racher & Robinson, 2003).

The notion of temporality or ‘inner time consciousness’, was emphasised by Heidegger as becoming intrinsically part of the meaning of the ‘lived experience’. It refers to the fundamental structure of consciousness (Thompson & Zahavi, 2007). Temporality is not a definition of chronological time that is measurable, rather, Heidegger (1962) states in his influential work *Being and Time*, that temporality is the horizon for the meaning of being overall (Galt Crowell, 2005). Temporality is a basic structure of ‘being-in-the-world’ with time being an ontological structure not an entity (Blattner, 2005) and past experiences influencing both the present and future (McConnell-Henry, Chapman, & Francis, 2009a). “Time must be brought to light - and genuinely conceived - as the horizon for all understanding of Being and for anyway of interpreting it” (Heidegger, 1962, p. 39).

Heidegger’s phenomenology is only possible with prior understanding of ‘being’ in which Heidegger (1982) writes:

The a priori character of being and of all the structures of being accordingly calls for a specific kind of approach and the way of apprehending being – a priori cognition. The basic components of a priori cognition constitute what we call phenomenology. Phenomenology is the name for the method of ontology, that is, of scientific philosophy. Rightly conceived, phenomenology is the concept of a method (p. 20).

According to Heidegger, this pre-understanding is a necessary structure for ‘being-in-the – world’. Pre-understanding relates to the knowledge humans have just by ‘being-in-the-world’ and therefore, eliminating understanding as a reductive process (Earle, 2010). Understanding is never without presumptions and understanding from a purely objective position is not possible, rather understanding is from within the context of the mood (*befindlichkeit*) and involvement in the world (Johnson, 2000). Heidegger argued that understanding is a reciprocal event proposing the notion of the ‘hermeneutic circle’. Derived from the Greek verb *hermeneusin* meaning to understand or interpret (Palmer, 1969) the ‘hermeneutic circle’ is “between pre-understanding and understanding” (Dowling, 2007, p. 134). Earle (2010) states that within the ‘hermeneutic circle’:

the interpreter seeks to understand lived experience by first examining his/her own *forestructures* of ‘the things themselves’ and by then moving from the whole to parts and then back to the whole in a reciprocal way (p. 288).

It relies on the circular motion interdependent on construction and deconstruction (Boedeker, 2005) describing the historical, cultural and personal preconceptions from which understanding is derived (O’Brien, 2005).

Descriptive phenomenology as a methodology and the relevance to clinical practice

Qualitative methods are progressively being implemented by researchers for the exploration within healthcare (Charalambous, Papadopoulos, & Beadsmoore, 2008). Researchers have been reported to have utilised qualitative research methodologies since the 1960s, however, it was in the 1980s that a broad acceptance of phenomenology as a research method was evident with further development in the 1990s (Todres & Wheeler, 2001). Phenomenological research has become a dominant means of knowledge development in the field of social sciences and nursing, offering a distinguishable approach for understanding phenomena that focuses on the 'lived experience' (McConnell-Henry, Chapman, & Francis, 2009b). In recent years, phenomenology has become increasingly utilised in the area of rehabilitation exploring the 'lived experience' of the recovery journey (Finlay, 2009). Over the last decade more than half of qualitative studies published were of a phenomenological nature with the need to explore the 'lived experience' (Finlay, 2009). The value of phenomenology exists in the fact that it holds the participants' subjective experience as the central focus (Hallett, 1995). The richness of the 'lived experience' is not adequately explored through an empirical approach, therefore adopting a phenomenological methodology captures and reveals how people really do experience the world in which they live (Rapport & Wainwright, 2006).

Substantiating the argument for change in clinical practice, health policy and delivery can be assisted by utilising a phenomenological framework. Phenomenology enables the researcher to directly explore and analyse phenomena, arriving at a genuine explanation of the individual(s)' 'lived experience' (Streubert & Carpenter, 2007). This provides descriptions rich in detail and reveals meanings entrenched within the context, as opposed to deriving inferences or identifying causality (O'Brien, 2005). Fundamentally, it is important to articulate which methodological approach will guide the research question(s) and the philosophical assumptions that underpin the research. A lack of clarity regarding a study's methodology often creates difficulty in understanding how knowledge and data is to be assessed and utilised (Lopez & Willis, 2004).

Researchers are more inclined to adopt a phenomenological approach to explore patients' experiences when an empirical approach is not a viable option (Rapport & Wainwright, 2006). However, some researchers have not made clear the philosophical assumption that frames their research. Researchers have assumed that Husserlian and Heideggerian phenomenology are the same (Koch, 1995) leading to misuse. Utilising a descriptive

phenomenological approach is often implemented when there is insufficient knowledge, with the aim being to enlighten and understand the essence of the phenomenon under investigation directly from those experiencing it (Giorgi, 1997). Phenomena that have been poorly conceptualised benefit from a descriptive phenomenological approach (Beck, 1992). Furthermore, descriptive phenomenology “offers a method for accessing the difficult phenomena of human experience” (Giorgi, 1997, p. 237) making no attempt to interrupt; instead, the researcher develops themes based on the verbatim transcripts from participants in order to construct the essential meaning of the phenomenon (Penner & McClement, 2008). To attain the true meaning, utilising a descriptive phenomenological approach requires researchers to bracket all preconceived notions in order to understand the participants’ reality (Colaizzi, 1978). Therefore in developing a phenomenological framework to support the exploration of patients’ perspective of rehabilitation after a severe burn injury, a descriptive (Husserlain) method is considered the best approach to illuminate the understanding of these unique experiences. A descriptive approach facilitates revealing the richness and complexity of the phenomenon that examines the unique nature of burn injury requiring an essential understanding of the ‘lived experience’.

In contrast to this, an interpretive (Heideggerian) approach requires reinterpretation influenced by the researcher’s knowledge, and pre-understanding to the text (Kleiman, 2004; Koch, 1994). Therefore, the use of an interpretive approach is utilised in order to uncover the hidden meaning and the relationships that they hold (Penner & McClement, 2008). Despite the differences between the descriptive and interpretive approach, both of these methods results in the development of knowledge reflecting greater insight into the phenomenon under investigation. Consequently, for this reported study, a descriptive phenomenological framework was selected as a research methodology which allows the opportunity to explore the ‘lived experience’ of patients’ rehabilitation after a severe burn injury and impart a rich description of participants’ experiences. Such an approach is fundamentally appropriate when considering the lack of research exploring patients’ perspectives and experiences of this specific group of patients and the necessity to understand and accept their ‘lived experience’.

Summary of chapter

Chapter three discussed the philosophy that underpins the phenomenological research reported in this study. A historical overview of phenomenology encompassing the emerging phases of phenomenology was presented. Key concepts of descriptive and interpretive phenomenology were explored incorporating both Husserlian and Heideggerian schools of phenomenology. Descriptive phenomenology as the chosen research methodology was justified, aimed at describing and exploring the 'lived experience' of patients' rehabilitation after a severe burn injury and the relevance to clinical practice. The following chapter, chapter four describes the methods used to conduct this descriptive (Husserlian) phenomenological inquiry.

CHAPTER FOUR

METHODS

Introduction

Chapter four discusses the methods utilised in this Husserlian descriptive phenomenological study that investigates the ‘lived experience’ of patients’ rehabilitation after a severe burn injury. An in-depth account follows, encompassing the research design, including the population of interest and the inclusion and exclusion criteria for those participating. The recruitment strategy employed and the method of data collection and analysis using Colaizzi’s method are presented. The process of obtaining ethics approval (Kornhaber, Abu-Qamar, & Wilson, 2012) and ethical considerations are discussed ensuring the adherence to National Health and Medical Research Council (NHMRC) ethical standards for human research. Strategies that were utilised to ensure trustworthiness and methodological rigour are described.

Phenomenon of interest

The phenomenon of interest of this current study is adult burn survivors’ ‘lived experience’ of rehabilitation. The phenomenon of burn rehabilitation is at times perceived to be restricted to the rehabilitation centre. However, the notion of burn rehabilitation commences at the time of injury and continues well after discharge home. Those with severe burn injuries often require regular follow up for some years after the initial injury to combat the complications experienced.

Population

The population of interest for the current study were adult patients with severe burns that had previously required the services of an intensive rehabilitation program. Although these patients constitute the eligible population, the sample that is readily accessible to the researcher must be considered (Porter, 1999). Due to the vast distances between the states and territories in Australia and difficulty of access to remote locations, travelling to participants needed to be feasible. Therefore, the participants to be studied were those from the population who lived within the geographic location that was reasonably accessible to the researcher

(Porter, 1999). The researcher travelled across three Australian states for the purpose of the study.

The study's focus was adults' 'lived experience' of rehabilitation after a severe burn injury. Paediatric burn patients were not included as the needs and care provided for such children are different to those of an adult (Berman, et al., 2008; Birchenough, et al., 2008).

Inclusion and exclusion criteria

Participants were included in the study if they met the following criteria:

- They had to be over the age of eighteen years at the time of the burn injury.
- They had to have sustained a severe burn injury greater than 20% of the TBSA.
- They had to have been admitted to an adult burns unit of a tertiary hospital in Australia and required rehabilitation within a rehabilitation facility.
- They had to be able to read and speak English so as to read and comprehend all necessary information pertaining to the study.
- They had to have experienced their rehabilitation within the last eight years. (The intention was to recruit participants within four years of their rehabilitation. However, due to low participant numbers the inclusion criterion was extended to eight years as discussed further within this chapter).

Participants were excluded from the study if they met either of the following criteria:

- They were a mentally incapacitated patient such as one who was profoundly autistic or one who was neurologically impaired, as such impairments could affect the participants' ability to interact with the researcher and recall their experience.
- If the burn injury had been sustained as an act of suicide or self-harm, as this cohort of patients requires specific needs (de Macedo, Rosa, & Gomes e Silva, 2011) that is not the focus of the current study.

Recruitment methods

Sampling

Phenomenology does not investigate variables but explores the phenomenon of interest specific to the objectives of the study. Therefore the strategy of purposeful sampling was utilised to recruit participants for this study. Purposeful sampling is the dominant sampling strategy in qualitative research (Hoepfl, 1997). This allows the selection of participants

whose qualities or experiences of the phenomenon enable an understanding of the research question (Patton, 2000) providing rich data to gain an insight into the phenomena (Sandelowski, 2000). Therefore, the volume and richness of data gathered from participant interviews explains the relatively small sample recruited (Ayres, 2007). Moreover, Morse (1999) states that:

In qualitative research, each participant in the relatively small sample has been selected purposefully for the contribution he or she can make toward the emerging theory. It is this selecting that ensures that the theory is comprehensive, complete, saturated, and accounts for negative cases. The knowledge gained from the theory should fit all scenarios that may be identified in the larger population (p. 5).

Recruitment process

Those meeting the selection criteria were recruited through burn injury units of tertiary hospitals within Australia.

The hospitals included:

- Concord Repatriation Hospital, Sydney, New South Wales.
- Royal North Shore Hospital, Sydney, New South Wales.
- Royal Adelaide Hospital, Adelaide, South Australia.
- The Alfred Hospital, Melbourne, Victoria.

In order to identify and recruit patients with a severe burn injury, the Clinical Nurse Consultant (CNC) from each individual burn unit was contacted by email, informing them about the study and how they could assist in identifying and locating potential participants (Appendix 2). The CNCs were located by contacting the nursing unit manager from each burn unit and requesting their names and contact details. Their involvement was unpaid and consisted of speaking to patients who had sustained severe burns and been discharged home. The CNCs provided potential participants with a copy of the participant information sheet and consent form (PICF) (Appendix 3), explaining the purpose and nature of the research. If the potential participant expressed an interest to participate in the study, their name and a contact telephone number was forwarded to the researcher.

After obtaining the details of potential participants, the researcher contacted each by telephone, introducing herself, and further discussing the details of the study to determine whether they met the inclusion criteria for participation. If the potential participant met the

inclusion criteria and wished to participate, a mutually agreed time and place was arranged to conduct an interview.

Participant numbers

To guide the researcher in ascertaining the appropriate number of participants for recruitment, a strategy known as data saturation was utilised. Data saturation is a key element in qualitative research for attaining ‘data adequacy’, the point at which data collection ceases once no new information is forthcoming (Morse, 1995). As such, the resultant data are quality driven not sample number dependent. Without data saturation phenomenological research lacks rigour and may be deemed invalid. The frequency of a phenomenon is not the key to data saturation, rather saturation involves bringing forth the phenomenon in all forms (Morse, 1995). In some cases, there may only be a few people eligible to be involved in the research because of the uniqueness of the investigation, for example as in this study. A diverse sample may provide a wide range from which to ascertain the essence of the phenomenon. However, data from several interviews has the capacity to provide an in-depth account of the ‘lived experience’ (Starks & Trinidad, 2007). Smith and Osborn (2008) suggest that for novice researchers, three participants is an adequate sample size. Although, it has been recommended for a phenomenological study, that at least six participants are necessary (Morse, 1994) others suggest that two to ten participants is sufficient to reach data saturation (Boyd, 2001). Conversely, it has been suggested that a range between five and 25 interviews as opposed to participants is required (Creswell, 1998). Furthermore, Starks and Trinidad (2007) state that one participant may suffice for a phenomenological study. Therefore, prior estimation of the number of participants necessary to produce the amount of data required to create patterns or themes was difficult to establish.

For the current study, a target of 25 participants was set as the researcher anticipated that 25 participants would prove enough data to gain an in-depth understanding of the ‘lived experience’ of patients’ rehabilitation after a severe burn injury. However, it became evident early in the recruitment stage that limiting the inclusion criteria to within the last four years of their rehabilitation experience was restricting the sample size. Consequently, the timeframe for inclusion was extended to eight years post-trauma, a decision which was approved by the ethics committees concerned.

Data collection

Participants were individually contacted and a date, time and place were set at the convenience of the participant and researcher. Of importance was a quiet non distracting environment that permitted participants to impart their experiences and allowed for a high quality recording. The settings included were various locations: participants' private residence, an interview room at Royal North Shore hospital and various cafes within Sydney. The researcher personally conducted all interviews to gain an in-depth insight of the whole experience. Listening to participants' accounts of their rehabilitation enabled the researcher to reflect on their 'lived experience'. A semi structured face-to-face interview method (appendix 4) utilising open-ended questions allowed for greater scope in the responses provided by the participants. This provided the researcher with the means to pursue a participant's response and seek clarification on an issue when required. The benefits of semi-structured interviews are that the researcher can unearth the essence of the phenomenon by prompting, a richer account of the participant's 'lived experience'. Open-ended questions are one of the most frequently used tools for data collection in phenomenological research (Streubert & Carpenter, 2007) as they allow participants freedom to control the interview in relation to issues discussed and to completely describe their experience without a rigid interview guide (Robinson, 2000). Furthermore, not restricting participants' response, results in richer data (Moyle, 2002).

Prior to the commencement of the interviews, the purpose and objectives of the research was once again clearly explained to all participants. In particular, participants were again informed that the transcript of the interview and the exhaustive description would be sent to them requiring participant validation. Each participant was asked to sign the informed consent and was left a copy of the participant information sheet that contained the researcher's contact details as well as that of the ethics committee should they wish to make a complaint or inquire further. All participants were reminded that they could withdraw from the study at any point in time without repercussion. It was essential for recording purposes that a quiet environment with minimal distractions be used to conduct the interviews. If the participant's carer or partner was present, the researcher politely requested they do not partake in the interview, for the focus of the research was the participant's 'lived experience'.

Interviews began with a broad question asking participants to describe their 'lived experience' of rehabilitation with encouragement for elaboration and clarification: 'Tell me about your experience of rehabilitation after your severe burn injury'. During the interview

process the researcher prompted the participant to facilitate a richer, fuller account and to explore a particular point in more detail with such prompts as:

- How do you think you coped with this event?
- Can you elaborate on that point some more.
- Can you describe in more depth how this made you feel.
- What did this mean for you?
- How did you feel when that happened?

The interview drew to a close when information became repetitive and no new information was forthcoming (Morse, 1995). After interviewing 21 participants it became apparent that a sufficient amount of rich data had been gathered to provide the researcher with an in-depth description of the phenomenon under investigation. The interview process for each participant lasted from 35 minutes to 83 minutes with an average of 57 minutes. The interviewing process commenced in February 2011 and finished in November 2011.

The Audacity[®] 1.3.11 (Beta) digital audio program (free, open source software for recording and editing sounds for Windows, Mac OS X and other operating systems) was used to record interviews in which all the participants were aware of the recording device. The recorded interviews were transcribed verbatim with the services of a professional research transcription service. According to Colaizzi (1978), the narration does not have to be transcribed verbatim, as long as the essence of what is being spoken is captured within the transcript (Edward & Welch, 2011). However, the researcher deemed verbatim transcription important to ensure transcripts remained faithful to the participants' responses including all nuances (verbal and non-verbal) that revealed significant emotions and expressions of diverse feelings (McLellan, MacQueen, & Neidig, 2003). All 21 digital audio recordings were transcribed within 48 hours of each interview. The digital recordings of the interviews were then cross referenced with the transcripts to ensure accuracy of the data transcribed. This ensured that the transcriptions accurately reflected the experience of the dialogue. The participants were sent a copy of their transcript via email and encouraged to read and verify the texts. If there were areas that participants felt were not adequately clear or wanted to change what they had originally said, they were instructed to make any changes in red to the Word document. Giving participants the opportunity to alter their transcript aided the validity

and credibility of the description by ascertaining confirmation by the participants. The majority of participants responded with verification within a two week period however, three participants required follow up phone calls. The recording of each interview was deleted after the transcript was analysed to ensure anonymity.

Each participant was given a unique identifying number (such as participant 1). All transcripts were de-identified by the researcher, whereby names and places were removed and replaced with a generic phrase within parentheses. For example, Royal Ryde Rehabilitation was replaced with [rehabilitation centre] or a participant's wife's name was replaced with [my partner]. However, with the de-identification of data, the researcher was aware of the importance of retaining the contextual nature (McLellan, et al., 2003).

Ethical considerations

Ethics approval for this research was obtained from five different ethics committees within four Australian states which included the University of Adelaide Human Research Ethics Committee, Northern Sydney Health Human Research Ethics Committees, The Alfred Health Human Ethics Committee, the Royal Adelaide Hospital Research Ethics Committee and the Royal Brisbane and Women's Hospital Health Human Ethics Committee (appendix 5). However, no participants were recruited from the Royal Brisbane and Women's Hospital due to a natural disaster in Queensland at the time of recruitment. As part of the review process, the research proposal was academically peer reviewed and confirmed by the School of Nursing at the University of Adelaide as part of the researcher's PhD candidature. In addition to this, the Northern Sydney Health Human Research Ethics Committees required three independent scientific reviews of the research proposal from health professionals (appendix 6) in order to assist the Human Research Ethics Committee in its consideration of the proposal. Recruitment and the subsequent data collection process did not commence until after ethics approval was granted from the University of Adelaide's Ethics Committee despite already having ethics approval from other participating ethics committees.

In order to ensure that participant rights, confidentiality, dignity, and privacy were protected and minimal risk to participants, the following ethical principles were exercised throughout the duration of the research:

- Participants were informed of their rights, the level of participation and commitment required including the verification of the transcript and exhaustive description at different stages of the study.
- Informed consent was obtained.
- The ability to withdraw from the study at any point without prejudice was explained.
- Privacy and anonymity were strictly maintained.

Participant information sheet

During the recruitment phase, potential participants identified by the CNCs, were provided with the PICF which explained, in simple language, what the study entailed and what was expected from the participants, ensuring that the identity of the participants involved would not be identifiable. Subsequently, the information sheet remained with the participants. In the event that further information was required or if they wished to make a complaint, the names and contact details of the researcher, the supervisors and the Chairman of the Ethics Committee were provided on the PICF. After the CNCs provided participants with the PICF, the researcher enquired if there were any concerns, questions of clarifications needed in respect to the study and their level of involvement. Assurances were given to participants that they had the right to withdraw at any point in the study without prejudice to their on-going care. In addition and as previously stated, it was decided to allow the CNCs to contact the potential participants due to having an existing professional relationship with the patient and to eliminate any perceived threat of coercion by the researcher.

Informed consent

Once the participant had read the PICF and the researcher had answered any queries pertaining to the study, participants were asked to sign the consent form that indicated their willingness and commitment to participate in the study. Prior to the commencement of the interview, consent was obtained from each participant. The consent form detailed the following aspects: the nature and the purpose of the study, participants' benefit or lack of benefit from participating in the research, assurance of anonymity and confidentiality, freedom to withdraw from the study without prejudice, willingness to participate for no monetary return, access to medical records for the collection of demographic data, interviews digitally audio recorded and names and details of the researcher, supervisors and ethics committee chairperson provided.

Confidentiality, privacy and anonymity

The NHMRC (2007) states that “confidential information must only be used in ways agreed with those who provided it” (p. 2.3). The information shared with the researcher remained confidential; the researcher was the only person able to link the names of participants with the interviews. The participants were informed that all data would be securely stored to protect their privacy and anonymity, ensuring no one had access other than the researcher to the confidential data. Additionally, all electronic data including transcripts, audio recordings, demographic data and the contact details of participants, were password protected to ensure that access to files was not possible. The digital recordings were deleted on completion of the data analysis in order to ensure anonymity.

Transcripts of interviews contain many indicators of a person’s identity and institution (Richards & Schwartz, 2002). Therefore participants’ names and other potentially identifiable information were not contained in the transcripts in order to maintain anonymity and privacy. Participants’ names and any other potentially identifiable information were removed from all data pertaining to the study. As an added precaution due to the low incidence of severe burn injury in Australia and the unique nature of burn injury, the genders of the participants were not released as it was felt that revealing the gender could potentially result in the positive identification of a participant. As a result, chapters five and six do not use gender specific language such as ‘he’ or ‘she’ instead refers to participants in the sense of ‘they’ and ‘their’. Furthermore, direct quotes incorporated into the findings were de-identified to ensure the participants and others anonymity. In the event that results of this study are published, no identifying information or the identity of the participants will be released.

Data storage

The NH&MRC (2007) recommends that data should be kept for a minimum of five years prior to being destroyed; after this period, all data will be destroyed. However, one ethics committee required all data be retained for a period of seven years. During the course of the research study, data generated in the form of transcripts, consent forms and other paperwork pertaining to the study, were kept in a securely locked filing cabinet in the researcher’s office. All electronic data generated was stored on the researcher’s computer and each file was password protected.

Specific considerations

The researcher was aware that emotionally sensitive issues may potentially arise from an interview due to the trauma patients had experienced. There is a responsibility to anticipate the

probable outcome of an interview and therefore weigh up both potential benefits and harm that may result (Orb, Eisenhauer, & Wynaden, 2001). Sensitive issues and information possibly arising from the interview could potentially result in emotional trauma to the participants involved. Therefore, it was decided that in the interest and welfare of the participants, the interview would be suspended or ceased if they became distressed. However, data collected would be included in the analysis for it serves as a rich source of information. Furthermore, if the interview were suspended or ceased due to any distress encountered, with the consent of the participant, the burns social worker at the hospital where the patient was admitted would be contacted for follow up. In respect to the participant's physical welfare, if the participant appeared to tire or stated they wished to take a break; the interview would be suspended until a time they wished to resume the interview again. Fortunately, no incidents arose during the interviews to warrant any such action. As a precautionary measure requested by the University of Adelaide's Ethics Committee, the carer/partner would be present if the interview was conducted in the participants' private residence which assisted in providing support for the participant and a safe environment for the researcher. Prior to the commencement of the interview, it was important to develop a good rapport with each of the participants and their family. The researcher achieved this by means of a formal introduction, providing some background information about her and getting to know them in a relaxed setting over a period of half an hour before commencing the interview. The day after each interview, the participant received a phone call from the researcher inquiring how they were and to ensure that they had not suffered any traumatic effect from recalling their experiences.

Data analysis

Colaizzi's method of data analysis

In the current study, a descriptive phenomenological approach using Colaizzi's method of data analysis was chosen in order to capture the essence of rehabilitation after a severe burn injury as experienced by the participants. Theorists of phenomenology such as Giorgi (1970), Paterson and Zderad (1976), Colaizzi (1978) and more recently Van Manen (1990) and Hycner (1999) provide frameworks to guide phenomenological data analysis. Although there may be degrees of variation between analysis methods, all methods essentially involve extraction of themes from the verbatim transcripts which are then further developed (Paley, 1997). This forms the core essence of the phenomenon which is incorporated into the final description of the experience. Colaizzi's approach aims to unearth the meaning of the 'lived

experience' through the interpretation of the transcribed text (Sundin, Jansson, & Norberg, 2002), where the primary goal is to enhance the understanding of the meaning of these experiences. Colaizzi's (1978) method utilises elements of Husserlian phenomenology, placing an emphasis on the description of the 'lived experience' (Beck & Watson, 2008). This facilitates achieving objectivity in which Colaizzi (1978) himself stated that "...objectivity is fidelity to phenomena. It is a refusal to tell the phenomenon what it is, but a respectful listening to what the phenomenon speaks of itself." (p. 52)

In this study Colaizzi's (1978) phenomenological method of data analysis was utilised to analyse the transcripts. Colaizzi's method consists of seven steps as shown in

Figure 3. Each interview was cross checked by the researcher with the audio recording for accuracy and validated by the participants prior to analysis.

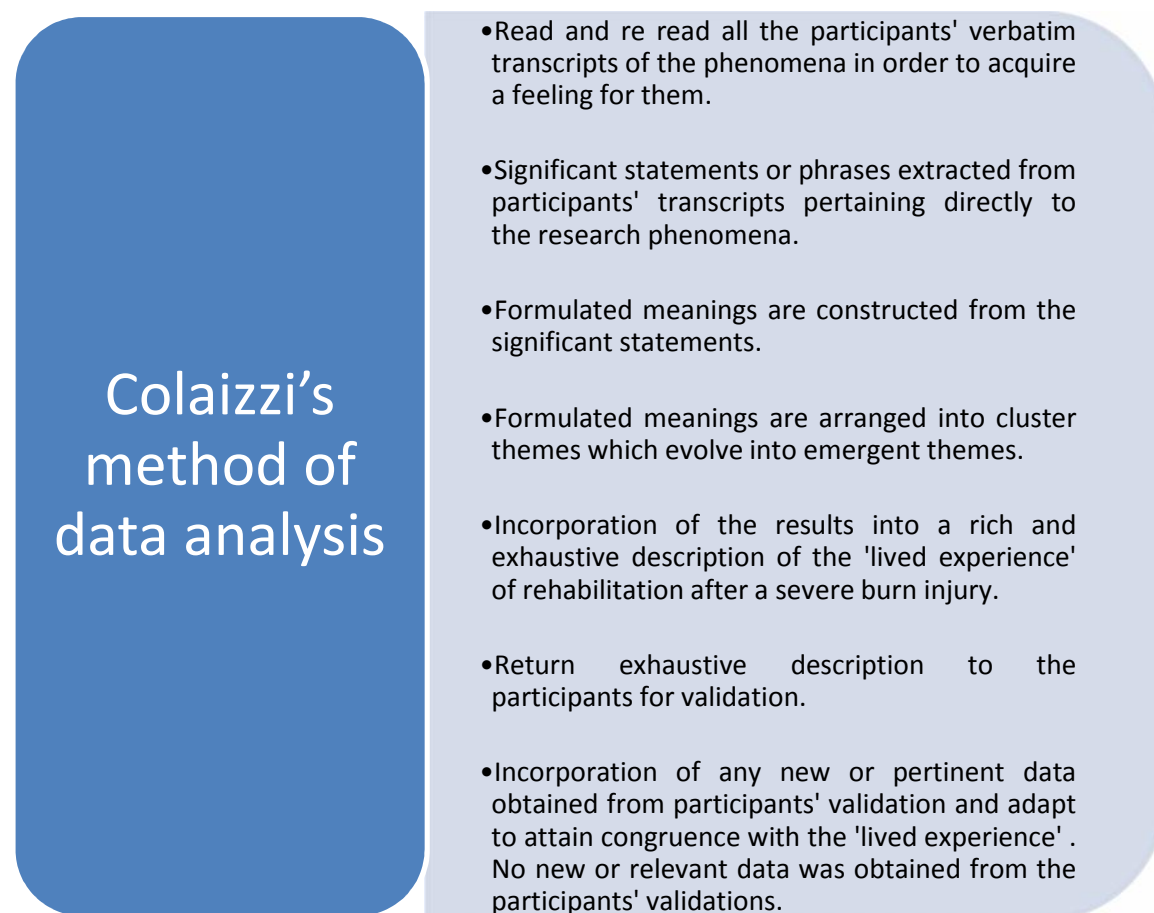


Figure 3: Summary of data analysis process

Step one:***Read and re-read all the participants' transcripts of the phenomena in order to acquire a feeling for them:***

To gain a sense of the participants' descriptions of the 'lived experience' of rehabilitation after a severe burn injury, the researcher actively listened to each participant's digital audio recording and each transcript was read no less than five times. Table 3 below is an extract from one of the participant's verbatim transcripts of an interview conducted.

Table 3: Extract from one of the participant's verbatim transcripts

Facilitator: What difficulties were you confronted with during your rehab?

Participant: The only difficulties I'd say I was confronted with were probably my own demons. I'd go back to the three or four days that I sat doing nothing at the beginning of the rehabilitation centre, but other than that, here, the physios were really good to me. They were pushing me, so that - so I started pushing myself. At the rehabilitation centre they were pretty good. The rehabilitation centre had staff coming and going. You didn't know who you had one week from the next, which made it hard for continuity that way. They were all really good to me. I think because I was motivated myself to do stuff, then it rubbed off on each other. Well difficulties - my leg was a difficulty. My stump was - because of the burns on the stump it had swollen. So when I got the first mould made for my socket it was bigger. Then it shrunk, so I had these wool socks. It just never seemed to fit right, compared to what I've got now. So the pressure was on the wrong spots. They were telling me to walk, and I'd walk. I'd get breakdowns and - so that was a difficulty. That probably made my walking a lot slower. It was partly me pushing. I wanted to get the leg - to walk on it. Then I probably wasn't ready - the stump wasn't ready I don't think. If I had have waited until my stump had shrunk a little bit first, then I may well have had a better run; it would have fitted better and I would have walked a lot better sooner. So that was a difficulty. That disheartened me a lot sometimes. I'd have a couple of good days on my leg and then I'd get a breakdown. So I'd have to stick it in the corner and I couldn't wear it. The skin side of it has all been pretty good really. I still get the odd little breakdown and stuff where some dry skin flakes off. I think because my wife knew so much about it that was good that way.

Oh well, the demons - am I going to - that little bloke on your shoulder: you're not going to get any better; this is as good as it's going to get; you're just going to have to be a cripple for the rest of your life. Which is - there's a big poster in the thing: don't dis my disability. I shouldn't say things like cripple, but I suppose that's just something that - so that's probably what I'd say my demons were; just thinking - sometimes you get those - when you're in those quiet moments you think maybe it's not going to get any better. I had so much luck to be still be here. As I said before about - overriding that in my mind, I'd just say put your head down and keep going. That's what it's all about. (transcript 11: 706-743)

Step two:***Significant statements or phrases are extracted from participants' transcripts pertaining directly to the research phenomena:***

Six hundred and seventy three significant statements and phrases pertaining to the phenomena of the 'lived experience' of patients' rehabilitation after a severe burn injury were extracted and coded from 21 transcripts. Each significant statement was given a sequential number beginning from one and so forth up to 673. A participant number and line number indicating where the significant statement was extracted from within the transcript. The significant statements were then reviewed multiple times by the researcher to ensure that statements extracted reflected all the objectives of the study. Within each individual transcript there were found to be statements that were repetitive, therefore the most rich and descriptive statements representing the phenomenon were included. Extracted significant statements were reviewed by supervisors to ensure that a rigorous and auditable process was adhered to throughout. Table 4 below demonstrates how significant statements were extracted from participant interviews. The sentences in bold and underlined illustrate the significant statements extracted.

Table 4: Illustration of extraction of significant statements

<p>If I had have waited until my stump had shrunk a little bit first, then I may well have had a better run; it would have fitted better and I would have walked a lot better sooner. So that was a difficulty. <u>That disheartened me a lot sometimes. I'd have a couple of good days on my leg and then I'd get a breakdown. So I'd have to stick it in the corner and I couldn't wear it.</u> The skin side of it has all been pretty good really. I still get the odd little breakdown and stuff where some dry skin flakes off. I think because my wife knew so much about it that was good that way. Oh well, <u>the demons - am I going to - that little bloke on your shoulder: you're not going to get any better; this is as good as it's going to get; you're just going to have to be a cripple for the rest of your life. Which is - there's a big poster in the thing: don't dis my disability. I shouldn't say things like cripple, but I suppose that's just something that - so that's probably what I'd say my demons were; just thinking - sometimes you get those - when you're in those quiet moments you think maybe it's not going to get any better.</u> I had so much luck to be still be here. As I said before about - overriding that in my mind, I'd just say put your head down and keep going. That's what it's all about. (transcript 11:724-743)</p>
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Step three:***Formulated meanings are constructed from the significant statements:***

Formulated meanings were constructed for the corresponding significant statements. A formulated meaning is a statement or phrase formed by the researcher reflecting the essence of the significant statement. This step required the researcher to be consciously aware of the statements and phrases before and after each significant statement ensuring that the researcher remained true to the contextual significance of the transcripts. This process is referred to by Colaizzi as the “precarious leap” from what the individual said to what they mean requiring a “creative insight” (Colaizzi, 1978, p. 59).

From here, the formulated meanings were numerically coded with the same number as the corresponding significant statement. In total, 673 formulated meanings were constructed from the significant statements and phrases extracted. ngs with nominal amendments.

Table 5 below illustrates examples of how the process was undertaken in the creation of formulated meanings from the significant statements. Once again, ensuring a rigorous, trustworthy and auditable process throughout the data analysis, both the significant statements and corresponding formulated meanings were reviewed by supervisors who confirmed the formulated meanings with nominal amendments.

Table 5: Construction and coding of formulated meanings from significant statements.

Significant Statements	Formulated meanings
That disheartened me a lot sometimes. I'd have a couple of good days on my leg and then I'd get a breakdown. So I'd have to stick it [prosthetic leg] in the corner and I couldn't wear it. 471 P11: L 727-730	Setbacksexperienced were disheartening. fm 471
... the demons - am I going to - that little bloke on your shoulder: you're not going to get any better; this is as good as it's going to get; you're just going to have to be a cripple for the rest of your life. Which is - there's a big poster in the thing: don't dis my disability. I shouldn't say things like cripple, but I suppose that's just something that - so that's probably what I'd say my demons were; just thinking - sometimes you get those - when you're in those quiet moments you think maybe it's not going to get any better. 472 P11: L 733-740	Troubled by negative thoughts of not making a meaningful recovery. fm 472

* fm denotes formulated meaning

Step four:***Formulated meanings are arranged into clusters themes which evolve into emergent themes:***

After the development of formulating meanings was complete, organisation of the formulated meanings into clusters and finally emergent themes commenced. The formulated meanings were grouped into 25 cluster themes. Each thematic cluster was given a title that represented the essence of the thematic cluster.

As part of the thematic analysis, the 25 cluster themes were merged to form seven emergent themes that provided a rich description of the ‘lived experience’ of patients’ rehabilitation after a severe burn injury. Table 6 below illustrates an example of the formation of formulated meanings and the associated cluster and emergent themes.

Table 6: Illustration of the formation of formulated meanings and associated cluster and emergent themes

Formulated meanings	Theme cluster	Emergent theme
21*. Arduous process of rehabilitation to regain independence. 95*. The importance of reflecting on the achievements of rehabilitation goals. 107*. The importance of focusing on tasks that were achievable and not dwelling on things that one cannot do. 100*. Rehabilitation progress was slow and challenging. 112*. Coping with the notion of rehabilitation by breaking it up into smaller manageable steps. 114*. Developing a routine to manage daily activities. 117*. Determination and motivation to keep moving more and more each day. 139*. Collaboration with multidisciplinary team to plan and implement rehabilitation progress on a weekly basis gave structure and development of achievable goals. 175*. On reflection, despite the pain experienced there are improvements evident in regaining function. 193*. Embracing gaming technology to facilitate rehabilitation. 194*. Importance of having clear goals to achieve and regain a sense of normality and independence. 195*. The role of goal setting in rehabilitation and achieving small goals. 197*. Motivation by the goal of returning home and fulltime work. 244*. Goal setting is a dynamic process. 250*. Importance of attaining specific individual goals in regaining independence. 252*. Goal setting assisted with overcoming challenges of rehabilitation. 299*. Understanding the importance of maintaining flexibility throughout and beyond rehabilitation. 300*. Rehabilitation a slow process involving the achievement of small goals. 321*. Rehabilitation was a series of small slow steps. 323*. Loss of independence meant the need to learn how to perform basic tasks again. 334*. Learning to cope by finding alternate ways to do basic activities of daily living. 335*. Determination and ingenuity to adapt and adjust to the environment. 394*. Feeling positive about small but significant progress. 589*. Insight into the burn injury assists with understanding the need of corrective surgery in order to achieve rehabilitation goals. 596*. Focusing on achieving goals distracts from the devastation of the injury. 621*. Gaining confidence in achieving small steps during	Milestones	Endurance

Formulated meanings	Theme cluster	Emergent theme
<p>rehabilitation process. 626*. Toileting independently after a long period of dependence was a significant occasion. 636*. Driving again symbolised the achievement of regaining complete independence. 647*. Determined and focused in order to regain independence. 670*. Setting goals help stay focused throughout the rehabilitation journey.</p>		
<p>14*. Motivation and understanding supports rehabilitation efforts. 16*. Display of motivation. 29*. Motivation and determination to gain as much independence and function swiftly. 38*. Having a positive attitude and acceptance of the burn injury facilitated with the rehabilitation journey. 41*. Importance of taking responsibility and learning the necessary techniques for an optimal rehabilitation. 57*. The role of determination and self-motivation is critical to rehabilitation. 68*. Determination and motivation are critical elements of rehabilitation. 78*. Remaining focused and committed to the task of regaining function. 89*. Gaining confidence assisted with adjusting and adapting in order to gain some independent function. 97*. Having a positive outlook facilitates the rehabilitation experience. 98*. The importance of remaining positive throughout the rehabilitation journey. 101*. Determination and motivation is critical in the rehabilitation journey. 104*. Display of determination and motivation. 105*. Display of determination and motivation creates a positive relationship between the therapist and the patient. 108*. Coping with the injury by remaining positive and focused. 125*. Initially ambivalent and struggled with the rehabilitation, however gaining insight into the importance of continuous rehabilitation. 127*. Motivation and determination to regain movement and function. 128*. Grounded in the reality of the necessity of rehabilitation. 138*. Mindset of determination to embrace the rehabilitation experience reinforced by those first few steps forward. 140*. Motivation and determination was a critical element to push forward and regain function. 141*. Embracing and accepting rehabilitation with a positive outlook. 145*. The need for the drive and determination to continue rehabilitation after discharge on a daily basis to regain independence. 147*. Immense determination displayed in order to reclaim former life prior to injury. 149*. Determination and motivation to reclaim former self. 185*. Achievement through encouragement, determination and motivation. 202*. Display of motivation and determination fosters a support surrounding among others. 251*. Returning home to a sense of normality and family was a great motivational factor in the rehabilitation journey. 266*. Importance of motivation and compliance with rehabilitation. 279*. The thought of being confined to a wheelchair inspired the motivation and determination to keep walking. 297*. Facing and overcoming the fears. 301*. Absolute determination to recover from burn injury. 338*. Having the motivation and determination to adapt in any environment. 361*. Patient's display of intense motivation and determination creating conflict between the therapist and burns patient. 428*. Continual determination and motivation to adapt and regain independence. 557*. Taking responsibility and the initiative with rehabilitation impacts positively with the relationship between the therapist and the patient. 569*. Rehabilitation requires determination to push forward through the pain experienced. 600*. Social support assisted with accepting and confronting difficulties experienced and provided motivation. 601*. The goal of returning home was a motivating factor to continue with rehabilitation.</p>	Tenacity	Endurance

**Numbers indicate coded formulated meanings*

Step five:

Incorporation of the results into a rich and exhaustive description of the 'lived experience':

Following the thematic analysis was the development of an exhaustive description of the phenomenon based on the integration of all dimensions of the 'lived experience' presented as a narrative account constructed from the participants' interviews. Colaizzi (1978) recommends to "formulate the exhaustive description of the investigated phenomenon in as unequivocal a statement of identification of its fundamental structure as possible" (p.61). This was achieved by incorporating the formulated meanings, cluster and emergent themes that created an overarching structure containing all components of the 'lived experience'. According to Denzin (1989) the exhaustive description should present "detail, context, emotion, and the webs of social relationships that join persons to one another.... the voices, feelings, actions, and meanings of interacting individuals are heard" (Denzin, 1989, p. 83).

Step six:

Validation of the exhaustive description from the participants involved in the research:

In keeping with Colaizzi (1978), the researcher returned the exhaustive description to all participants to validate, therefore representing their experiences as faithfully as possible. The validation process was undertaken by emailing the exhaustive description to all participants asking them if the researcher's depiction confirmed their own personal journey of rehabilitation after a severe burn injury. Most of the respondents replied within a two week period. However, three participants required follow up and prompting. Of the 21 participants contacted, 20 responded with only one non-responder.

Step seven:***Incorporation of any new or pertinent data obtained from participants' validation, and adapted to attain congruence with the 'lived experience' of the participants studied:***

Colaizzi's (1978) final step states the incorporation of any new or pertinent data obtained from the participants' validation, and adapted to attain congruence with the 'lived experience' of the participants studied. However, the 20 responding participants articulated the researcher's depiction of the 'lived experience' of rehabilitation after a severe burn injury was an accurate description congruent with their own experiences and therefore no new or relevant data was incorporated from the participants' validation. Table 7 is an excerpt from one of the participant's validations in response to the exhaustive description.

Table 7: Excerpt from a participant's feedback of the exhaustive description

On reading your attached study and report, relating to burns victims and their relevant experience from that point on, I found very accurate. In my case, I constantly found myself reminded of what the real meaning of being burned is. You mention the importance of all that follows after the act of being burnt, the rehabilitative challenges, the ongoing psychological impacts. It is very much a learning experience when you take into account what happens after the 'fire'. You must face facts that you have never even considered, let alone deemed equipped to consider. The sheer overwhelming presence of pain is your whole world. There is nothing else that matters other than "how am I going to endure this second in my life?" This experience alone impacted enough on me at the time that I promised myself that when I was objective and could be analytical (without the influence of pain) I would write an article on "pain". I realised I had experienced a challenging state. I realised the limitations of those wanting to help including rehab. Even the inability to put into words what one would consider good old logical, level headed discussion or rationale. I believe the 'true meaning of' is only present on reflection, when emotions no longer cloud our judgements or perceptions. Thus, I totally relate to all you have written and verify in my case, this is so.

Trustworthiness and rigour

The need for rigour in phenomenological research is to accurately depict the experiences of the participants in the study (Streubert & Carpenter, 2007) and the necessity to ensure an accountable high quality research methodology is presented (Morse, Barrett, Mayan, Olson, & Spiers, 2002). Rigour is critical for the credibility, trustworthiness and validity of the information (Bradbury-Jones, et al., 2008; Streubert & Carpenter, 2007). Without methodological rigour the research may be viewed insignificant, fabricated and the utility of

the research lost (Morse, et al., 2002). Trustworthiness of the research encompasses four aspects: credibility, transferability, dependability and confirmability (Lincoln & Guba, 1985). However, it was the researcher's responsibility to ensure trustworthiness and methodological rigour which can be assured through activities such as bracketing, audit trails, participant feedback and the incorporation of negative cases (Lincoln & Guba, 1985; Morse, et al., 2002). Rigorous research must be transparent with ability to describe to the reader what they did in an unambiguous manner. Strategies used to increase the trustworthiness of the current study included: making explicit all biases and preconceptions held by the researcher, verification of participants' feedback, a protracted encounter with the transcriptions, the use of extracts from the participants' narratives to support findings, maintaining an audit trail and continual debriefing about the conduct and decisions with the appointed academic supervisors. The following methodological strategies of bracketing, journaling, member checking and maintaining an audit decision trail are discussed in attaining rigour in this descriptive phenomenological study.

Bracketing

The notion of bracketing is a key epistemological approach of descriptive phenomenology and requires the researcher to consider preconceptions, biases and assumptions related to the phenomenon prior to and throughout the study (Dowling, 2007). Through phenomenological reduction, the researcher becomes absorbed into the phenomenon and through the use of bracketing, views data in its pure form as if it is for the first time (Oiler, 1982). However, the reflection of the researcher's biases prior to data analysis does not necessarily ensure that the researcher will remain neutral during data analysis.

A lack of guidance on how and when to bracket frequently forces researchers to develop their own concept of bracketing (Penner & McClement, 2008; Wall, Glenn, Mitchinson, & Poole, 2004). Bracketing was continuously implemented prior to and throughout the entirety of the study. Prior to the commencement of the current study, the researcher reflected upon any preconception or biases that the researcher held relating to the rehabilitation of patients with severe burns, then listed these in a reflective journal. The process of reflection allowed an acknowledgement of preconceptions that facilitated the researcher to navigate the process of understanding the 'lived experience' of the survivors (Lopez & Willis, 2004). In addition, advocated within the realm of descriptive phenomenology, the researcher did not conduct a detailed literature review prior to the commencement of the study with no specific research

question other than to describe the ‘lived experience’ of patients’ rehabilitation after a severe burn injury (Streubert & Carpenter, 2007).

As previously mentioned, the researcher developed a reflective journal documenting assumptions, actions, events, discussions that required reflection and consideration. Journaling reflections amplifies awareness to inherent issues (Russell & Kelly, 2002) and assists with understanding how biases, preconceptions and feelings can potentially influence the research outcomes (Watt, 2007). The development of a reflective journal aided the researcher’s understanding of the phenomenological journey and how preconceptions’ including the researcher’s professional background, can taint the data analysis. Therefore reflection can be a strategic and powerful tool in uncovering the pure phenomenon, unshrouded by biases and preconceptions. In addition, the development of the reflective journal was strategic as it contained information about the decision trail that promotes rigour and trustworthiness of the current study (Koch, 1996).

Bracketing skills were facilitated with the development of a reflective journal throughout the study. Bracketing requires the researcher to have a “psychological orientation towards oneself rather than an observable set of procedures to be adopted” (Wall, et al., 2004, p. 22). The following is an extract from the researcher’s journal of the current study with an example of a preconception that required bracketing:

“Burns patients should be rehabilitated within burn units and any other non-burn facility is not equipped to manage a severe burn injured patient. It appears the nurses in rehabilitation centres do not have the skills to attempt basic wound care let alone dress a complex burn injury”.

Bracketing is a developmental process and it is unrealistic to be proficient from the commencement of the study (Wall, et al., 2004). This became clearly evident early in the data collection as described in the following extract from the researcher’s journal:

“I was very apprehensive about my ability to conduct the interviews and remain neutral. I questioned my ability to bracket. The first few interviews that I conducted, I was very aware of my own personal thoughts and feelings towards the rehabilitation of patients with a severe burn injury. This became all too obvious when the participant started to share their experiences which were similar to my perceptions of burns rehabilitation. I was expecting the participant to express experiences that were in-line with my own perceptions”.

During the interview process, consideration was given to the participants’ description of the phenomenon under investigation so as to obtain a rich in-depth account. This extract from

the researcher's reflective journal demonstrated the importance of bracketing during data collection so as not to lead the participant:

“Keep steering the interview toward the experience of the phenomena (what was it like? how did you feel? What was the impact? However, I must not respond to the participant with my own commentary or insights therefore bracketing my own thoughts and ideas of the phenomenon”.

As the process of bracketing continued throughout the study, reflection and consideration for the researcher's own perceptions and beliefs were required so as not to distort the findings. During the data analysis, all transcripts needed to be examined thoroughly to capture the depth and richness of each interview. The following extract from the researcher's journal demonstrated the need to be aware of judgments that may alter or not be representative of the participants' experiences:

“When extracting the significant statements, I needed to be aware that my own clinical judgement did not become dismissive to issues raised by participants”.

Thus the researcher attempted to demonstrate and provide consideration for reflective journaling as an effective tool in attempting to achieve bracketing as a key epistemological aspect in this descriptive phenomenological inquiry.

Participant feedback (member checking)

Participant feedback (also known as member checking) is a key aspect in the establishment of credibility (Lincoln & Guba, 1985). It enables the participant the opportunity to validate their transcripts and the interpretations of the findings (Doyle, 2007) thus enhancing a study's credibility (Taylor & Bogdon, 1998). It is essential that the participants' accounts and descriptions of their experience reflect the framework, perspectives and environment. Credibility, rigour and validity are achieved with continual clarification, which is essential in order to capture and reflect the essence of the phenomenon. Unless the researcher's data reflects the experience of those participating through seeking validation, a distorted and misinterpreted perspective of the 'lived experience' will be portrayed. As part of Colaizzi's method of data analysis, the researcher sent participants the transcript of their interview and the exhaustive description to verify. Participants were asked to read their verbatim transcripts of dialogues in which they had participated. The emphasis of participant verification should be on whether the participants consider that their words match what they actually meant, accurately capturing the articulations (Shenton, 2004). Reading the actual interview transcript assists participants with the stimulation of further information and clarification of their

responses. Giving participants the opportunity for feedback reduces the risk that participants will report, at a later stage, that they were misrepresented or misunderstood (Doyle, 2007). However, prior to participant verification, the transcripts were checked against the recordings for accuracy so as to provide a high quality transcript and reduce the incidence of transcription error. However, there are reported risks in engaging in participant feedback with participants' ability to recall events and emotions as experienced requiring consideration. The inability to recall events may result in the participant feeling obliged to concur with the researcher's findings (Sandelowski, 2002). In line with Colaizzi's sixth step of data analysis, all participants were asked to validate the exhaustive description. The feedback from the 20 respondents demonstrated their experience was accurately depicted and represented their experience of burn rehabilitation (Table 7).

Maintaining an audit trail

Documentation and data tracking practices of all processes related to the research are imperative to the credibility of a study (Sanders, 2003; Whiting, 2001). An audit trail clearly demonstrates decisions made about theoretical, methodological and analytical choices made throughout the research inquiry (Koch, 1994) that must be regularly backed up with a data management system (Miles & Huberman, 1994). Although an "audit trail helps to establish the credibility of qualitative studies and serves to convince the scientific community of their rigor" (Wolf, 2003, p. 175) it must be kept in mind that audit trails are only proof of decisions taken throughout a study and that inadequate practices will still threaten the integrity of the study (Cutcliffe & McKenna, 2004; McLellan, et al., 2003). However, the absence of an audit trail does not necessarily challenge the credibility of findings, especially if the researcher is an expert in the chosen qualitative methodology (Cutcliffe & McKenna, 2004).

It was critical to the final analysis and reporting of results, that all data were adequately processed throughout and analysed with the ability to easily access specific data swiftly and all files were regularly backed up onto to an external hard drive. The researcher performed the data analysis independently, adhering to each step of Colaizzi's method of data analysis with the analysis discussed and verified with the researcher's supervisors. This was performed to ensure that the interpretive process was auditable depicting the participants' 'lived experience'. Tables 3 - 8 clearly demonstrate an auditable trail that can be scrutinised by others to determine the credibility and validity of the findings. Findings need to reflect the experiences narrated and themes must be consistent with the data collected. The audit trail

utilised in the current study serves to demonstrate openness by disclosing decisions taken throughout the course of the study.

Summary of chapter

This chapter has described the methods used to conduct a descriptive (Husserlain) phenomenological inquiry of a thesis exploring the ‘lived experience’ of patients’ rehabilitation after a severe burn injury. Discussed was the recruitment of participants that employed purposeful sampling methods and the semi structured open-end interviewing technique for data collection. Permission to conduct the research was obtained from five ethics committees across four Australian states encompassing the areas of participant information and consent, researcher and participant safety, privacy and anonymity, and the storage and legislative requirements of storing data. Colaizzi’s method of data analysis was described to demonstrate how data were analysed with the extraction of significant statements and formation of formulated meanings, cluster themes and finally the development of emergent themes. Finally, rigour and trustworthiness of the methodological approach was addressed. The next chapter, the backstories, introduces each of the 21 participants in this descriptive phenomenological study.

CHAPTER FIVE

THE BACKSTORIES

Introduction

This chapter introduces the participants' stories that are fundamental to this descriptive phenomenological study. Provided is a brief descriptive biography of each participant encompassing their age, percentage of TBSA burnt, the length of hospitalisation, their current work status and family support. This will allow the reader to contextualise the participants within the study. The genders of all participants and specific personal information have been withheld to ensure their anonymity as certain elements of their case history could potentially result in the positive identification of a participant given the uniqueness of their burn injury and the often intense media coverage. The sequence in which the participants are presented in this chapter follows the order in which they were interviewed.

The participants: overview

The participants of this study consisted of one female and 20 males. Each participant received a participant number in order to conceal his or her identity therefore maintaining strict anonymity. At the time of the interviews, 14 participants were married and residing with their family. One participant encountered a marriage breakup during their rehabilitation; five participants were single and one participant lost their partner at the time of the injury and was therefore widowed. Nineteen of the participants were born and educated in Australia; one participant was from the United Kingdom and the other from a country in the Far East. The participants were from the states of New South Wales, Victoria and South Australia. Seven participants lived on a farm and the 14 remaining participants resided in suburbia.

At the time of the burn injury, the mean age of the participants was 44 years, with a mean TBSA burned of 55%. Ten participants sustained a significant facial burn, eight were unable to return to gainful employment, six participants returned to their prior employment, and one participant was required to find alternative employment due to the injuries sustained. Three participants were unemployed prior to the injury and remained so and six of the participants were retired prior to sustaining the injury. The average total length of stay from the time of admission to the ICU until their discharge from the rehabilitation centre was 185 days, of which the average length of stay in ICU was 33 days, 86 days in the burns unit and 66 days in

the rehabilitation centre. Appendix 7 shows a tabulated format of the demographic data of all participants.

Participant 1

Participant 1 was 42 years of age when involved in a motor vehicle accident sustaining 50% burns to the body with significant facial burns, partial loss of fingers, scarring and skin contractures to the upper body. Participant 1 spent nearly a month in ICU, a further four months hospitalised in the burns unit and then two and a half months in the rehabilitation facility. At the time of interview the participant was living at home with their family and had a fulltime carer and was receiving physiotherapy and occupational therapy three years after the injury occurred. Employed fulltime prior to the burn, Participant 1 is unable to return to work.

Participant 2

Participant 2 was 59 years of age when involved in a workplace accident sustaining a 35% burn to the body. Hospitalised in ICU for one and a half months, Participant 2 was then transferred to the burns unit for one month and then spent a further one and a half months at the rehabilitation facility. This participant was living at home at the time of interview and was unable to return to work and has now since retired. Having made a substantial recovery, Participant 2 is able to live independently with assistance from their partner.

Participant 3

Participant 3 was a single 21 year old when a farming workplace accident resulted in 70% burns to the body, loss of fingers, skin contractures and significant scarring. Spending nearly one month in ICU and nearly five months on the burns unit before referral to the rehabilitation facility for a further two and a half months, Participant 3 finally returned home to the family farm. In light of the magnitude of burns sustained, Participant 3 has made a substantial recovery and returned to work on the farm where previously employed.

Participant 4

Participant 4 was a single 30 year old who was involved in a serious car accident sustaining a significant trauma and 20% burns to both legs. Although only spending five days in ICU and a month on the burns unit, Participant 4 had multiple admissions to the rehabilitation facility over a two-month period. At the time of the interview, Participant 4 was living at home with one parent who is the fulltime carer. Participant 4 was unemployed prior to the injury and due

to the injuries remains so. Additionally, the main carer has had to give up their job to attend to Participant 4's daily needs.

Participant 5

Participant 5 was 61 years of age when involved in a bushfire in rural Australia having endured a 70% burn with significant facial burns, scarring, partial loss of fingers and skin contractures to upper and lower limbs. The participant lives with the partner who is the primary carer for all activities of daily living. Participant 5 was an integral part of the local community, a former Emergency Services officer, however retired prior to the injury. Participant 5 spent nearly a month in ICU, a further four and a half months on the burns unit and two and a half months at the rehabilitation facility. Nearly four years after the burn injury, participant 5 is still requiring reconstructive surgery because of contractures and wound breakdown stemming from the burns sustained.

Participant 6

Participant 6 was 62 years of age when involved in an explosion, which left this participant with 45% burns to the body with significant scarring and skin contractures. Participant 6 spent initially two months in ICU before a four month admission to the burns unit and then referred to the rehabilitation facility for a further two months. A retired Emergency Services Officer, an active member in the local community and a keen sportsman, Participant 6 was married and living at home independently with their partner at the time of the interview. However, Participant 6 does still require a further contracture release in the near future.

Participant 7

Participant 7 was a single 33 year old when the family home burnt down leaving this participant with 80% burns to the body with significant facial burns, scarring and contractures to the upper body. Due to the injuries sustained, Participant 7 although a trained tradesperson was unable to seek employment. Participant 7 spent a month in ICU and close to two months on the burns unit and a further two months in the rehabilitation facility. At the time of interview, Participant 7 was living at home with the family.

Participant 8

Participant 8 was 42 years of age when involved in a workplace accident that resulted in 60% of the body engulfed in flames with significant contractures and scarring experienced and the loss of fingers. Participant 8 spent a lengthy three months in ICU followed by multiple admissions to the burns unit that encompassed near to seven and a half months requiring

several admissions to the rehabilitation facility over a five month period. Participant 8 has made a full recovery and has returned to work in their former capacity.

Participant 9

Participant 9 was 32 years of age when involved in a major motor vehicle accident that saw the car burst into flames that resulted in burns to 52% of the body. Participant 9 spoke with a raspy soft voice because of sustaining a significant burn to the airway, face and the upper body with skin contractures and significant scarring. Having young children and estranged from the partner, Participant 9 was living in the family home with the parents who remain primary carers. Participant 9 is unemployed and unable to seek employment due to the nature of the injuries. Having spent nearly two months in ICU and a further four and a half months on the burns unit, the participant experienced multiple admissions to the rehabilitation facility lasting just over eight months before returning home.

Participant 10

Participant 10 was a single 38 year old who was working with petrol in the backyard, when engulfed in flames sustaining 80% burns to the body with significant scarring, and skin contractures. With the duration of only four days in ICU, Participant 10 stayed on the burns unit for nearly four months and a further one and a half months at the rehabilitation facility and has had further contracture releases. Originally, from the United Kingdom, Participant 10 lives alone with a pet dog for companionship. Having a profession and employed, Participant 10 cannot return to work due to the burn injuries sustained. At the time of the accident, Participant 10's parents came to Australia however have now since gone back home to the United Kingdom. Currently receiving a disability pension, participant 10 has made a substantial recovery that allows for independent living.

Participant 11

Participant 11 was 43 years of age when involved in a workplace accident on a rural farm that resulted in receiving 70% burns to the body with facial involvement, significant scarring, skin contractures and the loss of a lower limb. Participant 11 endured just over a month in ICU and a month hospitalised on the burns unit before referral to the rehabilitation facility for a further month. It was at this point that participant 11 received outpatient care while living in the community. Despite the injuries sustained, Participant 11 returned to work.

Participant 12

Participant 12 a self-employed 49 year old, was involved in a workplace accident that resulted in sustaining burns to 27% of the body with significant scarring and skin contractures. After spending two weeks in ICU, participant 12 spent a further two weeks on the burns unit and nearly a month at the rehabilitation facility, which was very close to home. Married with school age children living in the family home, Participant 12 did not want to return to work and has now since retired pursuing other interests.

Participant 13

Participant 13 was 55 years of age when burnt to 60% of the body in a workplace accident on a remote rural farm. After nearly a month in ICU, Participant 13 spent two and a half months on the burns unit and just under three months at the rehabilitation facility. Participant 13 chose not to return to work and semi-retired, handing over the family business to the children.

Participant 14

Participant 14 was a 38 year old and married with young school age children living in rural Australia, when a tragic accident eventuated in 40% burns to the body that involved significant facial burns, scarring and loss of fingers. Participant 14 endured nearly two months in ICU, a further two months on the burns unit and one and a half months at the rehabilitation facility. Participant 14 made a substantial recovery living independently and returned to work.

Participant 15

Participant 15 was 65 years old when burnt in a garage resulting in 40% burns to the body. As result of the accident happening in an enclosed space, Participant 15 required a two-week admission to ICU, following transfer to the burns unit for a month and eventually referred to the rehabilitation facility for one month prior to discharge home. Retired prior to injury, Participant 15 lives at home with the partner having made a full recovery to independent living.

Participant 16

Participant 16 was 45 years of age when whilst at work using volatile chemicals in an enclosed space, was engulfed in a fireball ignited by a spark from a nearby welder. This resulted in 90% burns to the body with significant facial burns, scarring, skin contractures and loss of many fingers and other body parts. Initially admitted to ICU for nearly three months, Participant 16 spent a further four months on burns unit before referral to the

rehabilitation facility for a period of five months. It was during this period that Participant 16 required multiple readmissions to the rehabilitation facility due to ongoing surgical treatment. Not being able to return to work, Participant 16 at the time of the interview was living at home with their partner who remains the primary carer for all activities of daily living.

Participant 17

Participant 17 was a self-employed 59 year old when an accident at home resulted in a 30% burn to the body. After five days in ICU, Participant 17 spent nearly one and a half months on the burns unit before admission to the rehabilitation facility for a further month. Participant 17 at the time of the interview was living independently with the partner and has not returned to work, however wishes to do so.

Participant 18

Participant 18 was a married 37 year old with young children who was involved in a workplace accident that resulted in sustaining 40% burns to the body. Participant 18 spent one month in ICU followed by one and a half months on the burns unit and a further one and a half months in a burn rehabilitation programme. Participant 18 has made a significant recovery, returning to work in the same field of employment.

Participant 19

Participant 19 was 40 years of age when whilst at home working on the house, sustained burns to 55% of the body with significant facial burns, scarring and skin contractures. Participant 19 was initially admitted to ICU for just over one month, followed by a lengthy admission to the burns unit for five and a half months, and then referred to the rehabilitation facility for a further one and a half months. Having been working fulltime, as a professional in the business sector, Participant 19 unfortunately has not been able to return to work and has relied on the assistance of family members with ongoing care and rehabilitation on a daily basis.

Participant 20

Participant 20 was aged 34, when at work sustained a 60% burn to the body with significant facial burns, scarring, loss of fingers and skin contractures. Participant 20 was admitted to the ICU for just over one month and then spent four months on the burns unit and a further two months at the rehabilitation facility requiring multiple readmissions as a result of requiring necessary contracture releases and reconstruction surgery. At the time of the interview, three years after the initial burn injury, Participant 20 still required further

contracture release procedures with the last few operations alone involving the fingers, eyes, elbow and mouth. Participant 20 has made a substantial recovery with the ability to return to work in the capacity prior to the injury.

Participant 21

Participant 21 was aged 36 when in the backyard shed at home an explosion saw this participant engulfed in flames sustaining 78% burns to the body with significant facial burns, scarring and skin contractures. After the initial ICU admission lasting just over a month, Participant 21 spent two months on the burns unit followed by one and a half months at the rehabilitation facility with further outpatients rehabilitation required at the district hospital near home. Living in rural Australia at the time of the interview, Participant 21 was married with three small children. Having made a significant recovery to be able to return to work, Participant 21 was unable to resume employment in the field in which they trained due to the injuries sustained and experienced a change in career.

Summary of chapter

The purpose of this chapter was to offer an insight into the lives of the participants in this study to enable the reader to contextualise the participants within the framework of the study. Provided was an overview of all participants followed by the introduction of each participant who chose to volunteer and participate in this research concerning burn survivors' 'lived experience' of rehabilitation. The following chapter presents the findings of this descriptive phenomenological study discussing the themes that emerged from the data analysis.

CHAPTER SIX

FINDINGS

Introduction

With rehabilitation commencing at the time of the injury and continuing for many months and even years after discharge, the purpose of the current study was to provide a rich description of the ‘lived experience’ of adult patients’ rehabilitation after a severe burn injury, and contribute to knowledge that leads to improved patient experiences and health outcomes. A descriptive phenomenological methodology using Colaizzi’s method of data analysis was used to answer the research question: *What is the ‘lived experience’ of patients’ rehabilitation after a severe burn injury?* The focus of this chapter is to report on the 25 cluster and seven emergent themes that formed the ‘lived experience’ of patients’ rehabilitation after a severe burn injury. To present the thematic analysis and to provide a clear audit trail, each of the emergent and the cluster themes are described and supported with direct excerpts from the participants of this study. The participants’ validated exhaustive description of their ‘lived experience’ encompassing the essence of burn rehabilitation.

Cluster and emergent themes

Through the process of data analysis, 25 cluster themes that emerged from the participants’ transcripts that described their experiences of rehabilitation after a severe burn injury were developed. The 25 cluster themes were further developed into seven emergent themes forming the basis of the findings reported in this study (figure 4). The seven emergent themes: *Spatial environment, endurance, acceptance, impact, vital supports, progression and challenges* will be defined and discussed with excerpts from the transcripts used to highlight and support each theme.

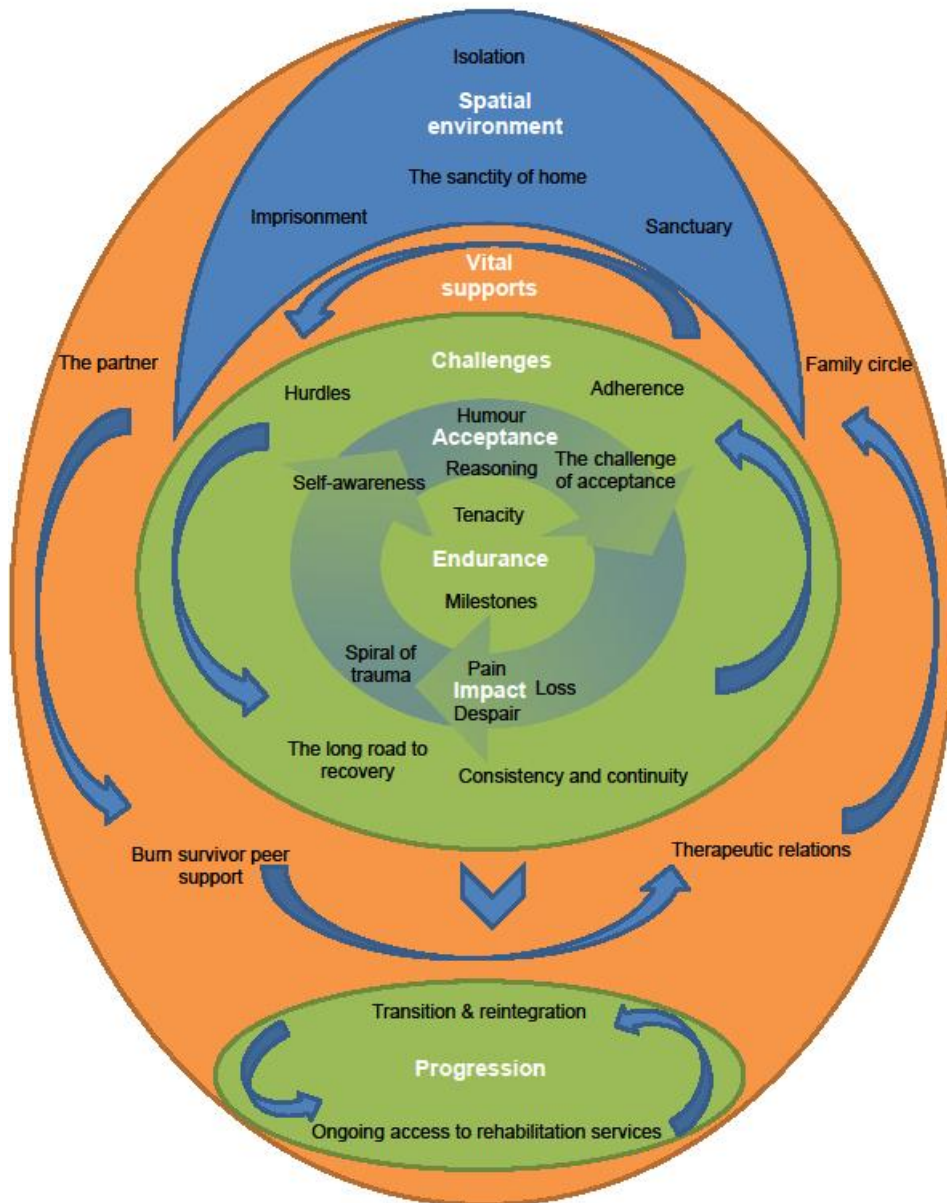


Figure 4: Thematic mind map

Figure 4 is a mind map of the thematic analysis and illustrates how the participants of this study experienced their burn rehabilitation. The foundational structure of burn rehabilitation was the support that participants received from their family, friends, and staff and for some peer support. Within this structure, the participants' environment influenced their rehabilitation journey that encompassed feelings of isolation and imprisonment. Despite experiencing these emotions, the protection of the burns unit and thoughts of returning home facilitated participants' rehabilitation. Participants were confronted with a myriad of challenges and hurdles that encompassed consistency and continuity of care, adherence to

burn care and therapy and the realisation that burn rehabilitation was a long journey. The impact that participants experience after a severe burn injury included emotions as pain, loss, despair and the spiral of trauma experienced during their journey. Acceptance was a challenging notion for the participants with the use of humour and rationalisation often used to facilitate their sense of self-awareness and the acceptance process of their altered self. Core to the rehabilitation experience was their endurance, of which the notion of tenacity and goal setting were key elements. Despite the often traumatic experiences endured, participants needed to focus on their progression, transition and reintegration with the prospect of ongoing rehabilitation needs.

Vital supports

The emergent theme *vital supports* were the foundation of the participants' rehabilitation experience demonstrating the importance of strong social support during a traumatic time throughout their rehabilitation. The participants found support comforting giving them the necessary motivation and inspiration during their often arduous and lengthy rehabilitation. The cluster themes that developed were: *The partner, family circle, therapeutic relations and burn survivor peer support*.

The partner

Participants who were in relationships regarded their partners to be their primary means of support whereby one participant expressed:

Um so [my partner's] support was um [pauses] I suppose um first and foremost. Um I don't believe I could have achieved what I have without [my partner's] support. [Sighs] um so I suppose that was just between the two of us. Um [my partner] spent as much time on the ward as [my partner] could and I think...even organise with um [pauses] [NUM burns unit] to even have extended visiting hours and that sort of thing. (Participant 18, L: 100-106).

The support and dedication displayed by partners was unwavering, full of love and devotion for their injured partner, as shown by one of the participants' description of their partner's support:

...the ones I didn't really want to see anymore, they don't help me in anyway other than they helped to wash me and bandage me. So they helped me physically but not necessarily mentally and then there were others who sat and cried with me when I had my low days. And I will always hold them dear in my heart but compared to [my partner], they pale into insignificance. [my partner], was so powerful and strong in... support of me and the ability to get me through my seven and a half months in hospital. (Participant 5, L: 101-109).

Love was a powerful emotion that allowed participants to confront their injury together as this participant so aptly claimed:

*My partner....was my, um - I didn't face it alone; I had [my partner]. (**Did that assist with your rehab?**) Oh yes, yeah, so love is the most important quality that can - wherever you've got love, you never face anything alone. (Participant 17, L: 441-444).*

Emotional support was not the only form of support that partners provided; partners were actively involved in dressing changes which was of benefit when participants were discharged home:

...one of the big things that helped me a lot was, initially - even in the intensive care, [my partner], was involved in the bandage changes. So [my partner], got to know more about it than I did. When we got to rehab I think [my partner] knew more about some of the bandages than the staff did. So [my partner], would come in and assist, and sometimes half take over, doing the bandage changes at rehab. That was great, and when I got home, that I had someone that had so much knowledge about it. (Participant 11, L: 255-262).

Family circle

The family unit was a fundamental source of support for participants that provided participants with a reason to push through the pain and trauma as vividly expressed by this participant:

And you just have to go on. I made a promise to [my partner]. [my partner], said, I'll let you go if you want to and – but if you don't, I'm here for you; our children are here for you. And if you decide to keep going, I'm here for you and I made a promise that I'd keep going and I did. (Participant 5, L: 236-239).

Another participant conveyed a similar experience:

My family were there all the time. My son and my daughter were there a lot, and my [my partner], was there every day. (Can you elaborate on your relationship with your family?) Never wavered, never got weak, no. It was always very strong. I think had it not been for that, I don't know whether I would have pulled through. (Participant 13, L: 41-45).

In addition to the family unit, friends were also influential in providing support for the participants and their families. This participant described how the different elements of support assisted throughout the rehabilitation journey:

Biggest support's family, without question, [my partner] and family and friends, yep, without question biggest support. The whole community was a huge support. I mean obviously in the initial stages the medical staff were the biggest support, they were the ones that kept me alive. But once I got past that you're not going to die thing - yeah the OTs and that, they were a big support. But yeah family and friends - and when I say support, everything. If I was having a down day people would pick me up. Friends would come in and [laughs] make you feel guilty about feeling bad. Look how good you are, so you'd get over the feeling bad things. (Participant 14, L: 476-485).

The greater community was also found to be a fundamental form of both emotional and financial support during such a turbulent and traumatic period of the participants' lives. In

particular, one of the participants expressed that the overwhelming support received was a motivating factor that allowed such a fruitful recovery:

...my [my partner], got a hamper and stuff from the school, donations of money from the local rugby club which I was a past president of, and the Lions club, Rotary club, the services club; all the different clubs just gave cash donations to us - without even asking for it, it just turns up. Other friends, they'd come down with big eskies full of frozen food for [my partner], for meals. [My partner], got a hamper one day - this big box...It's this massive box of food from the local Catholic Church. They'd heard about it through a friend of a mother's friend; so I was in their prayers. They'd been saying prayers for me, and they sent this massive box of food. All that sort of stuff, it just blew me away. I have a wide circle of friends, but I never thought that - it felt very humbling that they jumped in and helped like that. That was definitely another big motivating factor to push me to what I did; to get back there and just to thank them and to show them that I didn't waste my time down here for eight months. (Participant 11, L: 473-488).

Another participant conveyed how the greater community was of invaluable assistance during rehabilitation and after discharge maintaining:

...the community was very, very helpful. Oh you know, visiting me every day, I mean including even local member comes to see me, he comes to see me at home too and my members of my local club where they always - they are the ones who still take me to hospital, they take turns to take me to the hospital and back. They've got very supportive to [my partner], and family, have helped with all the work at home and anything that...needed help, they're always there to get things done. Yeah, so community helped I think really good, was very good. (Participant 19, L: 78-85).

While others found a sense of belonging elsewhere within the community setting:

...the biggest factor for me um prior to the accident um I was very involved with ah karate. I still am [sighs] and um [sighs] ah on occasion um people from karate did come to visit me when I was in hospital. And um I've now gone back to karate ah because of the physical benefits and the fact that um I feel comfortable with everyone there. They're very supportive. I've known them for years and um I just enjoy it. It's just a nice place to be. So um that's been a very big um [pauses] ah thing to move forward with. That's social interaction and social acceptance. And um [laughs] not that I would have but if I had have started feeling sorry for myself or that sort of thing I'm sure that um they would have quickly ah got me back into line. (Participant 18, L: 552-562).

Therapeutic relations

The health professionals involved in the care and treatment were found to have a positive effect on the participants' rehabilitation. In particular, the therapeutic relations between the participants and the clinicians were influential in providing positive reinforcement and encouragement throughout and beyond their rehabilitation. Participants described how the nurses were a wealth of support however; the nurse's support alone was insufficient:

Um [pauses] I found very supportive because again initially ah in the early stages I could not feed myself so I had to be fed. So I had time to um - you had that time to talk um with whomever it was that was feeding you in the morning. Um [pauses] so yeah I found the nurses - they were very supportive um but in saying that obviously [pauses] you need more support than what a nurse can offer. Um because they've got a job to do and there's other patients. So although they do the very best they can and they are very supportive um personally I don't think it was enough. Um [pauses] but yeah I felt supported by the nursing staff, absolutely. (Participant 18, L: 223-232).

Another participant also reiterates how nurses above other clinicians were central to their rehabilitation claiming:

...the support from, er, maybe the nurses more so than anybody else, the care. They give you the feeling that nothing is beyond whatever you want to achieve or are trying to do... (Participant 17, L: 431-433).

Another participant stated that in particular, the nurses' persona and attitude was central in assisting them with coping with such a traumatic injury and the rehabilitation journey:

...the only thing really that helps me get by...was the attitude, the caring of the nurses and other people that worked there. (Participant 8, L: 130-132).

Other participants found the nurses' dedication both in the burn unit and rehabilitation centre, facilitated the formation of a collaborative relationship between the nurses, the participant and their partner as demonstrated in this participant's narration:

There were a couple of dedicated...nurses – older nurses – who took great interest in wounds and were guided by [my partner], who had learnt how to dress me in the burns unit. [My partner], was encouraged to come in and participate in the dressings... (Participant 5, L: 641-644).

Therapists such as the speech pathologist, social worker and in particular the occupational therapists and physiotherapists played a vital role in providing support. This support would prove to be a driving force providing the necessary encouragement and reinforcement to keep advancing with their rehabilitation:

It was a hard slog and if it wasn't for the physiotherapists and OTs [occupational therapists] I don't think I would have coped. I had - the greatest respect for them. They went a long way in my rehabilitation. (Participant 13, L: 61-63).

The following participant also found that positive reinforcement facilitated the motivation to keep moving forward:

But I think the positive reinforcement is what makes it - the physiotherapy is hard, but I think the reinforcement of - when you - still it's hard and you don't want to do it, but positive reinforcement saying, no, no, let's not do it today, let's try it again another time and keep working on it, is very important. (Participant 19, L: 18-22).

It was important that therapists instilled confidence and belief in the participant as this provided reassurance that things were going to improve:

So [the physiotherapist] was very reassuring about - don't worry about it; it's going to take you a bit of time, but you will get there. So I think that was important too; just to know that - there was none of this oh God, I don't know how we're going to go here. It was really don't worry about it; you're going to be sorted; you won't know yourself. (Participant 11, L: 393-397).

Other participants felt that the sheer presence and guidance that the therapist provided, was influential in attaining success:

I had a physio [physiotherapist] partly assigned to me. When I was able to be with her there is a total difference. Instead of being going along sort of blindly hoping you're doing the right thing, you know you are doing the right thing and you can put everything on the line, give your 110 per cent and you know you're going to reap the rewards. (Participant 4, L: 164-169).

Apart from requiring the necessary encouragement and positive reinforcement throughout their rehabilitation, participants felt that just having someone professional to talk about issues of concern was of great benefit:

It was good to have somebody to talk to. My social worker at the rehabilitation centre was brilliant as well. If I had any problems he was there to try and resolve them for

me and he did a brilliant job. He found me a house to live in. I mean even now I still have a few ongoing issues and the social worker was in contact with me and I went to see him a few weeks ago. I mean he said he'll do anything he can to help me. (Participant 10, L: 307-313).

Burn survivor peer support

Of considerable significance to the majority of participants was the provision of burn survivor peer support. Burn survivors would at times visit the burn unit or rehabilitation centre at the discretion and request of the social worker. Willing burn survivors would support participants by means of exchanging their experiences of their burn injury and subsequent rehabilitation. Support provided by burn survivors was seen as particularly enlightening:

I just remember looking at him up and down and the horrific injuries that he sustained, missing all fingers...ears gone and facial burns, head, everything...After he left, I thought Christ almighty, that guy makes my burns look like a walk in the park. Maybe this is possible and maybe we can do this. It was only then at that moment, seeing him that my attitude starting wavering and changing slightly. Then again, there was no determination then but it was hoping that I could be like him that maybe I could recover like that. (Participant 8, L: 104-113).

Besides providing hope, visits from burn survivors filled participants with courage, inspiration and the belief that a meaningful recovery was possible as expressed by this participant:

[A burns survivor] coming in and talking, I think that made a big attitude change when I was in the hospital... So [the burns survivor] came to see me and he talked about his experience and what he'd been through and how is now today after six years - six years at that time when he came to see me after his accident. That gave me, even though I was in bed and unable to move and all that, but that gave me a lot of courage

and inspiration, I can do it as well...able to one day get out of this and go about doing my work. (Participant 19, L: 141-152).

Other participants found speaking to a burns survivor a comforting and reassuring experience:

So that is just a comfort. Just being able to [pauses] not only share that story with somebody but have them tell you their story and understand exactly what that person's saying is um very comforting. It's reassuring and it just makes you feel like you're not alone. And especially because a lot of these people are at various stages of recovery and living life again and that sort of thing so it's so reassuring to see that life can ah carry on. (Participant 18, L: 676-682).

Some participants in this study received burn survivor peer support at various stages of their rehabilitation and yet some were not offered peer support or were unaware of the existence of burn survivor peer support groups. However of significant interest, was the timing and locality that participants received peer support. This participant reports feeling unreceptive to any intervention from burn survivors' experiences stating:

They had people come and see me when I was still in [the burn unit]. I think maybe I would have been more receptive to them if I'd have seen them when I was at the rehabilitation centre. I'd probably be more open to talk about things whereas when I was in the burns unit I just shut off and I didn't really want to talk about it. I suppose I had the attitude that I've got my own problems to sort out with, I don't really need to know about yours as well, do you know what I mean [laughs]? (Participant 10, L: 517-524).

While not all participants were extended the support offered by burn support groups or other burn survivors. This participant expressed how if offered, they could have reaped the benefits of peer support earlier:

I think in the waiting room in the outpatients at the hospital in the burns unit there was a brochure for the Burns Foundation. And I think that's how I initially came across it. (So it wasn't offered to you?) No. So um yeah upon taking that I um looked on the website and got in contact with the group that way. So initially I had no contact with anyone or um anything like that. I wasn't informed that this was a group or anything. [Pauses] um as for being involved with the group um I've found it personally um [pauses] very helpful. Because you're able to talk with people that um understand what you've been through and in some cases have been through worse than what you have. And I know that sounds silly and stuff but it makes you feel a little bit better [pauses] um you see that someone's pulled through something maybe a little more significant than what you have. Um [pauses] so that I found very good. Ah [sighs] nurses, [my partner], psychologists, people can be supportive. But until you can talk to somebody that you know really understands what you are saying [sighs] to an extent the rest of its just talk. (Participant 18, L: 578-595).

Not all participants were willing to engage in burn survivor peer support groups and share their experiences with other burn survivors. However, on reflection this participant found that a chance encounter with another burn patient was an eye opening and reassuring experience:

There's all these support groups, I could have gone to this group, that group, I said, no, it's like wanting to know what the person next door's story is. I didn't really want to know. But I was offered all these services, yes. But what came to my head was my first visit to the burns unit, I told them who I was and then the receptionist said, look just take a seat, she'll be with you in a minute. The only seat, like there's like three or four seats and there's a person sitting there with the full pressure suit on, face mask,

but his gloves - his fingertips were cut off and his gloves were open and the fingertips and to break the ice I sat down next to him and I said, look that's not fair, how come your gloves are open and mine aren't. He said, oh don't worry, you'll eventually get them. It was the only time I ever asked. I said, look I never ask, but what's your story. [Laughs] he told me and I just - every 30 seconds, stop no more, no more. This poor fellow was a farmer. He just left me speechless... Then he took his mask off and I tell you, he looked great. (Participant 12, L: 431-448).

Although other participants expressed an unwillingness to engage with other burn survivors not wanting be part of their plight:

I didn't really want to be entangled in their lives [other burn survivors] or be a part of whatever they had - because most of them were negative in terms of, um, how they coped. I don't really want to criticise people, but just for me, it wasn't where I wanted to be. I didn't want to join the burns victims group or no, no. I didn't want to do that; I never have wanted to. I just wanted to get over it and get on with my life and, um, I didn't really want to share feelings; I didn't feel that there was a lot to be gained. (Participant 17, L: 236-243).

Peer support was evident among burn patients throughout their rehabilitation. Participants would share their experience between other burn patients during therapy sessions or in the hospital corridors as described by this participant:

Ah we knew exactly what each other was going through. Even though our injuries were different um we knew the same pain or virtually the same pain. Um we could bounce off each other in doing things. If he'd go away to do this OT [occupational therapy] and I'd do mine we'd come back and we'd talk to each other. Righto what'd you learn today? He said I learnt this. I went I learnt this. Well that would work with me too. Oh that'll work well for me. So then we'd go back to their OT

[occupational therapist] because we had two different ones. And then we're bouncing each other off what we could do and what they could do and then they'd swap it around. That was fantastic. (Participant 20, L: 386-395).

Others found solace in not being the only burn patient at the rehabilitation centre. Interacting with other burn patients and their families established a supportive atmosphere that made participants feel they were not alone:

[Long pause] the other burns guys I think probably helped a lot because my family and their families interacted. And it did become a little bit of group if you know what I mean. (Was it a form of support?) Yes, definitely was a form of support. You weren't [laughs] the only 'Darth Vader', you know what I mean? There were other guys there that looked the same so people didn't really look sideways at you. Because there's another [burns survivor] just up the hallway there in the same suit or whatever you like. It wasn't like you were anything out of the box. (Participant 14, L: 226-234).

Participants providing peer support for burn survivors found the experience to be uplifting and therapeutic. Such events as burn survivor camps were thought to benefit all involved as this participant maintained:

...me being a survivor I can talk to other survivors and tell them that there is light at the end of the tunnel after they've actually been a burns victim. With that, it helps them and that you can actually talk to family members, children, mothers, fathers, even friends. Because a lot of people bring their support team to the conferences and meetings and camps that we actually do have. So everyone benefits from it. (Participant 21, L: 132-138).

Another participant simply stated:

It's having that association and the credibility factor that they look at you and you're wearing the same scars that they are. (Participant 8, L: 789-791).

However, this uplifting encounter was not experienced by all the participants who provided peer support to burn patients. This participant, who had sustained a disfiguring facial injury, found visiting a burns patient with a lesser injury an upsetting and confronting experience:

But I know I've done it [visited a burns patient] with one patient in particular and it was completely different to what I thought it would be. I actually got - it upset me. I looked at this guy and he was down in the dumps and whatever and I couldn't help but think there's not a lot wrong with you mate. Suck it up, you're all right, that was my honest opinion. But you had to be really mindful of to this guy and his family he's the worst burns case there's ever been. That was a bit of a learning curve I guess for me because I thought it'd be easy. I thought you'd go in there [laughs] and you'd say hey you'll be right and you'd feel like the Red Cross. You'd come out feeling all warm and fuzzy. But it wasn't, it was not at all. It was the opposite and you felt cheated. I came out and I thought well shit look at his face, he's not burnt. How come my face is burnt? That was, it was hard. (Participant 14, L: 425-437).

Spatial environment

The emergent theme *spatial environment* was the overarching theme that defined how participants described and interacted with their physical environment. The surrounding environment influenced participants' experiences throughout their rehabilitation. Participants experienced varied emotions unearthing descriptions that included: *sanctuary, imprisonment, the sanctity of home and isolation.*

Sanctuary

As burn survivors are cared for in single rooms throughout their rehabilitation, they provided participants with a sense of security and safety from the outside world. Participants spent

many months enclosed in this one room, mostly confined to a bed for most part of the day. All in all, their room became their sanctuary. Leaving the room was a difficult task that left participants feeling apprehensive and anxious as one participant narrated:

I was quite frightened to leave the burns unit because I'd been there so long in this one room and it just sort of felt like leaving home and I found that very difficult. (Participant 5, L: 382-385).

Another participant described their room was like a 'cocoon' providing a safety zone:

I'd got so I was like in a cocoon in the burns ward. It was a little safe spot, room six, just down from the nurses' station. It was this little safe spot that I could stay in. I hadn't actually ventured out very much. (Participant 11, L: 67-70).

Burn dressings were physically and emotionally traumatic procedures to endure in which the four walls of the room provided participants with the privacy required to withstand such an ordeal as expressed here:

It was just good to have a single room because you had to go through dressings and everything every day and that, so I suppose it would have felt like a bit of an invasion of your privacy having a few other people. (Participant 3, L: 244-247).

The sanctuary of the participants' room may have provided a sense of security. However, participants expressed that they were becoming entrenched and institutionalised:

I had become institutionalised in the, err, burns unit, as you do after you've been there... We all become institutionalised and we develop a sense of security around us. That sense of security was well and truly entrenched in me because I knew the people, familiarity. Even though I couldn't travel, there was a feeling of I'd made it home but, hey, I wanted to leave home. I wanted to get out of there and go to my real home as soon as I could but I realised that I wasn't ready. (Participant 17, L: 296-302).

This sense of security that was deeply entrenched was evident with participants wanting to return to the safety of their room on the burns unit, only after leaving for short periods:

I guess when I started to get a little bit better, I started to feel strongly that I wanted to get out. [My partner] had a unit not far from the hospital and used to go back there every night. I used to wonder why I couldn't go back there at night. When I eventually started going back, I couldn't wait to get back to hospital because I just felt secure back at the hospital. It took me a long time to get that thought out of my mind.

(Participant 13, L: 139-144).

The same participant expressed how the staff became an extended family and upon return to the burns unit encountered a homely experience:

...the burns unit staff are more a family to me, whereas it was never like that out at the rehabilitation centre. I just didn't spend the time with each person out there. I never had the confidence there. I think I left there once to go - I had minor surgery. I left the rehabilitation centre and went back to the burns unit for about 10 days, I think. I just felt I was going back home. (Participant 13, L: 365-379).

Imprisonment

Feelings of imprisonment were expressed by participants throughout their rehabilitation. In particular, the environment of the rehabilitation centre was often described as being akin to a prison camp or cell. After a long isolative hospitalisation in the burns unit, participants often experienced an abrupt introduction to the rehabilitation centre as expressed by this participant's first impression upon entering the rehabilitation centre:

I was dumped in a ward that was fit to be a prison cell, with four other people, and they said, the look of horror on your face. I had a good mind just to tell the ambulance just to put me back on the stretcher and take me back to the burns unit.

(Participant 2, L: 8-11).

Another participant also described the admission to the rehabilitation centre as:

Uh [pause], it was different [the rehabilitation centre] to the Burns Unit but...like going into prison camp. (Participant 21, L: 306-307).

Some participants stated that the rehabilitation centre was not a favourable environment whereby one participant reiterated fervently:

I don't have fond memories of the place [the rehabilitation centre] at all. It was bordering on a jail cell. It was a jail cell. (Participant 14, L: 202-203).

Others were more philosophical, approaching their admission to the rehabilitation centre in a different light as articulated by this participant:

...you know you're not there on a holiday. It's not a social outing. It's another form of incarceration but a lesser form of incarceration. (Participant 8, L: 427-429).

As participants progressed and regained more independence, day and weekend leave was often permitted. Participants longed for and enjoyed returning home even for short periods but detested having to return to the rehabilitation centre as one participant conveyed sardonically:

All I wanted to do was go home which they did eventually give me the opportunity to go home on weekends. (And how was that?) That was fantastic. That was [laughs] - I guess that was like day release or weekend release from jail. (Participant 14, L: 236-241).

The environment of the rehabilitation centre was not the only setting described as a prison. Upon returning home, some participants found their home another form of imprisonment expressing:

I knew I was going to go home to another prison because everyone else would be out working and I would be there looking at four walls. (Participant 8, L: 466-468).

As well as feeling imprisoned by the environment, participants felt imprisoned by procedures such as splinting performed to avoid skin contractures. This participant asserted vehemently disdain for the use of the arm splints describing ways to escape the torture declaring:

I hated my arm splint tied up, I thought I was in jail because you're being tied up and all that. I hated that. I hated that and I did my best to make it difficult so I didn't want it to be so hard, so I used to make sure that I didn't extend my arm full in order to be tied up tightly. (Participant 19, L: 251-254).

Other participants expressed the difficulty with wearing the pressure garment for extended periods claiming it was like a prison sentence as this participant expressed when unable to remove the pressure garment without considerable assistance:

Once I was in the suit I was stuck, that's it, I couldn't get out of it. That was it and I was just stuck in it. So then ah obviously when it was time to shower next I'd have to be - [my partner] would have to get me out of the suit. [Sighs] and it was just a prison sentence. (Participant 18, L: 356-360).

The sanctity of home

Participants yearned to return home after such a long hospitalisation and rehabilitation period. Participants were often permitted to return home for short periods during their rehabilitation as part of the transition period. Short visits home were an uplifting experience:

Oh great, yeah. Yeah, it was just uplifting to me [returning home], I hadn't been home for three-and-a-half months. (Participant 15, L: 512-513).

Home was a place where participants could reconnect with their loved ones in a family environment away from the sterility and intensity of the rehabilitation centre:

...on the Saturday or the Sunday night the kids would generally stay around. They'd bring takeaway and we'd have dinner together. We'd sit down and just watch Dr Who on telly or something; be a normal family again. On my weekends home I'd have that situation; you'd go and get a DVD, get some Thai takeaway and sit down as a family

and - that is something that I was craving by that stage, to be back in that sort of family situation and out of the sterile rehab. (Participant 11, L: 596-603).

Another participant stated that home was a more natural environment, however expressed disenchantment upon returning to the same room at the rehabilitation centre:

It was good to go home. It felt more natural at home, being at home. It sort of was and wasn't, because it was only one day a week. It goes pretty quick and then you're back in the same room again. (Participant 19, L: 112-114).

Another participant said:

...going back was a bit, ah (pause), yeah, I wasn't looking forward to going back [to the rehabilitation centre], I was trying to think that I'd rather stay home, but - but yeah, it wasn't too bad. I'd rather be able to come back home for the day than not at all. (Participant 7, L: 272-275).

Another participant not only conveyed a similar experience, but also added that returning home for short periods was symbolically representative of the progression and recovery from such a traumatic incident:

After the first week I realised that I could actually - I could leave rehab as long as I told them for how long and - so what ended up happening was because I only lived 10 minutes away by car from rehab to home. Each evening I'd be picked up, I'd either go home or to my parents' or my parents'-in-law and spend a few hours, up to about five hours. I'd have dinner and yeah, that was good. I was out of hospital, I was in the home environment and I felt that whenever I was home or in the home environment it felt like I'm almost there. I didn't like going back, I sort of dreaded it a bit, but I did anyway. I felt comfort in being in a home environment, yeah. (Participant 12, L: 251-261).

Weekly visits home were a positive experience for the participants:

Every week I looked forward to it, going home. It was a positive thing. It was comfortable being at home instead of being at rehab. (Participant 9, L: 116-118)

One participant in particular, articulated that his premature departure from the rehabilitation centre was as a result of the desperation to return home after such a long hospitalisation:

At the rehabilitation centre, there was a lot of physiotherapy and all that, but I only stayed a month at the rehabilitation centre and I wanted to come home because it had been already nearly eight months that I was not at home and I wanted to come home. (Participant 19, L: 11-14).

Home was a precious place in the hearts of participants, the thought of one day returning home was the driving force for this participant's recovery:

I kept trying to keep my mind going thinking of my little dog and this farm and wandering over the farm and trees and things that I planted and loved and that's what kept me going. It was my future thoughts of one day coming home again. (Participant 5, L: 256-259).

The sanctity of home is expressed here implicitly:

That was probably the greatest day of the whole thing, to get to go home and know that you were staying at home. (Participant 14, L: 592-593).

Isolation

The physical isolation and loneliness was an ever present reality for the participants in this study. Confined to a single high dependency room for 24 hours a day for months at a time with minimal contact with the outside world was an emotionally taxing experience as one participant recalled:

You're not going home while you're in hospital...you're not going anywhere. You're there and every day's another day and that you're stuck there, you're isolated. Isolation is probably the biggest sole factor as well, you're alone. You're alone again for 95 per cent of the time besides seeing the nurses, your family for maybe when it comes down to the stage where it's once a week visits. You see them for maybe 30 minutes, one day of the week. Apart from that you wake up in the morning, especially being immobilised, you can't move, you can't go for a walk downstairs. You can't go to the coffee shop so you're restricted. You're in that bed 24/7. (Participant 8, L: 116-125).

Isolation often resulted in boredom and feelings of depression. In this regard one participant expressed:

I was just seeing the same thing every day at rehab. It was just sitting in a room looking at four walls every day...It was just boring. I just felt like I wasn't doing anything. I just felt like I was stuck in a rut, not going forward, not going backwards. Looking at four walls each day got pretty boring and it gets you down. You get unhappy a lot. (Participant 9, L: 118-124).

The isolation and loneliness experienced with a long hospitalisation impacted emotionally upon participants:

But it was lonely because you knew those people weren't there to come in and say hello to you for two minutes. They just walked past like you weren't there. So you just laid there and looked out and looked up and I couldn't sit up at that stage so I just had to lay there and wait, wait, wait for the time to pass, it's a time thing. (Participant 5, L: 781-786).

The same participant further described difficulties experienced with isolation as clearly expressed here:

The worst times were the loneliness between going to sleep at night knowing – or getting up in the morning – knowing that it's going to be about six hours before I see [my partner] and somebody that's close to me; somebody that I wanted to be with, someone who was going to take my mind off the hospital and things and just ease my mind again. And then the other terrible time was when [my partner] would leave at night when it was time to go around eight o'clock and you knew the lonely nights. (Participant 5, L: 748-755).

Illustrating the extent of the loneliness experienced, this same participant described the strategy used to cope with the loneliness and isolation:

I know every hole in the ceiling; I know every corner and I know I've drawn lines between every – I did trigonometry and every – can I see well I'd count it, multiplied... (Participant 5, L: 242-244).

Being the only burn patient in the rehabilitation centre had an emotional impact upon participants engendering feelings of isolation:

I guess if there was any problem, it was the fact that I was a burns patient and they were amputees in the main. I seemed to be - well, I was the only one there from the burns unit. It did affect me for a short time. (Participant 13, L: 261-264).

Fundamentally, isolation had a considerable impact on participants' emotional well-being with little opportunity for participants to engage in meaningful interactions with others:

Um yeah I would have [liked more support]. Personally I would have, yes. Um I would have liked the opportunity just to um have someone to talk to, well just about anything. I felt um especially towards the end sort of locked away a little bit. You feel sort of quite isolated and um...(How did that impact on you?) Sort of locked away

from society, almost segregated if that's the right way to put it. [Sighs] so I would have liked that [pauses] because of my attitude, not necessarily for my family members or those sorts. But I would have liked the outside contact from [sighs] hospital nursing staff because I felt comfortable [pauses] dealing with them, do you know what I mean? So yeah I would have liked it a lot more of that outside type support. (Participant 18, L: 241-252).

A fundamental aspect to this theme of spatial environment is the notion of safety and security through the rehabilitation journey. The environment of the burns unit provided participants with a strong sense of feeling safe and secure within the confines of their room. However as participants transitioned and became more independent throughout their rehabilitation, participants began to feel less safe and secure and less in control, knowing the safety net that the burns ward provided was no longer there.

Challenges

The emergent theme *challenges* describe the adversity that confronted the participants of this study encompassing both physical and emotional aspects. Despite experiencing different challenges, each of the participants described feelings of frustration and disappointment throughout their rehabilitation journey. Cluster themes developed were: *hurdles, adherence, consistency and continuity and the long road to recovery*. Each of these four cluster themes maps the arduous journey taken in an attempt to regain a sense of self and independence.

Hurdles

Participants were confronted with numerous and varied hurdles at different stages of their rehabilitation. Early in the rehabilitation journey, the most basic of actions of simply standing up had become a huge effort that left this participant feeling helpless:

I was still attached to drips and had bandages from my feet up to the top of my head and so it wasn't easy for me to get out of bed at all. I had to be physically helped out of bed and of course, just the mere fact of sitting on the edge of the bed, made my head reel because I was very disorientated with being vertical instead of being horizontal. I was helped up and tried to stand on my feet which sort of didn't really

happen and I ended up having to sit back down again, aided of course by two physios [physiotherapists], one either side and I had also had difficulty sitting because my whole backside is grafted. (Participant 5, L: 22-30).

At times, participants often perceived their recovery as insurmountable, faced with a myriad of complications leaving some participants feeling frustrated by their limited mobility:

...frustration because I suppose the percentage of burns I had in the period of time, three months, 92 days in ICU [intensive care unit], a lot of immobilisation and of course, shortening of tendons and extensive nerve damage to legs and feet, bone ossifications forming in knees and elbows further restricting mobility and adding more problems... (Participant 8, L: 28-32).

Another participant stated:

Frustrated because I just wanted to do this, I just wanted to be able to walk and that's all there is to it. (Participant 4, L: 157-158).

Others were faced with similar hurdles created by the amount of scar tissue that formed around the joints making activities of daily living challenging:

Obviously I couldn't straighten them [my arms] because I had a build-up of scar tissue. But I couldn't - I couldn't bring them in either. (Participant 7, L: 232-234).

Despite displaying positivity and motivation towards rehabilitation, the hurdles participants needed to surmount often appeared at times to be an epic challenge:

In the main, I always thought I was going to be better, although I must admit there was the odd day when I felt I'd had enough. It just seemed all too hard. At that stage, I couldn't eat; I couldn't do much at all for myself. Because of my grafts on hands and arms and underarms my movement was almost nil. I found it hard to scratch myself. (Participant 13, L: 6-11).

Setbacks and disappointments were met throughout all phases of the rehabilitation journey that were often difficult to comprehend and accept:

I think it was just more the setbacks along the way. The hurdles I had to jump were the size of a hurdle so that was the thing. Whether it be that had an operation on my axilla and it failed. If you had a skin graft and the skin graft died. That to me was just like shit, we've just lost - three weeks of my life is just wasted. (Participant 14, L: 735-740).

For other participants it was one step forward and two steps back which was a disheartening experience having come so far with their rehabilitation and yet still encounter issues with their mobility:

That disheartened me a lot sometimes. I'd have a couple of good days on my leg and then I'd get a breakdown. So I'd have to stick it [prosthetic leg] in the corner and I couldn't wear it. (Participant 11, L: 727-730).

In addition to the myriad of physical hurdles experienced, participants were also confronted with the psychological scars that required time to heal:

I had a lot of emotional - I had a lot of psychological scars to overcome; I realised that. I couldn't see somebody - I couldn't light the gas. Petrol frightened me. With petrol and flames and matches and candles, I was a bit gun shy. Yes, I was aware of lots of fears and I had a lot of repair work to do. (Participant 17, L: 389-393).

Later in the rehabilitation journey, participants were met with new hurdles that still required the assistance of others to overcome:

...they were very stiff [fingers] and they're a lot better now. I've got a lot more movement in them now, but before I couldn't really move them that much at all, especially my left hand. It was just things like getting dressed and I couldn't do up

buttons or zippers or things like that. I had to have help pretty much all the time with feeding and dressing and just all that sort of stuff. (Participant 3, L: 192-197).

Another participant found the daily routine of getting ready in the morning a colossal effort impacting upon their rehabilitation:

So it was also hard for me to get from my house to the rehab centre for day rehab but I was just so tired all the time. I felt like it was too much for me. Well I mean they said to me that they were prepared to come round my house and do day rehab stuff at my house. But the thing was I would get so tired just getting myself up, getting myself washed and getting myself dressed that by the time I'd done that it would take me a couple of hours. Then I wouldn't want to go to day rehab anyway, I'd be too shattered. (Participant 10, L: 414-422).

Due to the nature of the burn injury, regulation of the body's temperature was severely diminished and any outside activity was difficult:

My first few weeks out of rehab and even in rehab, I couldn't even stand 30 seconds in direct sunlight. It just - I was having difficulty regulating my body temperature. Even though I was 30 per cent burns then grafting another 30-odd per cent, so my surface area's drastically reduced; a cool breeze which was - a normal person wouldn't even blink an eye and say - that would just rip through me. (Participant 12, L: 601-607).

This participant summed up the rehabilitation from a severe burn injury by saying:

So it was all a challenge, each day. (Participant 6, L: 263).

Adherence

Adherence with care was often a challenging experience due to the pain and discomfort endured throughout their rehabilitation. Among the participants, there was a realisation and understanding for the necessity of adherence to rehabilitation. This participant stated bluntly the need to cooperate with the clinicians and therapists:

...you just realise that these people expect certain things from you and you know they're not doing it to make them happy. They still get their pay at the end of the week. They do it to help you so if you're stupid enough not to take their advice, well you'll suffer for it in the long run. (Participant 5, L: 59-63).

Others were motivated by the loss of independence and function as clearly stated by this participant:

Like I couldn't bend any of my fingers and they torture you, they don't muck around, you want your flexibility back, well you're going to have to bend and stretch and force your fingers to bend. Yeah and that spurred me on, the fact - that scared me that if I didn't do this, I'd lose flexibility in especially my fingers and hands, so it's my livelihood. The worst possible place I suppose, your fingers and hands and arms. (Participant 12, L: 65-70).

This participant reflected on the importance of adherence to therapy contributing to the ability to eat and talk adequately; persisting with the mouth splints that would stretch the scar tissue on the lips and mouth avoiding skin contractures:

Well as far as the splints for the mouth, I had two different types and that took a bit of time to figure out which one worked the best. Had I not been using those splints to stretch the skin across my lips, I wouldn't be talking or eating as good now.... (Participant 16, L: 54-57).

Other participants were mindful of the necessity to regain movement and function despite the pain endured:

I guess I was a bit nervous to, kind of waiting, two of them would walk past and was that the OT [occupational therapist], but I mean later I realised that they have to really force the movement I think, because initially to get movement back later. But it's a bit hard to explain the first time that you go through it and you feel the pain and

a bit of the mindset, is this really necessary, but obviously it was. (Participant 7, L: 85-90).

Whilst some realised the importance of adherence to therapy early in their rehabilitation, others did not and sadly for some the window of opportunity closed:

...in hindsight you don't realise the importance of the early rehab until much, much later. (Participant 8, L: 7-8).

Wearing the burn pressure garment was a challenging experience for all participants. Pressure garments were worn for 23 hours in a day for a period of up to two years. Hypertrophic scarring, unique to burn injury, affected participants, reducing their mobility and function. Without the aid of the pressure garment, participants would be impaired physically. This participant described the dedication required to wear the garment:

I had a new [burn compression garment] fitted which was a tighter fitting one than the previous one that I had made at the burns unit. I didn't think I'd ever cope with wearing the new and tighter fitting full body suit. It was just one of those things I didn't think I could ever cope with. I guess I knew I had to. I'd been told the scarring was going to be raised and nasty. The only way I was ever going to give my skin a chance to be anything like normal was to wear a pressure suit 100% of the time. I guess I just had very good people with me at the time who helped encourage me to persevere. (Participant 13, L: 218-226).

Others found wearing the pressure garment too challenging and ended in non-adherent behaviours as expressed by this participant:

It's like being in a straitjacket [pressure garment]. It's just a pain. And because I'm on - myself and a few other blokes that are always out going and doing things you just don't need that restriction. So probably down the road I'd say yeah I should have

had it on and should still have it on. They said it's only for ah two to three years but because I'm so active [pauses] that's just not for me. (Participant 20, L: 443-449).

A lack of education and information regarding the rehabilitation from a burn injury was expressed by some participants. Potentially, a lack of understanding could lead to non-adherence as seen with this participant's response:

Oh I hated them [burn compression garments], I absolutely hated them. I think I might have asked, why do you want me to wear these? Then, I thought well, okay, I'm not going to - are they for aesthetic reasons? Are they just to make me look better and less scarring and all that? I didn't fully understand why I was putting them on. Eventually, I just thought, oh well, I'll just see how things go without them so I didn't wear them over a period of time; I just put them aside. Yeah, so I was very bad in that respect. (Participant 17, L: 542-549).

Another participant maintained:

...there's a lot of things I've picked up and I fully understand now, but initially for someone who is unaware of burns and the consequences, more information would have been great. (Participant 12, L: 424-427).

In addition to the importance of education, was the manner in which information was delivered. This participant aptly described the approach of the occupational therapist being fundamental in encouraging adherence to burn therapy:

In a lot of ways the OT [occupational therapist] was my lifesaver. Because [the occupational therapist] was so good she just - maybe I think differently to a lot of other people. But she seemed to be able to put things in a perspective in my head that made it matter to me. As where some other people would come in and say okay we want you to do this and give no rhyme nor reason and you just go well no I'm not doing that. Then [the occupational therapist]would say well look the reason you

need to do this is because this, this and this. That then gave me enough reason to go through the agony of whatever it was to do it. (Participant 14, L: 101-112).

This same participant further added that being bombarded with masses of information through multiple avenues, made digesting and comprehending the amount of material an overwhelming experience:

They put the nose prongs in to spread your nose. I couldn't tolerate that. I just couldn't tolerate that so I'd take them out. They said oh your nose will collapse and I said well I don't care. Now I look back three years later - almost three years later - and I think well maybe if I'd kept the nose prongs in it may have solved some of the problems that I'm having now. At the time it's really hard to - you're just bombarded with that much stuff that you have to do. Like you say, be it the OTs, physios, whatever, everybody comes in with their time slot and they have an agenda for you. It's all about helping you but at the time it's almost information overload. (Participant 14, L: 119-128).

Consistency and continuity

Consistency and continuity or the lack of, was an area of concern for many participants in this study. The main issues revolved around the notable lack of experience in the management of burns at the rehabilitation centres instilling a lack of confidence in participants. Participants were often mindful of the care and management of their injury, taking an active role in dressing changes. However, the lack of dressing skills of the rehabilitation nurses evoked this response from one participant:

Each day the dressings were done in a different way and they decided to use different materials and different solutions. Some didn't know if ...they weren't directed by yourself or [my partner], it was done differently every day. (Participant 5, L: 650-654).

Participants were often well informed about the dressings and other materials used to dress burn wounds. This participant in particular was confronted with nurses, who were ill equipped to perform a complex burn dressing, requiring the necessary consultation and coordination of the burn unit:

Well to start with they were getting done all - the materials, the Bactigras and all the Silverzine and stuff like that - each person that was on were using what they thought was right. So there was a discrepancy each day. It was like a different lot of treatment. So then what they did when I went back for a little review at the Burns unit, they said, no this is what you're going to have to have and they wrote that down in stone. They did that and from then on my legs healed faster and it was much easier for everybody because they were all on the same page. (Participant 4, L: 74-82).

Other participants also became frustrated with the lack of education concerning dressing and managing burn wounds and their complexity, displayed by some staff in the rehabilitation setting:

...there are stages with your burns. They just didn't know or understand the type of dressings that you would have to put on and, if they [rehabilitation nurse] did know, they didn't have them....always running short and they would substitute for something else. Now, how is a burns patient supposed to recover or get better when they don't have the right dressings there? The right equipment, the right dressings - how are we supposed to recover? (Participant 1, L: 55-61).

Some participants felt that there was also a lack of experience and apprehension concerning the therapist's management of their burn as described by this particular participant:

They would be concerned because you'd had a couple of fingers splintered so they weren't going to touch them and then the hands still had wounds on them so they didn't really want to touch that because it'd aggravate the wounds. So very little was done because in the end, there was only two or three fingers they could do anything

with that they felt comfortable with. So you didn't really want them to play around with your raw wounds and the fingers that didn't really want to move anyway. So it was a real – a bit of a hit and miss effort the whole rehabilitation centre to me. (Participant 5, L: 556-565).

Of importance to participants was consistency and continuity of care which engendered a sense of security and confidence enabling the formation of relationships based on trust:

Forming relationships and trust in the people I guess, that was a big thing I think. That you knew that that person - you had them last week and they were good and you knew that you were going to be good. (Participant 14, L: 30-33).

Keeping lines of communication open by means of providing an explanation and rationale for treatment further enhanced trusting relations between the clinicians and the participant as demonstrated here by one of the participants:

[The Clinical Nurse Consultant] came in and said well this is what we're going to do. [Pauses] some nurses would come in and say oh we're changing your dressings and that but they didn't elaborate what they were going to do. Where [the Clinical Nurse Consultant] and a couple of the more experienced nurses, they'd come in and say right this is what this stuff does to you. And then ah this is a different type of bandage we're using today because it does this. (How did that help?) Great because you knew what they were - they were talking to you and you knew the reason why they were doing it is recovery stage, for recovery. But um every time I'd ask somebody what's this for they didn't know. To them it was just another bandage or another ointment or another um dressing they were doing. (Participant 20, L: 80-92).

Having a coordinated rehabilitation schedule provided some order and structure into their lives after enduring such a traumatic and capricious injury as a severe burn:

...but you look every day at the schedule, the timetable, you knew what was happening when and all that. (Participant 19, L: 186-187).

However, without consistency and continuity, participants found it difficult to adjust to the changing environment:

The rehabilitation centre had staff coming and going. You didn't know who you had one week from the next, which made it hard for continuity that way. (Participant 11, L: 712-714).

Despite the level of expertise experienced on the burn unit, some participants claimed that they were not receiving enough therapy due to a perceived lack of resources:

The burns unit, as far as your burns went and your surgery, they really knew what they were doing there, but they haven't got the resources to have enough occupational therapist there to actually give you physio every day. They did when they could... (Participant 2, L: 90-93).

While another participant expressed extreme frustration at not being able to access the rehabilitation centre's facilities outside of hours:

*Because on the weekends it shut, other than for food there was nothing happening. No physio, nothing, nothing at all. I mean you didn't get a lot through the week but on the weekends they weren't even there. **(How did that impact?)** That was frustrating. Even through the week it was frustrating in the point that I knew what I had to do. Or I basically thought I knew what I had to do to get better, to get out of there. It'd been drummed into me at the burns unit. I wanted to do it and get out. I'm big on timeframes. I want to get this done and get on with it so when the physio didn't work out or whatever for that period I would have liked the opportunity to go to the gym*

and do it myself. Because [my partner] or whoever might have been there to help me get there and stretch my head on the things or my arm stretches or ride the bike or whatever. But you couldn't, the gym was locked. Unless you were actually there with your trainer you couldn't be there. It was just frustrating. You were locked in this place and you knew you had to do X amount of miles to get out but they wouldn't let you do the miles. The miles come at their pace. (Participant 14, L: 243-261).

The level of coordination of care between the burn units and the rehabilitation centres was at times questioned by participants that felt:

I didn't think it was as good as it could have been [coordination of care], as there was confusion from time to time. There didn't seem to be much coordination between the two units. (Participant 13, L: 255-257).

It was considered by some participants that a greater presence of burn specialist clinicians was necessary in order to bridge the lack of coordination and continuity of care in the rehabilitation setting:

Well [pause] I felt - I think maybe they should have a burns specialist in rehabs. Even though my OT [occupational therapist] had a fair knowledge, she wasn't perfect. She actually made a few flawed errors, she made a few errors in correct advice. She was actually learning as well. So with hindsight - again it's all with hindsight - with hindsight I think a burns specialist would be ideal in rehab, especially for burns patients. After leaving rehab I continued with my routine, that's all I basically knew, that was the advice given to me. (Participant 12, L: 290-297).

The long road to recovery

The emergent theme *The long road to recovery* described the great lengths taken by the participants to recover from such a traumatic injury as a severe burn. Participants endured many months of painful dressings, therapy and on-going surgery throughout the rehabilitation journey and for some, rehabilitation does not stop. The length of time required to recover was

often inconceivable early in participants' rehabilitation. Participants needed to relearn basic activities of daily living:

In the early days I couldn't walk. I couldn't believe when I woke up that I couldn't walk. I had to learn to walk again. My hands, I couldn't use my hands. Everything basically had to start from scratch. That was a long haul, a very long haul. (Participant 14, L: 725-728).

Participants were grounded in the reality that their rehabilitation would be a protracted process with setbacks along the way:

...one step forward, two steps back. Yeah, it's funny, I finally - the reality's set in. I fully understand that this is going to be a very slow, long process. Yeah. (Participant 12, L: 128-130).

Another participant also displayed being grounded in the reality of the length of time necessary to fully recover from the burn injury despite making good progress:

But I can remember it certainly made a lot of difference as I started to get my independence back. I mean and even now I think I'm still making steps forward and it's still going to be a hell of a long time. (Participant 10, L: 471-474).

Others discovered through education, the length of time required to recover:

...with each day that went by, I learnt more and more about burns and skin and burnt skin and the length of time needed to recover. (Participant 12, L: 54-55).

While others were informed that it would be many years before they regained an independent life:

[Long pause] everything's been really difficult to be honest. I mean the burns doctor told me he reckoned it would be five years before I would return to any degree of normality in my life. (Participant 10, L: 342-344).

Continuing reconstruction surgery and skin contracture releases throughout the rehabilitation journey was a disruption to participants' on-going rehabilitation as recollected by this particular participant:

[Pause] Yes, it had been a step backwards and I had no trouble with the staff in the burns unit because they have to do a lot more work on my back, not only to find more skin that I had left to rebuild it but also part of the muscles towards my [pause] left shoulder had to be replaced with some form of filler to rebuild the missing fat tissue. [Pause] So that was originally to be a week to two week stay and ended up being four months. (Participant 16, L: 223-229).

Another participant described the continuing repeated surgery due to the severity of the burn injury sustained:

Yeah. Um ah I've only just got over having my fingers done and the eyes, they've done that. Ah before that there was ah [pauses] the elbow and before that it was the mouth and then ah fingers again. Ah and it's just ongoing. (Participant 20, L: 504-507).

Regaining any sort of function and movement in the limbs was an incredibly lengthy process as recalled by this participant:

...that's probably the thing that took the longest, was getting any movement back, even when I was at rehabilitation centre, it still took quite a while to really get movement back and this hand was like very hyper-extended. (Participant 7, L: 91-94).

On average, the total length of hospital stay for participants was 185 days. However this particular participant struggled emotionally with spending a total of 223 days hospitalised knowing that it was going to take an extended period of time for their wounds to heal:

You know, other people break bones and have operations, they're out of there in a month or two maximum. They're not there for month in month out and that's the

whole thing about burns is the length of time that a burn takes to heal – the body to heal to get back to some normality. (Participant 5, L: 765-769).

Another participant took a more comical look at the length of time hospitalised:

...being in a burns unit for almost eight months, you become part of the furniture. Other patients come and go and you're still there. (Participant 8, L: 136-138).

Acceptance

The emergent theme *Acceptance* described the traumatic nature of a severe burn as a challenging experience for the participants in this study. It was observed that participants felt the need to accept their injury which manifested itself in different behaviours. Cluster themes identified were: *reasoning, humour, the challenge of acceptance and self-awareness*. Of interest, participants often used reasoning and humour to come to terms with the injury and the subsequent changes that frequently confronted them throughout the rehabilitation journey.

Reasoning

Some participants compared their own tragic circumstances with others who they felt were worse off than themselves:

...comparing myself to these other people in the...rehabilitation centre there was also the brain injury unit and when you see all these people and you know that they're probably never going to get better...you just think yourself so lucky that you're not one of them. Even though you know you're still going through something pretty horrific yourself but they're just degrees of horrible things aren't they? (Participant 5, L: 458-464).

Again, the same participant struggled to comprehend and come to terms with surviving the accident that resulted in the burn injury attempting to find a hidden meaning within such a tragic accident:

I often ask why I was spared when you see things on television now like those miners and now the earthquakes in New Zealand, you go, well, you know, 160 odd people;

what suddenly snuffed their life out? Were they bad? Were they – they weren't Godly or didn't they believe or how does it work, you know? Why was I spared? Have I got some hidden meaning or was I just lucky or? (Participant 5, L: 895-900).

Others found solace in looking at the positives by comparing themselves with other burn patients who were grossly disfigured:

I was told that I'd got third degree burns to 60 per cent of me. That was pretty extensive. But, again, look at the positives. I was looking at the positives now. Young...fellow whose hands burnt, no fingers, I said well these are my fingers. They mightn't be working too well at the moment, I've got hands, I can eat more than peanuts... He was pretty badly disfigured. I thought how I'm not badly disfigured... But again I looked at the positives there. The positive is I'm not as bad as that. (Participant 6, L: 296-305).

Similarly, this participant in struggling to accept the reality of the physical changes also found some level of comfort when confronted with other patients that had sustained disfiguring facial burns as expressed here:

When I was in hospital I was miserable and thought I'd never get a partner again. I suppose it was trying to accept what my body was like now. But I pretty much accepted the fact that I'd probably be on my own now. But then when I saw some of the other burns victims who had really, really bad disfigurement on their faces and some of the other people in rehab who weren't necessarily burnt but who had it worse than I did. It made me thank my lucky stars in a way do you know what I mean? Because I think if I'd been badly disfigured in my face I think I'd have been a completely different story. I think I would have probably become really recluse. I'd have never gone out. But luckily most of my burns I can cover up. (Participant 10, L: 296-305).

Despite sustaining a significant facial burn, this participant found consolation in differentiating themselves from others that were physically impaired due to the scarring:

Well [pause] to me I thought I was - had bad injuries face-wise. But I have seen since that there are worse injuries, scar-wise, that are worse than I am, ah, physically.

(Participant 16, L: 108-110).

A toughened attitude was often necessary when participants reflected upon their own circumstances in which they found themselves in due to the burn injury:

When I saw people that had been in car accidents and things like that, just going oh God, if that had happened as well, then I would be buggered. As it is I've just got one leg a bit shorter than the other and a few burns; so take a bit of cement and harden up and keep going. (Participant 11, L: 589-593).

This same toughened attitude is again demonstrated here with one of the participants who claimed:

But basically being able to see that my face was okay and that socially I probably won't be [sighs] looked any differently upon compared to some others that I now know. Um from that point on I was able to adopt the attitude that I was now not going to let anything beat me and it was just onwards and upwards from there. So that was really the point for me. (Participant 18, L: 324-329).

Humour

Humour played an important role for some participants in this study. Humour was used as a means to cope and accept the circumstances in which participants found themselves after the burn. Despite enduring such a tragic accident, one of the participants still found some hope among the devastation:

That was something that helped me through all of this was humour. Humour, to me, has always been a big part of my life. I've always had the ability to - and I've always

looked for humour in situations because I realise that from all tragedies come good things; it's not just devastation equals devastation. (Participant 17, L:71-76).

This same participant continued to clearly demonstrate how humour was used as a means of overcoming the pain of physiotherapy:

...to me, physiotherapy is, find something that someone can't do and then make them do it [laughs]. I mean, how could you describe physiotherapy, other than are they really sadists in disguise? Several times, I asked people had they ever done any prison work? I felt they were so ideally suited for prison situations [laughs]. (Participant 17, L: 344-349).

Other participants found the staff's sense of humour and general demeanour made the injury easier to accept:

All the staff in the burns unit have got great sense of humour. That made it a lot easier and having the burns doctor come in and speak to me like a friend rather than a surgeon and have a laugh with me, it made everything a lot more easy to accept. (Participant 10, L: 499-503).

Humour also assisted some participants communicating with others by making light of an extremely tragic and serious situation as demonstrated here:

I found the perfect way to burn off some calories. They'd look at me in horror most of the time and go, I can't believe you said that. I go, well what do you do? That's why I think humour helped me in that aspect. Stimulating banter and trying to make light of it. (Participant 8, L: 897-901).

Once again the use of humour is demonstrated as a means of communicating in difficult circumstances where others may feel uncomfortable or awkward due to the physical appearance of someone with a disfiguring burn injury:

...humour plays a really big part. You've got to have [pauses] in amongst all the stuff that's going on you've got to have a laugh. You need to have a laugh at yourself um other people and a laugh with people. I'd pull the mickey out of myself all the time. And the people around me here that know me, they see that as an ah icebreaker. Yeah. It's an icebreaker...And with the ah girls there as well um we were always pulling the mickey out of each other. It's great. It was an icebreaker and the same with people in the street. The people here in the street that know me always come up and [pauses] um have always got a joke or something like that. (Participant 20, L: 648-659).

The challenge of acceptance

Ever present were the challenges experienced with accepting the burn injury. For some participants acceptance of their injury and how it affected them was virtually impossible to come to terms with. Some participants were plagued with guilt while others were more pragmatic and deemed it necessary to accept before being able to move on with their lives. For some participants acceptance was and still continues to be difficult:

Oh, just daily life is difficult to be honest. I look forward to closing my eyes at night and when I wake up in the morning for a split, split, split second I often hope that it's a dream; that it didn't really happen and you know, I still struggle with my mind all day and every day. When I go for walks on my own I pray that I get normality back in life and the use of my hands again. (Participant 5, L: 918-923).

Acceptance was a gradual process that encompassed the slow realisation of what had happened and how it was going to impact on their lives and future aspirations. Participants expressed just how exceedingly difficult it was in coming to terms with the fact that life as they knew it had changed from the time of the accident:

Oh you don't accept it in the beginning, in the early stages. You try and refuse to accept it...realising that your life's changed and you're never ever going to be the same again...when you start realising the extent of your injuries and the

consequences of those injuries of what the future holds and being told, because of those injuries, it's highly unlikely that you'd ever get back to doing what you love doing. (Participant 8, L: 71-77).

Despite experiencing difficulties with acceptance of the burn injury and its sequelae, participants were often insightful of their situation in which they found themselves knowing what they needed to do in order to move on; one participant recollected:

And I suppose in [pauses] focusing and setting those goals that goes hand in hand with then accepting the injury and what's happened to you. How you've changed and how your life is now going to change. And it's all obviously that [sighs] firstly you've got to accept it before you can move on. (Participant 18, L: 287-291).

Accepting the burn injury and subsequent limitations that restricted participants in both the physical and emotional sense, was a tempestuous journey. Some participants came to the realisation of the importance of 'moving on' and making the best of life:

To start with it was really hard to deal with. I get emotional by myself. I get down. I get upset. I tried just to stay positive. It's time to accept that it's time to move on and live life. (Participant 9, L: 211-213).

However, some participants found it difficult to 'move on' and simply just could not accept their injury and how it affected them:

*I know there's no going back, I need to go forward and get better, but some days you feel very down and you sort of - you're left alone. But then other days you'd just take it up and [laughs] go along and go on yeah. (**How did you come to terms with the injury?**) I didn't, I mean until I got out of the hospital, I didn't know what my limitations were. So I mean [pause] I still can't accept it... (Participant 19, L: 383-389).*

The realisation and gravity of the burn injury were not always initially evident. The recollection of events was often sketchy with participants having no insight into seriousness and magnitude of their circumstances:

...Just like I'd woken up, totally oblivious that I was in an induced coma for two weeks. I remember the emergency room was the last I recall. The next thing I know I'm in a hospital bed in a hospital room waking up. I'm all in bandages. I knew where I was and why I was there. I didn't realise the extent. In fact, after being burnt, I walked out of that laundry room and I looked at myself and I said, oh damn, I've burnt myself. I thought to myself, oh what an inconvenience, this is going to be painful, I'll be wrapped up in bandages for a few weeks and I'll be back to normal. I didn't realise I was that badly burnt. It didn't look like I was badly burnt. (Participant 12, L: 35-47).

This same underestimation and gradual realisation of the seriousness of their burn injury is also echoed here:

I think that I probably underestimated how badly I was burnt and I do know that from day one. Because I remember the day of the accident walking up to the house and getting in the shower. I thought, oh yeah, a bit black, I'll be right. I didn't think anything like that. (Participant 14, L: 730-734).

Participants reflected on the events that led up to the accident. Some participants experienced feelings of guilt which at times left them feeling immobilised because of the trauma that their families experienced:

I felt very guilty because - it was an accident, but in some ways there were some things that I think that I should have - there's ways that I should have avoided the accident in the first place. So I felt very guilty about that and what I put my family through. (Participant 11, L: 505-509).

In addition to feeling guilty, participants regularly tortured themselves by revisiting what happened and why as this participant so aptly described:

It was more about bashing myself up every day over my actions on the day of my injury. That I disregarded lots of my learning and training and found myself in the situation I'm in and now suddenly, I'm an invalid and I wasn't happy with that. And I'm still not happy about that today but I'm trying hard to change that. (Participant 5, L: 67-72).

Accepting responsibility for their actions was a cathartic experience that facilitated acceptance. However, the mode in which the accident happened seemed to influence how participants reacted:

Because my accident was totally and utterly because of my actions. Had I have been the victim of a car crash or some random guy threw petrol on me and burnt me I think it would have been completely different. But because I only had myself to blame for what happened, there was nobody else to blame, I just suck it up and get on with it. (Participant 14, L: 546-550).

In order to facilitate acceptance, participants needed to be candid and as flexible as possible with their approach to rehabilitation. Being positive, open and realistic gave participants a good grounding in their often long and arduous rehabilitation journey:

I tried to be as flexible with my thinking as I possibly could. I tried to approach it that it's a learning process; this has happened to you, learn from it - experience it; soak it up; you're going to get better; you won't be like this for the rest of your life. It's a period that you're going through, learn from it, get over it, and move on. (Participant 17, L: 148-152).

Pragmatism played an important role in facilitating some participant's acceptance of the injury. Having a matter-of-fact attitude emotionally enabled participants to get on with their rehabilitation:

Well I'd actually say to myself, I'm lucky. I'm lucky to be here but I was unlucky to be where I was... (Participant 21, L: 295-296).

In addition to being pragmatic, accepting one's limitations also enabled participants to move forward by means of focusing on their abilities and not disabilities. This participant articulated the importance of realising limitations:

I pretty much knew my limitations, so I wasn't going to go and do anything stupid, and so I just had to pretty much have a go at whatever I could do and that was where I found my limitations and, when I couldn't do anything, I'd just get a hand with it. (Participant 3, L: 328-331).

Self-awareness

The participants experienced a strong awareness of self, both in the physical and emotional sense. Physical appearance and body image were of significance to participants and this included the response of others to their injury. Having to confront their altered appearance was a poignant experience, especially when looking in the mirror for the first time after the accident:

Ah we walked - she said righto [pauses] be prepared because you're not the way you used to. I thought to myself I was just normal the way I used to be. I walked in and at that stage I had no - I still had staples and everything. Yeah. I walked in and yeah had a bit of a shock. Oh that's what I'm going to look like for the rest of my life. Ah... (So what was your first initial impression?) Oh shit. [Laughs] I went oh shit here we go. And then um [pauses] we sat down and talked about it and then we got a social worker in again and talked about it and everything. And I said well at least I'm still alive, let's get on with it. (Participant 20, L: 185-195).

This same sense of shock is echoed by this participant upon initially seeing the extent of the burn injury stating:

It was painful, but I think the worst was I actually, for the first time, face to face with my naked body all burnt and that was a shock. (Participant 12, L: 94-95).

In addition to the visual awareness and distress of seeing their burnt body during frequent dressing changes, was the stench of the wounds from the burnt skin. The smell emanating from their burns and onto the dressings was a disconcerting experience to endure. This participant described feeling sick from the foul-smell exuding from the wounds:

I had dressings on my legs still, upper body, my head. The dressings were done every day still and that required the shower. When I had the dressings taken off - I got sick of it. You get it taken off and then half an hour later it is all put back on. You've got to wear it every day. It stinks. The flesh on your body stinks from the sores... You get sick of the smell. Like you are turned off using your smelling senses because it does stink. To me it does anyway. I can smell the stench around my head, on my chest. You get sick of the smell of it. Just turn off from the smell. (Participant 9, L: 142-151).

Coming to terms with the altered appearance was a challenging experience for participants in which half of the participants in this study sustained significant facial burns. In this regard, one participant conveyed:

You know that your face is distorted and not what it used to be... (Participant 5, L: 440).

Another participant also expressed how coming to terms with the physical changes early in the rehabilitation was a confronting and unpleasant experience:

I suppose it's coming to terms with the physical change. (Can you expand on just that point?) It's not good [laughs]. Ah it's tough. Um obviously especially at the early stage because you're looking at um [sighs] - I don't recall looking at my injuries. Ah I recall looking at very [sighs] fresh grafts um so obviously you're

looking at [pauses] grafted skin that's stapled in places, weeping. Um it's not nice. Um [pauses] so it's very, very unpleasant just to see anyway and to be part of you. It's really tough to get your head around. (Participant 18, L: 163-171).

However over time, participants seemed to overcome the apprehension and anxiety of confronting their body image. In this regard, one participant narrated:

I do think that now I've got used to looking in a mirror - but photos are something that I'm not used to. I see a photo of myself I go oh shit. But to look in the mirror I don't take any notice, it doesn't bother me. (Participant 14, L: 492-494).

While others still find, years after, the burn injury confronting their body was an uncomfortable experience:

But I'm still hesitant of taking my clothes...or anything like that...my scarring is really bad. (Participant 19, L: 364-367).

Feeling uncomfortable in and unable to control their body was an on-going concern for some participants. It was difficult for participants to come to terms with the thought that they would never be the same; they experienced feeling alien in their own body:

I worried that I'd never be the same. My skin couldn't breathe, that I'd never sweat again, that I'd never be able to control my body temperature, that I'd look differently. You know, I've been told by other burn people that your skin will always feel different. You'll never relax that way. You'll always have that this isn't me feeling. (Participant 5, L: 841-845).

Another participant added to this experience in which the emotions of pain, anger and frustration were used to describe how it was when initially confronted with the devastation of the burn injury:

My experience was simply one of pain and anger and frustration because you wake up to a different world. You wake up as a different person. (Participant 8, L: 33-35).

Whereas other participants were constantly reminded of their burn injury making it difficult to move forward as described here:

I get reminded about it all the time when I have a shower and when I can't do things that I used to be able to do. I don't know. I suppose in a way I really just want to move on with my life and I don't want to keep being reminded about it... (Participant 10, L: 531-535).

As a means of accepting and coping with the burn injury, visualising photographic images of the injuries sustained facilitated understanding of what had happened as a result of the accident and what had transpired early in the rehabilitation. This participant described their reaction to seeing the photographs:

I was shown photos of what was actually done to me in ICU [intensive care]. They all thought that I wouldn't be able to cope seeing these photos, but I actually enjoyed seeing what had been done. (Why was that?) Because I, in myself, had an understanding that major things had been done to my body and so I was able to cope in a greater understanding that the doctor and [my partner] had seen. (Participant 16, L: 371-377).

Becoming aware of the extent of the burn injury and subsequent ramifications, compelled participants to review their life and how it had suddenly changed. Being in the right 'state of mind' was of significance and assisted participants in laying the foundations for the lengthy rehabilitation journey ahead. In doing so, participants expressed that their emotional state was at times, of a greater importance than their physical rehabilitation and recovery:

Um, I feel that my initial rehabilitation virtually started as soon as I became aware of the situation I had been accidentally placed in, about how my life had instantly changed, er, how I had to review - and so I knew that it wasn't a rapid process to get over the injuries that I'd sustained so I, more or less, had to work - I felt that my

mental condition was more important than my physical condition at the time.

(Participant 17, L: 3-8).

Participants often felt self-conscious of their altered appearance that often deterred them from socialising with others in the rehabilitation centre. This participant in particular felt quite disfigured and expressed immense resentment towards the staff, affirming:

...like a sore - you know, you stuck out quite severely because just the look of you...They said to me I must go down and have breakfast in the breakfast room. Well, I didn't want to do that and I didn't. I had breakfast in my room and that's where I chose to stay. That's the way I felt about it and I didn't appreciate being pushed or told that I would have to go down there. (Participant 1, L: 83-88).

Another participant conveyed that even though they were the same person on the inside, they felt self-conscious and concerned about how others would react to the significant scarring:

So I was particularly worried about how people were going to react to me in that situation. That was part of the reason, I think, I was going oh, I'm going to have all these lumps sticking out the side of my head and all twisted knotted scars; I'm just going to look different, be different. Even though I was the same person inside, I wondered what that exterior thing was going to do. (Participant 11, L: 113-119).

Aside from being self-conscious about burn scars, the negative reactions of others was at times emotionally disturbing for participants:

I remember coming back, people would be worried about, they'd go and put their hand out and then they'd retract it thinking that maybe my skin's going to fall off if they shake my hand... (Participant 8, L: 888-891).

Despite all the nihilism endured by others' responses, participants also experienced positive reactions from the general public as one of the participants surprisingly expressed:

I was surprised, people didn't stare. I was surprised and it still, to this day - I mean the stories I could tell. We went out for dinner at a restaurant in town one night as a bit of a celebration because I'd reached a milestone, reached a goal. Sat out in a restaurant and they couldn't have been more accommodating. As where you'd be a little bit inclined to think they'd want to push you in a corner, dark corner somewhere and say there's your chair there sir. (Participant 14, L: 498-504).

Impact

The emergent theme *impact* illustrated how the severe burn injury, emotionally impacted on the participants and their family. Participants described how they experienced a range of emotions for which they felt they had very little control over. The cluster themes incorporated: *spiral of trauma, pain, loss and despair*.

Spiral of trauma

The severe burn injury sustained not only affected the participant alone however, seemed to drag the whole family into this spiral of trauma:

...well this is one the downsides of trauma. It doesn't just affect the person it's struck down; it forms a large circle of trauma. (Participant 8, L: 549-559).

Participants sensed that having their family hear them in such pain was a distressing experience as this participant recounts:

And it was at the point where particularly [my partner] or - on the rare occasions I had a visitor or ah on the weekends if my mother was there. They would obviously have to leave - not only leave the room but they typically left the ward because the pain was so excruciating. Um obviously [pauses] again with the drugs you don't have a lot of control anyway. But um I imagine that the yelling and screaming would have just been [pauses] very unpleasant. (Participant 9, L: 205-212).

Some participants felt that seeing their young children was an upsetting experience for them as they sensed it was distressing and in turn found watching their children's emotional struggle a traumatic experience:

...my children...they were experiencing their own forms of trauma because they were very, very young and I was probably one of the most upsetting things was, while being in a hospital system and being completely immobilised and a shadow of one's former self and watching my children come in and be very fearful and apprehensive about what to say or even to touch you or stuff like that. That was upsetting. (Participant 8, L: 541-547).

For some participants, children were part of the rehabilitation journey through the different stages from ICU to discharge home:

Ah because they [my children] [pauses] were on the journey with me when I was down there um [sighs] I reckon they adjusted pretty well. Actually from seeing me in ICU to right through to when I came home ah [pauses] my daughter still had a little bit of a problem with it which is [pauses] understandable really. Because I tucked her into bed [pauses] gave her a kiss and said goodbye then eight months later...coming home. So yeah which is - it was pretty hard on her. (Participant 20, L: 493-499).

Others felt that when they returned home, their children found it difficult to see the participants' altered body image and scarring which had an impact on their relationship with their child as clearly demonstrated here:

I suppose the first week of home, he'd talk to me through his mother. He wouldn't look me in the eye and I was sad. I was [laughs] what have I done, you know and my partner's telling me take it easy, it's not - and [my partner] showed me some of the prayers he'd written out. It was quite emotional, yeah, very emotional, to know that

your son cares and loves you so much, but can't look you in the eye. He sits next to me now and he's fine, but he won't look at my burns. To him they look horrible.
(Participant 12, L: 240-247).

Pain

The immensity and intensity of pain endured by participants was unimaginable and inescapable. Pain manifested itself in the raw physical aspect as well as the apprehension experienced knowing that pain was an inevitable aspect of a severe burn injury. In this regard, one participant described how agonising it was having daily treatment to the burn wounds:

...to go into those daily washes was beyond, beyond imagination. It is difficult to describe the pain that you experience when someone's washing raw wounds and it had to be done and your body had to be debrided on a daily basis and there was no ifs or buts about it. You had to endure that... (Participant 5, L: 181-186).

Another participant also recounts a similar experience to pain and struggles to conceive how the human body can endure so much pain and still be able to function:

Ah yeah um [pauses] it hurts [laughs]. Um it's hard to imagine [sighs] that you can feel so much pain and still be conscious. [Pauses] yeah it's very hard for someone to understand that. I particularly [sighs] - what we used to call being rolled I found particularly distressing um unbelievably painful, just ridiculously painful. It has to be done but just unbelievable. So rolling was very, very bad. It was something that - I think my sheets were being changed probably three times a day maybe. It was regularly. [Sighs] so um yeah that was really [pauses] not a highlight. (Participant 18, L: 197-205).

Although necessary, burn dressings were painful procedures causing participants to feel depressed knowing that they had to endure another burn procedure in a day or two:

...the bandage changes every third day was depression day because that was usually the most painful part of things. (Participant 11, L: 76-78).

Others found it difficult to cope with the amount and intensity of pain experienced having never faced such an adversity before:

The pain side of it was another aspect of my injury that I was constantly aware of. I'd never ever faced anything like the pain that I was in, and I had no idea of how to cope with it because I don't think there's a drug strong enough to help people face just the trauma for the pain alone. Um, yeah, so that was my introduction... (Participant 17, L: 32-36).

Experiencing immense apprehension towards the inevitable onset of burn procedures and therapy was a common phenomenon among the participants of this study. The therapy participants endured on a daily basis was likened to agonising torture in which the therapists were relentless in their approach. This participant described vividly the feelings and actions experienced prior to the commencement of therapy:

Every day you watch the clock when they tell you they're [physiotherapist and occupational therapist] going to be in at 2pm to try and get you to stand or whatever and you dread that time. You look for any possible excuse whatsoever to not allow that to happen. You lie, you cheat, whatever, physically try and make yourself ill at the moment they come in to try and get them out. (Participant 8, L: 160-165).

The same participant described being emotionally overwhelmed by the thought of having to experience the pain and trauma of another dressing change:

...every second day you had to do all the dressing changes. They have a big impact on you because even a day that you're not having dressing changes, you're thinking about, in less than 24 hours, the changes are going to happen again tomorrow. So

that's constantly on your mind. I think the dressings are a big part of that – I suppose your psychological well-being. (Participant 8, L: 269-274).

However, just seeing the therapist was enough to manifest feelings of apprehension and anxiety for some participants:

The speech therapy stuff was one thing that I just recall as being - it was just absolute agony. I can't explain the feeling I used to get when they arrived. It was like I just wanted to hide. (Participant 14, L: 98-100).

Another participant claimed that upon seeing the physiotherapist:

The physio [physiotherapist] ...I love her dearly but I used to see her, and the bristles would stand up on the back of my neck. (Participant 17, L: 66-67).

Loss

Loss in the physical and emotional sense was experienced by all participants in this study. Participants experienced their personal loss and grief that result from the burn injury. This manifested in a multitude of ways expressing loss of independence, dignity, control, movement, functionality and for some, a loss of income.

The unmitigated loss of independence had an enormous impact:

Terrible because you've lost all your own independence. You've got no independence whatsoever. You're completely 100 per cent reliant on someone else. (Participant 8, L: 588-590).

The physical disabilities experienced by the participants, had a psychologically impact on their rehabilitation journey that commenced early in the recovery period:

I reached the stage, in a very short time, that I couldn't even do the most basic things like take a blanket off me because I was hot or if I was cold, I couldn't even put a blanket on me. I was at a stage where I totally depended on people and for me, um, I've never been in that position before and it was a double whammy of realising all of

that. There was a great big mental aspect about this illness before I even started rehabilitation in a physical sense; learning to walk and overcoming, um, physical handicaps. (Participant 17, L: 23-31).

It was difficult to come to terms with the loss of independence with participants claiming it to be an undignified or dehumanising experience having to heavily rely on others for assistance with the most basic of activities of daily living as this participant recounts:

Ah I'm a very independent person, always have been. And I hated the fact I had to rely on someone [pauses] ah and mostly later on [sighs] I really disliked the fact that I had to rely so heavily on [my partner] to do such basic things like showering, toileting and that sort of stuff. Really ah [pauses] not humiliating but really um [pauses] dehumanising or something I suppose. (Participant 18, L: 366-371).

Others found the loss of dignity and independence a disempowering experience. Conversely, there was an understanding among the participants about the necessity to accept help from those around them:

You lose all your dignity. I suppose to begin with when I first went into the burns unit it wasn't nice. But then you realise that you can't physically do things on your own and you have to have somebody do it for you then you're at their mercy really, do you know what I mean? You haven't got any choice. (Participant 10, L: 467-471).

Other participants found the loss of independence a demeaning experience. This particular participant stated that after being a fiercely independent individual and having had it all taken away so suddenly was a difficult burden to endure:

I didn't read 'cause I couldn't turn the pages and hold a book or do anything. I couldn't feed myself, I couldn't toilet myself. I've had it very long and hard and very demeaning. I lost all my pride and my dignity when I went into the hospital. And I

feel prior to that I was quite a proud individual but that was taken away from me.

(Participant 5, L: 244-249).

Great frustration was experienced by participants due to the inability to function independently as the burn injury had left them severely incapacitated. Physical disabilities such as skin contractures and heterotrophic bone ossifications often left participants with a limited range of motion:

I had to get the nurses to um feed me because both elbows were locked and I couldn't get them up to my mouth. (How was that for you?) Ah frustrating [pauses] yeah we had the comical side of it but it was frustrating. Waiting for the nurses to actually come back to do the rounds and then all of a sudden you've got a meal sitting there and you couldn't do anything with it. Ah had to get them to open your juices.

(Participant 20, L: 41-48).

Participants grieved for the loss of their former life prior to the accident:

I wanted to be back to normal, a normal human being as much as I was before the accident. (Participant 9, L: 132-133).

And others came to the realisation that their life would never be the same again experiencing limited independence, as so pertinently expressed by this participant:

I have thought about this even when I was in the rehabilitation centre and the burns unit - that when I get home, I still probably won't be able to do a lot of the things that I was able to do. And actually it's probably about 99 per cent of the things that I'm not able to do before the accident and so when I came home, those fears were realised. (Participant 5, L: 818-823).

Apart from the loss of independence and the subsequent loss of dignity experienced, some participants encountered a devastating loss of income due to the lengthy hospitalisation and rehabilitation period and the inability to return to work. Of the 21 participants, only six

participants returning to their previous employment, eight participants were unable to return to work and one needed to find alternative employment due to their disabilities. This participant described the financial losses incurred after spending a total of 448 days in hospital:

Well my business suffered because I was the owner of my business. I mean I was away all up for two years and two months and the business probably lost in excess of a quarter of a million dollars. (Participant 8, L: 634-637).

Despair

The confrontation with such a traumatic injury as a severe burn evoked an outpouring of despair from participants. This was clearly displayed with participants expressing such emotional reactions as hopelessness, suicidal ideation, depression and uncertainty. Some participants stated that coping was not always an option:

Well, there's no coping. You just have to put up with it because I had nowhere else to go.... (Participant 1, L: 22-23).

Another participant felt there was no choice but to survive, maintaining:

I didn't have any choice. I think I just had to go along with it. I mean I couldn't kill myself and I couldn't make myself better, do you know what I mean? So I didn't have any choice... (Participant 10, L: 102-105).

Other participants experienced periods of deep depression wanting to withdraw from the surrounding world:

[Long pause] depression - people talk about depression. If you'd have said to me five years ago I've got depression I would have said harden up, there's nothing wrong with you, get over it. But it's a real thing, I've learnt that. In the earlier stages the depression used to last for days. You'd just get into a [sighs] non-caring - you know that you shouldn't be depressed. You know that everything's coming good and it's getting better and whatever. But you'd still just get down and all you wanted to do

was just back into a dark corner and just close the world off. I don't want to see anybody. I don't want to have anything to do with it. That honestly still - from time to time, I get that. Now depression probably only lasts 20 minutes, in the early days it might last four days. (Participant 14, L: 441-452).

Aside from the physical trauma experienced, participants endured the psychological anguish as this participant clearly depicts:

...you've got the physical aspect on one side which is just a horror story but then you've also got the psychological trauma on top of that where you sink to the depths of despair, depression. (Participant 8, L: 39-41).

Some participants found the large number of elderly patients at the rehabilitation centre to be a depressing experience that impeded their recovery. Participants often shared rooms or dined with elderly patients during meal times which for some were an overwhelming experience to endure:

I wasn't going to go and sit there and participate because it just made my recovery a lot slower for the fact that you feel it's more depressing to sit down and be with these poor old people and think, well, how on earth am I going to recover? You're looking at them and their recovery is so slow and it's depressing. I don't need that. I went through enough as it was... (Participant 1, L: 95-100).

Participants were faced with great uncertainty throughout their rehabilitation journey, not knowing what the future would hold or if they would ever fully recover from such a tragic accident. This uncertainty was a cause for distress for some as demonstrated by this particular participant early in the rehabilitation journey:

That's the first thing I remember, I went to move and I couldn't because I was covered in bandages. It was bloody awful. I wonder what's going to happen here, because all sorts of things go through your mind... Well, am I ever going to move

again, what's the prognosis, what is the future, is there a future. (Participant 6, L: 20-26).

The uncertainty was entrenched within participants' thoughts throughout their rehabilitation as one participant experienced upon discharge home:

I mean that's the one thing you crave is the fact of going home and then when you finally did get home, your other bogeyman went into your mind because you then thought, well this is it; I can't go any further; I can't – if I don't get well here, I'll never get well. (Participant 5, L: 811-815).

While others had their fears realised upon returning home finding that life was difficult and it would take some time to reach a level of independence:

I thought I'd be really happy to get home. When I got home I was out of that safe - into another one. There were people going oh God, you must be glad to be home. I felt really bad because I really didn't feel glad to be home when I got there because it was hard again. I realised that I still had a long way to go with my recovery. I thought oh God, I'm still weak and I still can't walk properly on my new prosthetic leg; I can't get out and do what I want to do on the farm, and everything's going to crap. (Participant 11, L: 98-105).

The trauma experienced often made participants question their survival and the determination to continue:

Just a really long, slow, painful process. Sometimes I don't know whether I really wanted to survive. (Participant 13, L: 3-4).

Others expressed suicidal ideations because of the intensity of pain experienced with one participant saying:

There were times, mainly with pain. Pain made me feel as if, er, you can't feel this sort of pain for very much longer. Um, what do you do? If I had a gun, I couldn't have even pulled the trigger so, I mean, I'd need [my partner] to pull the trigger for me. (Participant 17, L: 156-159).

Another participant was more determined expressing details of how they were going to carry out their own suicide:

I used to think well probably the easy thing would be to go up high and throw myself out of a window...Or shit, I've dealt with pain now, just book a hotel room, get a Stanley knife or something, lay in the bath and slit my wrists and just you know. So I'd already researched so I knew that you eventually passed out from the loss of blood and you just cease to exist and that would be it. (Participant 8, L: 613-619).

This participant disclosed feelings of despair that resulted in an unsuccessful attempted suicide:

I only hit a low patch a year ago and I tried to take an overdose of tablets. But then afterwards I thought that was so wrong of me, after all of the work that everyone in the burns unit had put into me, what a selfish thing that was to do. I mean I'd never do it again. I think everything got to me; everything just seemed too much to cope with. (Participant 10, L: 490-495).

Endurance

Central to the participants' experiences was the emergent theme *endurance* describing the use of goal setting, accomplishments and the inner strength and tenacity required for the transition and progress through the lengthy rehabilitation journey. The two cluster themes identified were: *milestones and tenacity*.

Milestones

Recognition of the progress made during rehabilitation was an important aspect in which participants engaged in reflection to remind them of how far they had actually progressed. Recognition of these small but significant milestones assisted in moving forward:

I just have to constantly remind myself of a lot of things I couldn't do when I first came home and you tend to forget those things. (Participant 5, L: 941-943).

Another participant expressed that they could reflect on the progress made despite the pain endured:

If I look back, although I'm in a lot of pain and everything still, I can look back a few months at a time and realise that I can do things now that I couldn't do a few months ago. (Participant 10, L: 349-351).

Rehabilitation commenced with a series of small steps over a long period that was an arduous task however, always with a clear and determined focus in mind as expressed by this participant:

I had a lot of struggle to get up, real struggle. I took one step [pause] and that was a, ooph, that was a big. Then I took three. Then I took six. This is over a period of days. Then I wanted to - I think I took, yeah I took 18 going up the corridor and then come back. (Participant 6, L: 209-213).

This participant also described that at the beginning it was the most basic tasks of just lifting an arm and scratching one's head that provided confidence in a slow but progressive recovery:

Straight out of intensive care, first week in hospital, I couldn't really move. The sensation of being able to raise my hand and arm to my head and scratch myself for the first time, that was like sheer pleasure. Now I can reach to the back of my neck, I can shampoo my hair in the shower. These progressive steps, you gain in confidence, yeah I find relief in that sense. (Participant 12, L: 554-559).

Another participant also relayed a similar experience of realising the most basic of goals early in rehabilitation and building on those small achievements step by step and day by day:

So it was sitting up in bed and then it was standing beside the bed ah and then maybe taking a couple - this was progressing over days. Um, ah, taking a couple of steps towards the door ah and all these small achievements day by day. Making it to the door and then ah the next day I may have made it into the corridor. And the next goal would have been the following day to make it to the nurse's station and so on and so on. Until I was at the point where I was able to walk, with assistance still, up and down the corridor and do some squats and just some very, very basic exercises towards to the end. (Participant 18, L: 17-26).

In order to approach the immensity of rehabilitation, this participant envisaged the rehabilitation journey as a series of steps containing three distinctive phases:

...well it's another step on the road to recovery. There were probably three [pause] steps, well three stages. There was the burns unit, there was the rehabilitation centre and there was home. That's probably the three. I think it's fair to say they were the three major steps. (Participant 6, L: 692-696).

Participants were often goal focused during their rehabilitation which gave them a sense of direction and timing. It was vital that participants felt that they were moving forward in their rehabilitation and achieving the goal of regaining independence. This participant described how envisaging what needed to be accomplished facilitated regaining some level of independence:

I could see what I needed to do to get to where I could use the toilet myself and do more things myself - things like the OT [occupational therapist] breakfast where you cook your own breakfast - bacon and eggs. I did that a couple of times, which was good. It just felt like I was moving forward and making progress. (Participant 11, L: 380-384).

Another participant expressed that remaining goal focused was the key to managing their rehabilitation:

You just take every day, take every day as it comes. You fix yourself on goals. We were big on goals; that was a big thing. (Can you elaborate on the goal setting?) The goal setting, if you could achieve goals that did. Possibly yeah it was all about timeframe you know. Put the suit on, okay the suit will be on for 18 months so okay, yep, we've got two months of that 18 down. Like it was all about just jumping hurdles as they came to you and counting the hurdles in front. (Participant 14, L: 373-381).

Participants expressed the importance of recognising the value of goal setting during their rehabilitation as clearly articulated here:

...when I went to rehab - they've got to write in all these new age things. You've got write your aim down and your goals. My goal was to go to the toilet by myself and not have to call the nurse. After two and a half weeks I could do that. (Participant 11, L: 387-390).

The multidisciplinary team at the rehabilitation centre were also instrumental in assisting participants to establish and attain realistic goals for their rehabilitation:

...they used to have case conference every Thursday, the physios [physiotherapists], OTs [occupational therapists], everyone, the team at rehab and then on Friday the physio [physiotherapist] would come to me and say righto this is what we discussed at the case conference. This is what we've accomplished this week. This is what we're going to aim for in this next week... (Participant 8, L: 318-323).

Participants stated that having goals helped with rehabilitation although, having a central long term goal was particularly imperative for it helped them to remain focused throughout the rehabilitation journey as expressed by this participant:

...there were, there were goals that were there that actually helped. Well initially when I came out of the induced coma and my actual, even though I had, had the lows that I was actually down and I was a burden. My goal was to actually get home to my three boys, [my partner] and the family and the community...where I was from.

(Participant 21, L: 431-435).

Realising the major goals was an uplifting experience that held significant meaning for participants:

The day that I actually drove again, that was the best day. That was the day I think when it was - that was the beginning of the end if you know what I mean, the beginning of the end of the rehab. That was where I finally regained my independence. I didn't have to rely on somebody to drive me somewhere or [my partner] to get me there. I could actually do it. And if I didn't want to go straight home I could go and see somebody. That was a very, very big day, the day that I got to drive again. (Participant 14, L: 748-755).

Goals were not always fixed, there needed to be room for adaptability as participants progressed through their rehabilitation. The focus and importance of goals often shifted as explained by this participant:

I mean ultimately your goals change all the way. You want to go from surviving - as I recall they asked me one day about my facial scarring or whatever. And they said things that may help with the scarring and I said I don't care what I look like, just keep me alive. But as you progress you get to where you go from a survival mode to

caring about what you look like and caring about your ears and the nose. (Participant 14, L: 112-118).

In addition to establishing and attaining goals, it was important to remain flexible and adaptable in managing everyday activities of daily living:

Um [pauses] I couldn't pick a peg up so I used ah my pocket knife which is ah it's got all different tools on it. I'll learn how to open that up [pauses] I'm grabbing that and actually picking the peg up and putting that on the line. So ah putting a hook on the end of ah [pauses] an old broomstick. And take the um washing out of the washing machine. Just sort of trying to dive in because I couldn't stretch my arm out or this hand was still ah wrapped up. Just actually sitting back for five minutes going well I can do it this way. If it works, well good, if it doesn't yeah. A fair few times you'd crack it because you couldn't do it. And then you sat back and looked at it a different way, an easier way to do it. (Participant 20, L: 564-574).

Tenacity

Participants were found to display a tenacious resolve. Positivity, motivation and determination were characteristics found in all participants. Remaining positive in the face of adversity was often exhibited. Participants sometimes held onto the littlest glimpse of hope in order to move forward:

I've got a 30 per cent chance of living and not a 70 per cent chance of dying. Took me a while to have something to hang my hat on, I guess, so to speak, because there wasn't much there at the start. [Laughs] (Participant 6, L: 42-45).

Others chose to adopt a tenacious 'just get on with it' attitude despite the ups and downs endured:

Well, I was - I suppose I was pretty lucky. I had a pretty good attitude towards the whole thing. I just figured there was no point in whinging about it and just had to get

on with it and do all the physio and everything like that. There were tough days where I had down days and they sort of let the physio and that slide a bit on that day, and so they'd just let me have a day off and then get back into it the next day. I took it pretty well... (Participant 3, L: 162-168).

Another participant expressed a similar experience whereby accepting the fact that there was no mileage in doing nothing, thereby adopting a pragmatic attitude:

Well I really did not see any other option really, it was either do nothing and that would have just been a very sad existence, or just try to make the most of the situation I was in. To me, the option of doing nothing wasn't really an option. (Participant 7, L: 407-410).

For others the thought of staying in rehabilitation for an extended period of time, made this participant assume a positive outlook:

The idea of getting out of rehab is what made me do stuff. If I didn't do it, I wasn't going to get out. I boosted myself that way. Just made myself be positive about things instead of being down all the time. You've got to be positive and move on. The importance of that. (Participant 9, L: 199-202).

The motivation to recover was a fundamental factor in the rehabilitation of the participants in this current study. Participants often pushed themselves to the limit in order to achieve their rehabilitation goals. For this participant, the fear of not being able to walk again was the driving force behind their rehabilitation:

*Had I not pushed myself to do and go walk, get my legs walking, I would be in a wheelchair. (**What was your motivation?**) Motivation was to see myself walking and when I really got walking, I kept walking longer distances and if I was tired, that's the only time I would use a wheelchair. Most of the time I would force myself to do as much as possible, not seeing myself stuck in a chair for life, When thanks to all that*

physical work, I'm able to walk just about everywhere today. (Participant 16, L: 142-150).

However for others, their motivation was influenced by the thought of returning home and resuming their prior life before the injury with the re-establishment of relationships with family and friends:

Well motivation was to get home, to get back to my normal life. That was my entire motivation. And it was always - the motivators were my friends and family. But my motivation was our business at home, our farm at home, the kids, [my partner], everything. It was all there waiting for me to come home and I had to get there. I had to get there if it took a week or a year or 10 I had to get there. So that was the biggest motivation. (Participant 14, L: 363-369).

Tenacity and motivation during therapy sessions was often a determined approach displayed by taking responsibility for their rehabilitation as well as the initiative:

...the physio at the rehabilitation centre...gave me the run of the whole rooms. That I knew what to do and then they would just go and check me and say, okay, do 15 of those. I would do 30 and, do this now and now go and get on the bike. They didn't have to supervise me that much because, after I had been there about 3 weeks, I knew all the ropes, so that is why I used to go back in the afternoon and why they left me, because – you know, they had to keep an eye on me, but they didn't have to go hands-on all the time because they knew I knew what to do. (Participant 2, L: 188-197).

This tenacious resolve also resonates here with the description of one participant's motivation in wanting to recover:

But I used to do all my own physio. They tell me what to do, come round and say, oh you've got to do this because it was all tight under here, I had to stretch with this and I'm in the bed like this. I could go like that for hours because I just wanted to get

better. (Was that your motivation?) Oh yeah, I'm not one of these people who say, oh they do half hour for me and that's it. They do half hour, I do another two hours when they're gone. (Participant 15, L: 91-98).

Aside from motivation, determination was also a key aspect in the rehabilitation of participants of this study. They displayed immense determination and courage in the face of adversity. Participants had endured such physical and emotional trauma during their rehabilitation that they were determined not to let their injury deter them from resuming their everyday activities and employment. One participant expressed with great passion how they were determined to take back control of their life:

I haven't got no special abilities or gifts. All I had was determination...my life was stolen from me and no fault of my own. It was stripped from me, it was taken from me and then I was told that I would never get it back. Well that was just unacceptable. So I did the only thing I could, I took my life back. I make the decisions as to what I do, I've got my decision as to what my attitude is, what my determination is. (Participant 8, L: 864-870).

The same participant continued by exhibiting sheer determination in wanting to return to work and the means by which this was done:

...if I have to tie the spanners to my limbs I will be a mechanic again. While at rehab I started researching...the equipment that they could use for people without hands and stuff like that just in preparation. (Participant 8, L: 742-747).

This same level of determination also resonates here with this participant expressing early in their rehabilitation journey, the desire to not give up or give in to the burn injury:

Um [sighs] I think from very early on ah when I realised what had happened um I decided that um I was not - to be honest I don't know why. But I decided very early on that I was not going to let this beat me. And that's the attitude I've adopted ever since. So from the time I can remember that's what I thought. I don't know why I

thought, maybe it's just um [pauses] bloody-mindedness or something, I'm not sure [laughs]. Personality maybe, I don't know. Um but that was my decision. (Participant 18, L: 65-72).

In order for participants to tackle their rehabilitation they had to have had the motivation to do so. This required inner strength, tenacity and determination:

...physios [physiotherapists] are only five per cent of your recovery. The other 95 per cent is yourself. So I did as much as I could once I found out what was expected of me and I didn't really place a lot of emphasis on seeing them or not. (Participant 5, L: 325-329).

Rehabilitation did not stop when the participants were discharged from the rehabilitation centre. Participants still required intensive therapy upon returning home which demanded immense discipline and determination to continue. One participant explained passionately the need to drive one's self after discharge more so than ever:

...why baby the person when he's done so much time in the hospital system and he's been forced to do things he didn't want to do and then you're going to let him take it easy when they go out? What I would say to them, right you're going home now, this is when the work starts mate. Now you really need to step up a notch and get stuck into it and drive yourself every day, drive. (Participant 8, L: 504-509).

Regaining independence is one of the fundamental elements in the rehabilitation journey. The importance of being able to function independently is a prime goal. However, attaining an acceptable level of independence is also an important and necessary aspect. In this regard, one participant who never regained the full use of their hands nevertheless stated:

Uh, I haven't got full mobility of them [my hands] but, yes, well I can't, it doesn't stop me from doing anything in any way, shape or form. (Participant 21, L: 31-32).

Progression

Born out of endurance and tenacity, the emergent theme *progression* described participants' experiences of transition and reintegration that incorporates the cluster themes: *transition, reintegration and ongoing access to rehabilitation services*. Of importance was the recognition of the need to transition and reintegrate back into mainstream society. However beyond discharge from hospital, participants were often faced with another rehabilitative challenge of accessing services in their local area to assist with their ongoing rehabilitation needs.

Transition

Not all participants had a clear recollection of their admission to ICU due to being intubated and heavily sedated for most of their admission. However, the transition from ICU to the burn unit was a significant and meaningful step:

...moving from ICU to the burns unit and that was a really big step. I remember that. That was like I am going to live sort of thing. (Participant 14, L: 10-12).

Initially, having to leave the safety and security of the burn unit was a difficult step for participants to take having spent many months in the one room with little contact with the outside world. Participants were apprehensive at the thought of transitioning to the rehabilitation centre:

I just got comfortable in my room, drips are out and then to be moved to an alien place I knew nothing about. I knew where it was but I'd never been there. Yeah, I was a bit apprehensive, I suppose moving out of a comfort zone to somewhere else. (Participant 12, L: 181-184).

Another participant expressed apprehension about transitioning to the next rehabilitation phase and how they were going to regain their independence and the pain they would experience in the process:

I suppose it was a bit of apprehension as well when I left the burns unit. Because I suppose it is quite hard to deal with the situation as it was but then to be told I was going to have to do things a lot more for myself. When you're lying in bed 24/7 and

you now have difficulties to even get into a wheelchair the thought of having to do stuff. Like physio in the gym and everything which is going to hurt a lot more, it was something I didn't really want to have to do. (Participant 10, L: 176-182).

The realisation of having to become more independent was initially a daunting experience:

I'd gone from the burns unit, where the nurses had come in and get everything set up for me, and there it was a case of trying to do it myself as much as I could; that was a bit tougher for a start. (Participant 11, L: 346-348).

Although others found the transition to the rehabilitation centre an uplifting and positive experience that was to be embraced:

I found leaving the burns unit was good in the end because I spent that much time there. It was a change of life. It was good to be out of there. I felt better in myself and I felt that I had come forward in getting better. (Participant 9, L: 95-98).

Participants, who were briefed by the rehabilitation centre staff on their transition and ongoing rehabilitation prior to admission, believed they were better prepared mentally for the move across to the rehabilitation centre:

Transition [from the burns ward to the rehabilitation centre] was reasonably good because ah, I had [sigh] two people from the rehab centre come and visit me, so they got to know me and what they had to do. So the transition from the burns ward to the rehab centre was easy. (Participant 16, L: 117-121).

Others took it upon themselves to become familiar with the rehabilitation centre and its routines:

Well actually, what we did before I...was officially taken to the rehabilitation centre – [my partner] and I drove across in our car and we had a – about an hour. We were going through the rehabilitation centre by the head staff there and shown the room

that I'd be occupying and also the layout and how you're fed and where you're fed...and where the rehabilitation room was. We were taken there and shown and the thing is with the rehabilitation centre, they have a much larger array of people – not just burns people – they have brain injury, they have amputees, they have the lot ... (Participant 5, L: 367-376).

Some participants felt unprepared and ill-informed about transitioning to the rehabilitation centre as expressed by this particular participant:

I was a bit nervous because I wasn't actually - I didn't really know what to expect [at the rehabilitation centre] and I thought it would be more like a boot camp, get woken up at five o'clock in the morning and, you know, go through the paces, do the obstacle course and all that kind of thing. So I was a little bit nervous and I was - yeah, I was kind of thinking, am I really ready for it... (Participant 7, L: 126-131).

Participants' perception and expectations of their continuing rehabilitation were not always met and left some feeling very disappointed:

And so really I expected when I left the burns unit, I thought the rehabilitation centre was going to be some really one on one; where some person would say, right, now you're mine for the next two months and I'm going to work on you daily. This is what I thought was going to happen. (Participant 5, L: 580-584).

For other participants the reduction in the intensity of care experienced in the rehabilitation centre was difficult to cope with and accept:

...when I left the burns unit, having had that much attention in the burns unit, like it seemed like you were the centre of the universe. Everybody was working on you and you'd go into the OT's [occupational therapists] room and all your garments are there and it's all about you. To go from that to the rehabilitation centre was just the opposite end of the scale. You went from being the centre of attention to being room

seven or whatever you were. It felt like you'd been short felled, like you'd failed.

(Participant 14, L: 130-136).

The drastic change from a single room on the burns unit to the dormitory style at the rehabilitation centre was often a shock for some participants that made the transition in their rehabilitation a challenging experience:

I'd gone from a single bed ward to, the first night I was actually there I went into a six bed ward. That's a bit of a fairly big shock system...Yes, well that, was a big transition as in itself. Because being at the Burns Unit it's all climate controlled, your room and everything. Where you go into a six bed ward, you're actually in there with, uh, stroke victims that are actually - I've got nothing against stroke victims and old aged people. But when you're a 36 year old person and you've gone from a single bed ward that you had two nurses working with you around the clock. To going into a rehab centre where you've got six people in a ward with one nurse working with you, like, it's a huge change to your lifestyle. (Participant 21, L: 195-211).

Participants transitioned from the ICU to the burn unit then onto the rehabilitation centre which were significant milestones to surmount. However, the transition home was a turbulent experience as participants were unsure of the journey ahead:

...another thing that I found was a little bit difficult was the transition from - again I suppose it's all part of when you go home... (Can you elaborate on that transition from going from the ward to going to rehab?). Yeah um [pauses] okay. I suppose it's all part of the transition from the ward to outpatients. I suppose that was really sort of a first um experience of rehab. Um [pauses] [sighs] it's um really hard because you get so used to such a high level of um support and attention and um care. And all of a sudden it um drops off to a very minimal amount of support and care and um - so it feels very um [pauses] - I was very nervous because I didn't know.

[Pauses] I wasn't sure of whether anything was going to go wrong or what to expect or what to be looking for or what the process of rehabilitation was going to be. I didn't know that - there was no - I didn't know what the steps were. I didn't know what the journey ahead was going to be. I was just told to be here every second day [laughs] that was it. This was your appointment time and that was it. [Pauses] so the transition was um very daunting. Um [pauses] because of um lack of um, I don't know, lack of understanding, if that makes sense. (Participant 18, L: 605-625).

Reintegration

The act of reintegrating into society and everyday life was a step by step process for participants that required time and patience. Some found this experience frightening after enduring such a lengthy hospitalisation period:

*The first time I went outside was when I was given a day pass and I was brought home by [my partner]. So that was [pauses] the first um [pauses] time I'd been outside of the ward. Apart from [laughs] operations that was the first time that I'd been outside the ward. **(How was that for you?)** Frightened the shit out of me [laughs]. Um yeah it um [pauses] - very, very ah daunting. (Participant 18, L: 378-385).*

Whilst at the rehabilitation centre, participants were encouraged to engage in activities of daily living both inside and outside the hospital as part of their ongoing therapy to assist with reintegration. This participant described how specially designed tools facilitated regaining basic skills:

I had to organise my own breakfasts in their in-built kitchen there. I had - oh there's all these tools for handicapped people I suppose, had bottle openers, can openers, even coffee cups and mugs rather than handle there's a dent in the side, you hold it that way, polystyrene tubing you force a fork or knife in, gives you a larger gripping

area. Yes, I managed to fry myself two eggs on toast with a cup of coffee without any assistance and I pretty much do that on a daily basis. (Participant 12, L: 527-533).

Other participants were given the opportunity to venture outside the hospital as one of the many steps necessary in the rehabilitation journey:

...one of the girls took me down to...[the] Bowling Club and I put down some bowls there. That was just another part of the rehab...It was just...one of the first steps of many as far as rehab was concerned. (Participant 6, L: 676-680).

Within the reintegration process, this participant described some of the steps that were involved in order to facilitate with the rehabilitative journey:

...at first we'd do more exercise, bolts, pegs, end games and (pause)...and there was also just exercises, table top and monkey grip and that sort of thing. Then towards the end, it was more - we did a bit of cooking which involved going to the supermarket and actually getting the food. (Participant 7, L: 251-255).

In the process of reintegrating and resuming activities of daily living, participants were met with different reactions from the general public:

*I guess mainly just through going out there in small ways for a start, until you get used to it. Really, it's probably an irrational fear because when you're out there people either avoid you completely - which is what you want them to do - or - it's funny, little kids, especially in shopping centres - they see you with the mask and everything on and they think you're dressed up as a super hero or something. They're walking past with their mums and dads and their heads turn around like they're in *The Exorcist* or something - it's pointing back the other way. (Participant 11, L: 121-129).*

However, participants in general found reintegration a challenging experience to overcome as this participant plainly described:

I think if you only knew what I go through every day just to get myself integrating into society again. It's been really, really hard. (Participant 10, L: 477-479).

Ongoing access to rehabilitation services

Participants were well aware that their rehabilitation journey did not end upon discharge from the rehabilitation centre. Participants continued with their burn therapy and follow up for an extended period and some still continue today with ongoing rehabilitation. Some participants struggled to access rehabilitation services outside the hospital with minimal direction or arrangements made for those departing the rehabilitation centre. This participant described the frustration experienced:

They spend hundreds of thousands of dollars, give them the best care available in every aspect, physical and psychological, at both hospital and rehab and then it stops. Then there's nothing. (Participant 8, L: 458-460).

Other participants expressed how they did not cope, feeling overwhelmed:

Yeah I think if anything when I left the rehabilitation centre I felt like I was being thrown in at the deep end a little bit to be on my own. I didn't really feel like I was coping very well. Then I was looking forward in a way to go back in to have more surgery because I know I was going to get fed and looked after again [laughs.] (Participant 10, L: 198-202).

Some participants felt abandoned after discharge and given little advice about the road ahead:

But um for me personally I had no guidance or anything. So it really was - it really felt like um ah once I was discharged they sort of close the door behind you and say good luck and [pauses] I think for me they gave me a really big bag of tablets [laughs]. See you later. (Participant 18, L: 412-415).

Others were left wondering why there were no services available specifically for patients rehabilitating from a severe burn injury:

Now I thought it strange or I couldn't believe that an experienced unit like that didn't have these in place for people who were, I don't know, caught out in that time and place where I needed that extra help and bureaucracy, I don't know, everyone seemed to have their own little niche. If I was a pensioner, I would get help, if I was wounds and dressings, yes, someone would even come round and look after your medication, but they wouldn't touch a burns patient [laughs] and I thought that odd. So we took it upon ourselves to find someone. (Participant 12, L: 324-332).

This participant also obtained little assistance after discharge from the rehabilitation centre however offered some constructive advice:

Like if they had a - the burns liaison nurse could say to the different services we've got this person here, can you help them out? They need somebody to come in and actually say righto these are the things we can offer you. And these are the services we can give you. It'll make it a hell of a lot easier on [pauses] ah the spouses or family. So instead of going through - I know five or six blokes that are in there that had to battle to try and get on these services going together because nobody was there to explain it to them. (Participant 20, L: 419-426).

In the main, after discharge, a large number of participants in this study received little or no assistance in accessing rehabilitative services for burn patients. As a result, participants and their families were the main instigators of any ongoing rehabilitation accessed. This participant explained how there was no plan upon discharge, leaving many of the questions unanswered:

I think um - well I suppose the difficulty was that my rehabilitation I think basically between - well [my partner] organised it. Between the two of us we basically organised my rehabilitation. Um and the third party for me would have been work

because of their involvement. So [pauses] um it was [my partner] that had to organise um my physio [physiotherapy] for leaving hospital. It was um [my partner] that had to organise a um psychologist for me to go and see. Um yeah none of these services were talked about or um any sort of - again I can understand obviously the hospital can't promote things like that. But I really do think that they would be - someone should be able to sit down with a patient or even a support person of the patient beforehand. And just be able to come up with a plan [pauses], even if it was just ringing a few local people within the area for those very basic rehabilitation services. Like physio or psychology or something like that. Um just to have some sort of plan. Um [pauses] like I said eventually when we did go and use these services the people were very good. But um we just didn't know what was [sighs] required. I suppose it's an individual case but how often do I go and see a psychologist? Do I need to see them weekly or daily? I don't know [laughs]. Um anything like that, it was just there was no framework, you know what I mean? No plan. (Participant 18, L: 523-543).

Other participants who lived in remote areas in Australia were more creative engaging willing therapists through private practices to accept care in conjunction with the burn unit:

I am getting physio nearly every day now through a private practice and through the base, but it did take quite a while to get that in operation... we found a private woman that studied I was fortunate enough that the health service in [my town] had a physiotherapist there. She said I'm keen to have a go and the same with the nurses there. Because I actually had outpatients nurses because I actually still had dressings that needed to be done. They said we don't know anything but we're open to suggestions to be taught. To give them credit the physiotherapist, in her own time, from [my town] came down and met with the crew at the burns unit and said what do we need to be doing, communicated continuously through emails on one thing or

another... I know that we said that we wanted it in [in town] simply because of the travelling. Even Port Macquarie is a couple of hundred kilometres away from where we live. (Participant 14, L: 652-666).

However, a select few described a more organised and orderly experience after discharge. In this regard, one participant expressed:

Ah we booked into the district hospital and they've got a ah rehab sort of facility there...[pauses] - there was [pauses] two dedicated ah rehab people there. And they'd never - oh not never. They hadn't worked on a burn survivor before. They've worked on people with burns but not as significant as mine. So they [pauses] ah took it upon themselves to go and actually learn about it. They learnt ah different dressings and ah [pauses] different ways of looking after burn survivors. Ah the physio people, they actually went out of their way and did the same thing. The district nurses came in, did their job and took off where I'd go down to the hospital and they'd go right we've got this set up for you today. Ah once you're finished we'll do your dressing change. And they'd take you in a room; you'd do your physio. Take you in a room and redo your dressings. Take you back home. (Participant 20, L: 472-485).

Exhaustive description of patients' rehabilitation after a severe burn injury

The burns survivors' 'lived experience' of rehabilitation is a protracted journey with key transitional stages during the rehabilitative process: ICU to the burns unit, the burns unit to the rehabilitation facility and finally discharge home. It is clear that these key points during the rehabilitation phase are a disruptive, difficult and tumultuous period for the burn survivors that engenders feelings of insecurity and uncertainty at a time that where consistency and continuity is most needed.

The participants found their room on the burn unit like a cocoon, providing a sense of security. Participants felt apprehensive and insecure upon leaving their room and venturing

outside the burn unit with the need to return to the security of their room. Despite the sense of security the burn unit provided, participants felt extreme isolation and loneliness by being immobilised and restricted experiencing minimal contact with others. Feelings of imprisonment relating to the rehabilitation setting which resembled, for some, a prison camp or jail cell were expressed. Others felt imprisoned by their injury and the treatment regime of splinting and pressure garments used to minimise contractures and scarring.

Participants displayed immense tenacity throughout all stages of their rehabilitation. In particular, the characteristics of determination and motivation were highly prevalent among participants. Having confidence, a positive attitude, and a strong commitment towards rehabilitation, facilitated the ongoing journey. The act or thought of returning home was a powerful driving force for participants. Returning home for short periods during their rehabilitation proved an uplifting experience. While not wanting to return to the rehabilitation centre, participants were insightful of the need for continuing their rehabilitation. Participants were generally grounded in the reality that giving up was not an option with an emphasis on regaining and reclaiming their independence. Attaining independence often meant participants had to find alternative ways to perform basic tasks requiring creativity in order to adapt. Participants utilised the development of achievable manageable goals as a means of focusing and directing their rehabilitation. Goal setting was fluid; a dynamic process that was always shifting as participants progressed through their rehabilitation. Participants often reflected upon their goals in order to see how far they had progressed.

Acceptance of the burn injury was a challenging process for participants. Some participants initially underestimated the severity of the burn injury which made acceptance difficult. While most were eventually able to accept the reality that their life as they knew it had changed, it was a difficult process. Participants experienced great difficulties when confronted with their distorted and altered appearance upon visualising themselves in the mirror and during frequent dressing changes. Some participants expressed how the tough and hardened sensation of their skin made them feel alien in their own body. Consequently, most found acceptance and being comfortable with their physical changes was a slow and challenging process. Participants felt self-conscious of their appearance and reluctant to venture outside in public making, the process of socialising and reintegrating difficult.

The scars from the burn injury were both of a physical and psychological nature. Participants felt the need to accept their injury and subsequent limitations, in order to progress. However,

others chose not to accept the reality of their circumstances which impacted on their overall rehabilitation. Humour was at times used by participants as a means of coping with and accepting their injury. While others compared themselves with those whom they perceived were in a worse situation, therefore finding a positive in order to facilitate acceptance. Others were more pragmatic in their response, expressing a matter-of-fact attitude towards their injury and rehabilitation.

Participants struggled emotionally with the loss of independence rendering them feeling helpless, dependent and reliant on staff and their family for the most basic activities of daily living. This often resulted in a loss of dignity and control over their lives which was a demeaning experience. Some participants experienced a loss of income and the inability to return to their prior employment status, while others returned to work accepting their limitations. Participants frequently expressed the want and need for life to return as it was prior to the injury. The impact on others particularly family was acutely felt by the participants.

Pain was experienced in both the physical and psychological sense. However, participants were well grounded in the reality that rehabilitation is painful. The pain experienced during the routine washes and dressing changes was often expressed as horrendous, in which no amount of pain relief prepared participants for the pain they underwent. The thought of having to endure ongoing dressings every two to three days, engendered feelings of apprehension about routine burn procedures and was a depressive experience. Physiotherapy, occupational and speech therapy was described by some participants as torture due to the amount of pain experienced during therapy. Apprehension and fear were often experienced upon seeing the therapist prior to the commencement of their therapy.

Feelings of despair and at times desperation were encountered with participants stating that there was no coping and no alternatives. Some participants expressed the difficulties with moving on often wishing to give up, while others expressed not wanting to survive their injury experiencing suicidal ideations. Depression was often experienced by the participants as they sank into the depths of despair when confronted with the reality of their injury. At times participants experienced doubt that they would make an acceptable recovery and some had their fears realised when discharged home.

Support expressed by participants' partners or carers was unwavering and a powerful and uplifting experience during their journey of recovery. The support was largely emotional and

of great significance to the participants during the long period of hospitalisation and rehabilitation. Partners' and carers' commitment was evident with their involvement in the continuance of adequate care and treatment after discharge. The supports incorporated the participants' families, friends and the greater community. The family unit provided a rich source of emotional and physical support that was both inspirational and motivational in the rehabilitation journey. However an absence of family support, made everyday life difficult. Often, the community involvement provided participants with a strong social support network that had a positive effect on the participant and the family unit.

Staff generally provided a strong professional social support network for participants displaying dedication and instilling trust and confidence. Staff were encouraging, providing positive reinforcement and reassurance throughout the rehabilitation journey. Nursing staff in particular, provided a wealth of emotional support to participants throughout their rehabilitation journey. The physiotherapist and occupational therapists played a critical role in delivering a focused direction and education that facilitated patient adherence.

Burn survivor peer support was a unique and significant source of psychosocial support providing participants with a sense of comfort, hope and reassurance that there is life after a severe burn injury. Often patients felt inspired, determined and motivated after an interaction with a recovered burn survivor. The credibility of a peer support network was a significant factor when participants were visited by or had some form of interaction with a burn survivor bringing personal knowledge and insight into the rehabilitation journey ahead. However, the instigation and timing of peer support was seen as a significant element. Those involved in providing peer support often found that assisting other burn survivors helped with their own understanding and experiences of burn injury. However, not all participants were open and willing to be involved with the burn survivor peer support, finding it a challenging experience.

Transitioning through the various stages of rehabilitation was a challenging experience for most participants. Initially, the move from the high dependency of intensive care to the burn unit was an unsettling experience that required participants and their families to swiftly adapt and adjust to the new environment and routine of the burn unit. However once settled into the daily routine of the burn unit, they became emotionally attached to their surroundings and staff which made the transition to the rehabilitation centre difficult. Participants expressed that they were given little preparation, orientation or information about their often sudden

move to the rehabilitation centre engendering feelings of apprehension and ambivalence about taking the next step in their rehabilitation journey. However, participants were grounded in the reality that progression to the rehabilitation centre was the next critical step in their recovery. Some participants and their families decided to orientate and familiarise themselves with the rehabilitation centre prior to admission. Frequently expressed was the need for a smooth and coordinated transition period in order to adapt and adjust to the unfamiliar environment and routine of the rehabilitation centre. Of prime importance to participants generally was the existence of a structured rehabilitation programme with a shift in focus and emphasis on regaining independence. Participants valued the presence of a structured rehabilitation programme and wished one was there when it was absent.

Participants having to share a room with other non-burn rehabilitation participants found this initially a daunting experience due to the nature of their burn injury. In addition, participants were often the only burn victim in the rehabilitation centre at the time of their admission, leading to feelings of isolation amongst an often elderly mix of patients. The expectations and perception of rehabilitation were often not met leading to high levels of frustration. However, the implementation of the multidisciplinary team assisted in the smooth transition to rehabilitation for some participants as did the personal approach encountered by the rehabilitation centre's therapists.

Participants were grounded in the necessity of continuing rehabilitation after discharge. However, access to services and ongoing burn rehabilitation was often problematic for participants. They expressed that there was a lack of organisation and follow up after discharge from the rehabilitation centre. The participants themselves and their partners/carer were left to explore and find appropriate social support and therapists that were deemed competent to assist with a severe burn injury of which most were sought through private practice. Participants at times felt abandoned and unsupported after discharge with no clear structured plan for their ongoing rehabilitation and not knowing the best next step to take concerning their ongoing rehabilitation. As a burn patient, sourcing and initiating appropriate rehabilitation proved to be a difficult task due to the level of expertise and knowledge required. Those who accessed district hospitals found staff willing to assist with the ongoing dressings and rehabilitation, liaising with the burn team for direction and guidance with regard to treatment.

Participants experienced a lengthy hospitalisation and rehabilitation period expressing that the length of time encountered was challenging. Rehabilitation from their severe burn injury was a step by step process over many weeks and months fraught with setbacks, complications, uncertainties and frustrations. Participants expressed that it took a long time to regain their independence to perform the most basic activities of daily living. Burn dressings were described as lengthy and traumatic procedures to be endured on an ongoing basis with wounds healing at a slow rate. In addition, the continual surgical procedures were disruptive to their ongoing rehabilitation programme. Despite this, patients were often insightful as to the length of time required to recover from such an injury. Once discharged home, there was a realisation that rehabilitation did not cease and it is an ongoing process to reach a level of independence. Often participants found that returning home was not what they expected and were faced with many challenges and limitations requiring time to adapt and adjust.

Frequently, issues with adherence to burn treatment were experienced among participants. Non-adherence to therapy was often due to the intense pain experienced during treatment sessions and splinting regimes. However, it was stated by some that more education and rationale for the treatment regime would have improved their adherence to therapy. Most participants had an insight into the importance of adherence, demonstrating understanding of the necessity of rehabilitation and co-operation despite the pain and trauma endured. Others experienced being told the hard cold reality of non-adherence to burn care. However, for some participants, the importance of adherence became clear much later in their rehabilitation due to complications experienced. Often participants were motivated by the thought of being severely disabled and dependent therefore taking responsibility and ownership of their treatment.

Inconsistencies in burn care were experienced amongst participants throughout their rehabilitation. It was felt that the communication, coordination and collaboration of care between the burn unit and the rehabilitation centre were inadequate. Little contact was experienced between the burn clinical nurse consultants and participants engendering feelings of isolation and a lack of support. Some patients stated that there was a lack of structure and direction provided by the rehabilitation centre. However, others state that their therapy was focused and intensive. Most participants encountered a lack of experience, knowledge and confidence in the rehabilitation nurses regarding burn dressings and pain relief, which was an unsettling experience. This was also felt by some participants with regard to the rehabilitation therapists not being competent or confident in managing severe burn injuries and thereby

leaving patients feeling frustrated. However, experience, knowledge and competence instilled trust, motivation and confidence in participants throughout the rehabilitation journey. The continuity of staff, especially nursing staff was an important issue for participants to feel secure and confident in their continuing rehabilitation. Participants at times noted that the sparseness and limited resources experienced at the rehabilitation centre was not tailored to the dynamic nature of managing a severe burn injury.

Reintegration back into everyday living was a slow, challenging and often overwhelming process that required participants to adapt and adjust to their environment. Participants frequently expressed that the atmosphere and layout of the rehabilitation centre facilitated feelings of freedom in comparison to the enclosed burn unit. Patients felt that they could walk around or leave the grounds with their family which symbolised a step closer to home. Initially, participants felt apprehensive about getting out and socialising due to the length of time spent incapacitated on the burn unit. Participants were also apprehensive about the reactions of others to their burn injury. However, participants were most often insightful as to the importance of getting out and performing everyday activities of daily living. For some participants, the occupational therapists were fundamental in preparing and facilitating patients returning to daily routines by providing opportunities for shopping, cooking and leisure activities.

Summary of chapter

In this chapter the findings of the study are discussed incorporating extracts from participants' interviews to validate the findings. Despite participants delivering different perspectives on rehabilitation after a severe burn injury, there remains a common thread throughout that is evident in the seven emergent themes presented in this chapter. Throughout the presented themes, participants' descriptions and attributed meanings of their 'lived experience' are unearthed and illuminated. Furthermore, presenting an epistemological perspective assists with imparting unequivocally, the essence of burn survivors' rehabilitation. In the next chapter, chapter six, the implications of the presented themes are discussed in-depth.

CHAPTER SEVEN

DISCUSSION

Introduction

The Husserlian phenomenological approach seeks to provide a rich description and understanding by means of analysing the ‘lived experience’ in a particular context of those who encounter the phenomenon of interest. Phenomenology elicits the essence of the phenomenon through exploration of those experiencing it, offering a detailed and in-depth description of the ‘lived experience’. The aim of this study was to explore burn survivors’ ‘lived experience’ of rehabilitation. Utilising a phenomenological-epistemological perspective, the participants experiences were analysed to provide a rich and detailed description of the phenomenon that has contributed to the expanding body of knowledge concerning burn rehabilitation.

This chapter provides a comprehensive discussion of the findings in light of the literature and research question, “What is the ‘lived experience’ of patients’ rehabilitation after a severe burn injury?” Seven emergent themes were identified from the phenomenological analysis of participants’ ‘lived experience’ of burn rehabilitation. The chapter compares and contrasts the participants’ experiences and perceptions with current relevant literature. The findings of this descriptive phenomenological study demonstrate that burn survivors’ ‘lived experience’ of rehabilitation is both unique and tragic due to the physical and psychological trauma that reveals the resilience necessary for the rehabilitation journey. The following discussion addresses these aspects of burn rehabilitation and illuminates the needs and concerns of this unique cohort of patients from both the individual participants’ narratives and the themes in the context of the current and relevant research.

Synthesis of findings

The findings of this study relate to the experiences of the 21 burn survivors presented in this study and can be summarised as follows:

1. One of the key elements to burn rehabilitation is social support including family, friends, health professional and peer support that may influence the burn survivors’ psychosocial rehabilitation.

2. Those with severe burns often experience extensive physical and psychological trauma throughout the rehabilitation journey.
3. Despair is an emotion often experienced early in rehabilitation when burn survivors are confronted with the devastation of their injury.
4. The acceptance of an altered body image is often a slow and challenging experience for those with severe burns requiring the mobilisation of effective coping strategies.
5. An important aspect to burn rehabilitation is the development of coping strategies and the means of adaption.
6. Patient centred and owned goal setting may provide the necessary motivation and tenacity to progress through the lengthy rehabilitation journey that besets burn survivors.
7. Appropriate timing and delivery of burn therapy and education can assist in fostering patients' adherence to burn care.
8. Sustaining a severe burn injury can impact on the occupational and financial state of affairs of survivors and their family.
9. The process of transition and reintegration after a severe burn is often experienced as a significant event in the rehabilitation of burn survivors.
10. Access to ongoing rehabilitation services for burn survivors can be a challenging experience because of the lack of burn expertise that is often seen in the community setting.

Social support and psychosocial resources

The importance of social support after a severe burn has been well established (Altier, Malenfant, Forget, & Choiniere, 2002; Corry, Pruzinsky, & Rumsey, 2009; Lawrence & Fauerbach, 2003; Muangman et al., 2005; Pallua, Kunsebeck, & Noah, 2003). Subsequently, an increase in social support is reported to be correlated with survival (Muangman, et al., 2005). Social support is associated with positive physical and emotional outcomes that cushion the effects of the trauma (Lawrence & Fauerbach, 2003). The findings in this study suggest that social support is the core element in the burn rehabilitation journey. This is also documented in Holaday and McPhearson's (1997) research with social support flagged as a critical element for burn survivors that stimulates and sustains resilient attitudes. Consistent with the findings in the current study, Wu, et al. (2009) and Ciofi-Silva, et al. (2010) support the notion that social support contributes to the adaption process. Interestingly, the age of the patient at the time of the burn injury coupled with the level of social support received,

influences the quality of life (Anzarut, Chen, Shankowsky, & Tredget, 2005). In fact, sustaining their burn injury early in life, is reported to be a strong indicator for an improved quality of life (Anzarut, et al., 2005). However, the mean age of participants in this current study was 44 years of age with a quarter of participants over the age of 50 at the time of injury compared to Anzarut, et al.'s (2005) study whose participants' mean age at the time of injury was 28 years. Despite this, those that begin their rehabilitation early have more time to adapt successfully.

The findings of this study suggest that the support received from the partners, family, friends and the community, is a key factor both emotionally and physically that provides the motivation to not only survive, but to experience a meaningful recovery. Moi, et al. (2008) reiterate this by confirming that family members in their study reminded burn survivors of who they were, what was expected from them and refused to allow them to give up. This is also evident in Maher (2009) and Nolte's (2007) personal accounts of their rehabilitation after sustaining severe burns. Gonçalves, et al.'s (2011) integrative review of psychosocial factors affecting burn rehabilitation, also found that social support from relatives, friends and significant others was an influencing factor in the rehabilitation journey. Similar to the findings in this current study findings, Holaday and McPhearson (1997) found that those who experienced positive feedback in the community setting, usually had maintained relationships with the same people over many years and offered gratitude to the greater community for their financial and moral support.

Conversely, Park, Choi, Jang, and Oh's (2008) study that investigated the risk factors of psychosocial problems of burn patients, found that burn survivors who experience a lack of familial support are significantly burdened with rehabilitation issues. Additionally, as with the findings in this study, Ciofi-Silva, et al. (2010) found that burn survivors reported changes in their relationships with significant others, relatives and friends. This is congruent with others such as Na (2008) who explored re-engagement in activities and participation following severe burns in the adult population finding that close friends became distant and surprisingly, complete strangers were extremely helpful.

Psychosocially, the status of the burn survivor's psychological health pre-injury influences the recovery (Anzarut, et al., 2005). Consequently, the incorporation of social workers, psychologists and psychiatrists into treatment teams assists in the identification of patients with low levels of social support (Anzarut, et al., 2005). Nonetheless, nurses make up a

substantial component of burn care personnel and as such played a key role in delivering physical and emotional support to the participants of this study. This is also echoed by Birdsall and Weinberg's (2001), supporting the notion that nurses are key support personnel. Nurses provide reassurance and utilise the patients' concerns as an opportunity to educate on issues of wound care and use strategies to emotionally support those with severe burns that reinforces trusting relationships (Birdsall & Weinberg, 2001). Furthermore, as demonstrated in this current study, members of the allied health team, in particular, physiotherapists and occupational therapists are significant members of the multidisciplinary burn team that influence adherent behaviours in relation to burn therapy. However, a lack of social support provided by burn clinicians can render burn survivors feeling powerless with a decreased capacity for problem solving (Dahl, et al., 2012). Furthermore, Reeve, James, and McNeill's (2009) investigation of burn clinicians' perceived skill in providing physical rehabilitation support, found that clinicians feel less confident providing advice on issues concerning psychosocial rehabilitation compared to the physical aspects of rehabilitation.

Burn survivor peer support

There remains a high incidence of psychosocial difficulties and hurdles that burn survivors experience (Corry, et al., 2009; Fauerbach et al., 2002; Lawrence & Fauerbach, 2003; Wallis et al., 2006). As such, the role of peer support has become a pillar of strength, acceptance and hope for burn survivors (Tolley & Darton, 2012; Tolley, Travagila, Foroushani, & Darton, 2012). Peer support has long been recognised as an essential component of a supportive network for people facing adversity (Solomon, 2004). The rapid growth of peer support networks is suggestive that peer support has a critical role in post-burn adjustment (Badger & Royse, 2010b). However, burn survivor peer support has been grossly underrepresented in the literature with only a few studies focussing on the adult patients' perspectives (Badger & Royse, 2010a, 2010b; Cooper & Burnside, 1996; Sproul, Malloy, & Abriam-Yago, 2009; Tolley, et al., 2012; Williams, et al., 2003; Williams et al., 2002). This is surprising since there is a wealth of literature supporting peer support in the general patient population.

Peer support can be defined as "a system of giving and receiving help founded on key principles of respect, shared responsibility, and mutual agreement of what is helpful" (Mead, Hilton, & Curtis, 2001, p. 135) and founded on the premise of empowerment (Resnick & Rosenheck, 2008). Drawing from their injuries, burn survivors can impart their experiences that bring a unique, personal and credible perspective to other survivors through emotional and instructive support (Acton, et al., 2007; Solomon, 2004) which are clearly missing in the

professional realm. Furthermore, burn survivor peer support is correlated with a positive body image, self-esteem and a reduced incidence of depression (Orr, Reznikoff, & Smith, 1989).

These findings demonstrate that burn survivor peer support is a valuable and credible underutilised resource. Participants in this current study found that an interaction with a peer support burn survivor was an uplifting experience that fostered hope and motivation in their rehabilitation. These findings concur with Badger and Royse (2010a) concerning burn survivors' view of peer support, in which participants report positive views about the value and benefits of peer support providing hope, perspective and a sense of belonging. Sproul, et al. (2009) who investigated perceived sources of support of adult burn survivors, found that 89% of participants stated that speaking to a burn survivor assisted them in their on-going rehabilitation, 92% found it motivational and 91.5% agreed that speaking to another burn survivor gave them hope for the future. Additionally, 96.6% of participants in Sproul, et al. 's (2009) study, highly recommended that a newly injured burn patient speak to a burn survivor.

In contrast, as reported in this study, negative experiences of peer support are also evident in the burn literature. Badger and Royse (2010a) report negative experiences relating to poor choice of support personnel for the role of burn survivor peer support. Additionally, Sproul, et al. (2009) specified that 6% of their participants felt that speaking to another burn survivor made them feel hopeless about their recovery. Sproul, et al. (2009) question whether the negative experiences of peer support were due to the individual peer supporter, the appropriateness of the interaction or the characteristic traits of the burn patients or the readiness of patients to receive peer support. Readiness to receive support is evident in the findings of this study, with some participants stating that they would have been more receptive in the later stages of rehabilitation compared to the initial acute phase. Therefore the timing and readiness of the patient are key aspects to the success of peer support (Sproul, et al., 2009). Furthermore, there is an emotional toll that peer support burn survivors experience concerning the demands of supporting someone who has suffered a traumatic injury (Badger & Royse, 2010a). The findings of the current study demonstrate that some patients were not willing to be involved with a peer support network as they felt there was not a lot to be gained.

There are numerous burn survivor support organisations available to survivors and their families both globally and nationally such as the Peter Hughes Burn Foundation and the Burns Support Foundation in Australia, The Burn Support Charitable Trust in New Zealand

and the Phoenix Society for Burn Survivors in the United States of America. However, it is important to make the distinction between the two different types of peer support systems that currently exist under the banner of burn survivor peer support. One system is based on a structured program with trained peer support personnel that have been scrutinised for suitability as a burn survivor peer supporter. The second system is based on an unstructured program through a survivor support group. Despite the literature supporting both peer support systems, the former structured program that utilises trained personnel has gathered momentum due to the rigorous methods employed in managing such a program. In the past, burn units have utilised former patients to come and speak to patients that have sustained a severe burn injury (Sproul, et al., 2009). However, issues have arisen when the suitability and actions of the peer support burn survivor has come into question. Williams, et al. (2002) recommend that burn units develop peer support programs that screen and train all potential peer supporters and select individuals that are emotionally mature and specifically can place the needs of the patient before themselves. Such programs as the 'Sharing Hope, acceptance, Resilience and Experience' (S.H.A.R.E) program and the Survivors Offering Assistance in Recovery (SOARS) are both formal inpatient clinician led burn survivor peer support programs. An evaluation of the SOARS program reported an average of 6.3 on a seven point scale demonstrating a high satisfaction rate among the patients concerning their visit (Bennett, 2007). Likewise, the S.H.A.R.E program currently only conducted in New South Wales, Australia reported that 100% of patients felt that the program gave them hope, altered their attitude positively and made them feel less isolated (Tolley & Darton, 2012). These results are highly reflective of the findings in this study and therefore support the notion of a clinician led inpatient burn survivor peer support program.

Environmental factors and the impact on patients with severe burns

For those with severe burns, the surrounding environment is significant and influential to the recovery journey. As participants in this study progressed through and between the different stages of their rehabilitation, their surrounding environment was fundamental in how they perceived and experienced their rehabilitation. Participants often encountering a prolonged, isolative hospitalisation that bordered on imprisonment yet became their safe haven providing a sense of security and protection from the outside world. Despite this, home was never far from their thoughts and future aspirations of returning home provided the tenacity and motivation to move forward.

However, the literature concerning the patients' environment is extremely limited that tends to focus on the physical complication experienced from a protracted length of stay. Conversely, published biographies of burn survivors' experiences of their rehabilitation journey echoed many elements found in this study of which the theme of the spatial environment was clearly evident (Maher, 2009; Nolte, 2007; Pessotti, 2006). Of significance, Maher (2009) describes her room on the burns unit as a sanctuary stating "my room had become my home and I felt safe" (p. 61) and further states that the rehabilitation centre had become a home "Hampstead [rehabilitation centre] had become a secure home for me – a place where I felt normal..." (p. 83). This notion of the sanctuary of a patient's room is also evident with Nolte's (2007) account where he referred to his room on the burns unit as 'home' that provided the safety and protection needed during a tumultuous time. The goal of one day returning home motivated participants in this study which is also resonated in Nolte's (2007) account whereby he states "I was finally moving towards a goal – the goal of going home" (p. 70). Nolte (2007) also touches on the issue of isolation by providing a succinct account stating "how can I write this book with the intent of giving patients, burns victims and their families a complete picture of what it's like to be confined to the ICU for more than two months" (p. 77). Later he adds "...the evenings in the unit were the loneliest" (p. 119). Maher (2009) also conveys that confined to the room in the burn unit evoked feelings of isolation and loneliness stating "I often felt my loneliest on the weekends because I knew most people were out and about enjoying their lives...while I was stuck in hospital" (p. 56).

The theme of imprisonment evident in this current study is also discussed by Carter and Petro (1998) in their portrayal of the experiences of the severely burned that bears a strong resemblance of a jail sentence due to the enormity of limitations face by those severely burned. Carter and Petro (1998) state that the word imprisonment draws attention to the loss of freedom and the feelings of punishment as patients are confined to bed lying isolated in a burns unit. Carter and Petro (1998) claim that as patients start to become aware of their surrounding environment, they become conscious of the isolation, the profound changes thrust upon them including limitations, pain and grave concerns about the future. Moi, et al.'s (2008) phenomenological study of bodily awareness after a burn injury highlights issues concerning an isolative environment finding that if patients were unable to communicate by voice or body movements, they experienced panic attacks and feelings of insecurity despite being a short viewing distance from the burn clinicians.

The continuing challenge

Adherence to burn therapy

The terms non-adherence or non-compliance have been used interchangeably in the healthcare setting (Johnson, Greenspan, Gorga, Nagler, & Goodwin, 1994). Compliance can be defined as the extent to which a patient's behaviour coincides with healthcare advice (Hasford, 1992). However, adherence can be defined as active, voluntary and collaborative participation of patients in a mutually acceptable manner that produces therapeutic results (Ho, Bryson, & Rumsfeld, 2009). Consequently, the term compliance has been superseded by adherence as it does not reflect a paternalistic relationship (Laufs, Rettig-Ewen, & Böhm, 2011). Despite these semantics, there is extensive literature concerning patient adherence with over 32550 citations in PubMed alone and a further 10087 in PsychLit (Martin, Williams, Haskard, & Dimatteo, 2005). These figures are not surprising given that as many as 40% of patients fail to adhere to the recommended treatment or therapy (Martin, et al., 2005). However, it is noteworthy that research into non-adherent behaviours has been predominantly from the perspective of the health professionals with little concern for the patients' perspectives and experience (Stewart, Bhagwanjee, Mbakaza, & Binase, 2000). Patients' perceptions and experiences have been reported to be important in decision making (Stewart, et al., 2000). The findings presented in this study highlight the issues of adherence from the patients' perspectives that contribute to the existing knowledge of burn survivors' perspectives and experience. Such knowledge of adherence to therapy enlightens burn clinicians' understanding of the phenomenon of non-adherence to burn therapy.

Adherence to burn therapy often revolves around pressure garment therapy and splinting regimens that avoid considerable loss of function caused by contractures and hypertrophic scarring. Therefore, adherence to burn therapy is critical to maximise functional outcomes (Chown, 2006; Magyar-Russell et al., 2006) and lower the incidence of aesthetic and functional disfigurement (Rosser, 2000; Rosser, 1999). Within the burn care context, poor adherence to therapy is often related to restricted movement, physical appearance, pain, discomfort and psychosocial issues that unfortunately lead to undesirable outcomes (Brown, 2001; Johnson, et al., 1994; Macintyre & Baird, 2006; Magyar-Russell, et al., 2006; Manigandan et al., 2005; Manigandan, Gupta, Venugopal, Ninan, & Cherian, 2003). Poor therapist communication has been identified as a key element that compromises clinicians' awareness of the patients' well-being that impacts on the willingness to adhere to burn

therapy (Stewart, et al., 2000). The findings of this study demonstrate that adherence to therapy is a challenging experience that requires motivation, cooperation, social support and the delivery of appropriate knowledge and understanding. In fact, goal setting enhances adherence to therapy by enriching self-efficacy and motivation (Evans & Hardy, 2002). These findings are echoed in other studies that focused on adherence to burn therapy (Johnson, et al., 1994; Macintyre & Baird, 2006; Ripper, et al., 2009; Stewart, et al., 2000). In particular, Brown (2001) reported that the key to adherence was the notion of patient involvement and cooperation.

As found in the current study, appropriate and timely patient education has been reported to be an effective avenue for the improvement of patient participation and adherence (Lo, Hayter, Hsu, Lin, & Lin, 2010; Ripper, et al., 2009; Rosser, 2000; So et al., 2003). Knowledge regarding the benefits of adherence to burn therapy is a defining factor that positively influences adherent behaviours (Rosser, 2000). In particular, education from physiotherapists is reported to influence patients' attitudes (Rosser, 2000). However, a Taiwanese study of pressure garment compliance placed an emphasis on patient education to encourage adherent behaviours, clearly in the hands of the nurses (Lo, et al., 2010). Despite that all burn clinicians are charged with the responsibility of providing patient education, this has traditionally been the role of physiotherapists and occupational therapists (Parry, et al., 2011). In fact, Rosser (2000) found that less than one per cent of nurses were reported by patients as a source of information concerning burn therapy as opposed to 70% of patients claiming the physiotherapist to be the primary source of education relating to adherence to pressure garment therapy. Ripper's (2009) findings are similar whereby 48% of education was received was from the occupational therapist. Despite this, 57% of participants in Ripper's (2009) study felt inadequately informed regarding the intended purpose of pressure garment therapy which is also evident in this current study. This may be as a result of the anxiety levels experience by burn survivors in the acute phase of their rehabilitation which may inhibit the processing of education received (Ripper, et al., 2009). The findings in this study suggest that patients are bombarded with information in the acute phase of rehabilitation that may impact on patients' understanding and adherence to burn therapy. In recent years, it has been reported that a multifaceted educational approach to burn care that addresses the issue of adherence is a viable intervention (Lo, et al., 2010; So, et al., 2003) that focuses on critical aspects such as psych-education and strengthening available resources (Ripper, et al., 2009). Such programs that incorporate virtual reality (Fung et al., 2010; Haik

et al., 2006; Yohannan, Kwon, & Yurt, 2012; Yohannan, Tufaro, et al., 2012) verbal, written and audio visual material concerning burn education, further improve adherence rates (So, et al., 2003).

This current study clearly demonstrates that social support is a critical element in the rehabilitation of patients with severe burns. A lack of social support was identified by Ripper, et al. (2009) as a rationale for non-adherence to pressure garment therapy. Additionally, Stewart, et al. (2000) found that more than one third of the burn survivors in their study reported a lack of social support in wearing their pressure garments. Positive social support is highly effective in encouraging adherent behaviours with those who are adherent being more likely to report family support (Stewart, et al., 2000). In particular, this study demonstrates that burn survivor peer support is regarded as an important source of support that assists with adherence to burn therapy which is also echoed by others in the field of burn rehabilitation (Badger & Royse, 2010b; Ripper, et al., 2009).

Depression has been known to be a strong predictor of poor compliance (DiMatteo, Lepper, & Croghan, 2000) with the risk of non-adherence being 27% higher in those diagnosed with a clinical depression (Martin, et al., 2005). Magyar-Russell, et al. (2006) found that specifically depression plays a critical role in adherence to burn rehabilitation. This may be partly explained by patients' experiences of negativity, cognitive impairments and withdrawal from social support which all contribute to the reduction of motivation and the ability to cooperate with therapy (Martin, et al., 2005). However, accurately assessing symptoms of depression can be challenging in patients with burns due to the overlay between somatic symptoms of depression and the physical strain of the burn injury and its management (Thombs, 2007) that makes differentiation between the manifestations characteristically associated with depression as fatigue, feeling punished, dissatisfaction and loss of interest difficult to discern (Cavanaugh, Clark, & Gibbons, 1983).

Continuity of burn care

Experiences of a smooth and coordinated progression of care are fundamental in the patients' perceptions of care. Burn rehabilitation is a multidisciplinary challenge that commences at the time of the injury and continues for many months and even years after discharge (Klein, et al., 2007) . Therefore, to ensure consistency and continuity of care, multidisciplinary burn clinicians need to be collaborative in their approach to burn rehabilitation (Farrell, et al., 2006). The findings in this study demonstrate a lack of continuity of specialised burn care

evident across the rehabilitation sites and during key transition points in participants' rehabilitation. However, little has been reported on patients' perception of consistency and continuity of care in the field of burns. Dahl, et al. (2012) who explored patients' reflections on care after a burn injury, suggest that a lack of support and information were evident concerning patients' burn care. Dahl, et al. (2012) add that the nurses who plan the care were often not the nurses who carry out the care creating a lack of continuity, confusion and misinformation. Furthermore, the importance of patients' perceptions and experiences of continuity of care have been demonstrated in another study of chronic disease (diabetes) (Naithani, Gulliford, & Morgan, 2006).

It has been reported that a lack of consistently coordinated rehabilitation and follow-up of burn patients often leads to critical variations in outcomes (Dimick, et al., 2005). Aspects that may impact on these issues include inadequate personnel, inexperienced burn therapists and clinicians with limited years of clinical practice that interferes with staff continuity (Richard, et al., 2009). In particular, the geographical location of the rehabilitation facilities create challenges for patients' continuity of care that effect the timing of transfer to a rehabilitation facility (DeSanti, et al., 1998). With current burn practices, patients are often ready to transition to the rehabilitation setting prior to meeting the limited wound care abilities of the receiving rehabilitation facility (DeSanti, et al., 1998; Nguyen, Gilpin, Meyer, & Herndon, 1996). Additionally, the high metabolic needs of those with severe burns, are often not realised by rehabilitation facilities (DeSanti, et al., 1998). Subsequently, caring for those with severe burns is not commonplace in the rehabilitation arena. As such, creates many challenges for clinicians within those facilities (Hall, 2005; Schneider, et al., 2012) with limited skills in the area of wound care and metabolic support (DeSanti, et al., 1998). This ultimately delays the early transfer to the rehabilitation facility. Consequently, it is essential that burn rehabilitation be regarded as a continuum of care. However, there remains a lack of personnel and commitment directed towards burn survivors (Richard, et al., 2008).

Key to the continuity of care is the competency of burn clinicians. Nationally agreed standards for competence are required to define safe and competent burn rehabilitation practices (Parry, et al., 2011). A recent survey of physiotherapist and occupational therapist that had previously treated burn survivors were asked to complete a pre-workshop confidence survey which indicated that more than 75% of therapists were not confident in providing burn rehabilitation (Bergkamp et al., 2012). However, the post-workshop saw a significant improvement in all burn rehabilitation interventions (Bergkamp, et al., 2012). Despite

baseline confidence levels in therapists treating burn survivors being low, hands on burn education improved the confidence of therapists who treat burn survivors (Bergkamp, et al., 2012). In order to provide patients with the stability and continuity of care, it has been recommended that all new burn rehabilitation therapists undergo assessment of competence (Parry, et al., 2011). Furthermore, experienced burn rehabilitation therapists require reassessment of competence to be conducted biennially in order to reflect the scope and progression of current burn rehabilitation practices (Parry, et al., 2011). For clinicians working in rehabilitation who occasionally come into contact with severe burn injury patients and have very little experience and knowledge in burn care, the development of competencies may provide the necessary guidance to provide a consistent and competent background on burn rehabilitation competency tools (Parry, et al., 2011). Improved continuity of care may also contribute to improved efficiency and to lower care expenses (Naithani, et al., 2006). Additionally, the use of case management is a fundamental process which facilitates the consistency and continuity of care with the necessity to commence rehabilitation at the time of admission. The introduction of trauma case management, can reduce the length of stay and morbidity rates (Curtis, 2004). Permitting burn clinicians, in particular nurses, to follow inpatients to the outpatient setting, allows for continuity of care (Yurko et al., 2001). Within the Australian context, geographical problems could exist surrounding the matching of specialist care to where the patient lives due to the vast distances and remote areas. However, Western Australia's assertive use of telemedicine facilities brings the experts to the patient in remote areas and improves the quality of access to specialist care (Tait & Clay, 1999). In particular, since 2005, the Princess Margaret Hospital Telehealth Service has provided services for acute and long term assessment and management of paediatric burn patients living in rural and remote areas of Western Australia in collaboration with rural and remote multidisciplinary clinicians (McWilliams, Gilroy, & Wood, 2007). Furthermore, the use of telemedicine in burn care has been reported to support rural communities at low cost (Saffle, Edelman, Theurer, Morris, & Cochran, 2009).

Roads to recovery

The findings of this study demonstrate how those burdened with a severe burn experience a long and arduous road to recovery that is charged with frustration, setbacks, everyday challenges and hurdles that are associated with the complexity of a severe burn. Adjustment to life after a severe burn injury is a tedious and slow process that often results in high levels of stress and anxiety (Hulbert-Williams, et al., 2008) with psychopathology, depression and

personality influencing the outcome in adjustment to a burn injury (McLean et al., 2013, in press). Consequently, dependent on the extent of the injury and rehabilitation, patients with severe burns may be hospitalised for extended periods of time before discharge is a realistic option (Goggins, Hall, Nack, & Stuart, 1990). This is clearly demonstrated with the average length of stay of the participants in this study recorded as 185 days. Additionally, with the length of stay continuing to be a standard variable when evaluating the progress and rehabilitation outcomes in the management of those with severe burns (Johnson et al., 2011), the need to focus on the rehabilitation of burn survivors is tantamount especially when burn patients utilise significant financial resources and the length of stay has a significant impact on cost (Jansen, Hynes, Macadam, & Papp, 2012; Pereira, et al., 2004). Acton, et al. (2007) clearly point out the reality of a decreasing length of stay and limited human resources claiming that it is just the beginning of the long road to recovery with much of the rehabilitation now happening within the community setting and long after burn clinicians' contact with patients and families has been lost.

It is well documented that burn survivors experience the trauma of the injury long after discharge (Dahl, et al., 2012; Fauerbach, Lawrence, Munster, Palombo, & Richter, 1999; Fauerbach et al., 2005; Lawrence & Fauerbach, 2003; Willebrand, Wikehult, & Ekselius, 2005) with some survivors experiencing the physical and psychological aspects years after the initial injury. Common long-term physical and psychological problems experienced after a burn are varied with the most prominent issues involving pain (Browne, Andrews, Schug, & Wood, 2011; Byers, Bridges, Kijek, & LaBorde, 2001; Corry, Klick, & Fauerbach, 2010; Morris, Louw, & Grimmer-Somers, 2009; Patterson, Tininenko, & Ptacek, 2006; Tengvall, Wengstrom, & Wickman, 2009), post-traumatic stress disorder (PTSD) (Ehde, Patterson, Wiechman, & Wilson, 2000; Fauerbach, et al., 1999; Lawrence & Fauerbach, 2003; Park, et al., 2008), depression (Ptacek, Patterson, & Heimbach, 2002), altered body image (Birdsall & Weinberg, 2001; Fauerbach, et al., 2002; Lawrence, Fauerbach, Heinberg, & Doctor, 2004; Redstone, Shepherd, Bousfield, & Brooks, 2011; Willebrand, Andersson, & Ekselius, 2004) and loss of function related to contractures and scarring (McOwan, MacDermid, & Wilton, 2001; Purdue, Arnoldo, & Hunt, 2011; Shakirov, 2010). These findings are consistent with the findings of this study with pain, loss, despair and difficulties with accepting an altered body image reflected in the participants' experiences.

After discharge, the burn injury continues to create significant limitations that extend well beyond the physical trauma that incorporates emotional, psychosocial (Dahl, et al., 2012) and

financial implications. Furthermore, despite the advances in burn care in the last five years alone, survivors continue to experience functional and psychological impairments that realistically can never be resolved. These issues have become particularly prevalent and of equal importance, as the number of survivors with severe burns steadily increases (Pereira, et al., 2004). In fact, Fauerbach, et al.'s (2005) study that investigated burn size and physical and psychosocial functioning, found that there is a strong relationship between survivors' experiences and perception of their burn and long-term adaptation and their quality of life. Physical functioning was reported to be significantly impaired and the rate of recovery slower among burn survivors with either extensive physical or psychological encumbrances (Fauerbach, et al., 2005). Charged with these bleak facts, it is clear that it is no longer adequate for burn clinicians to be content with an increased survival rate. It is now time that the burn community facilitates through further resources and research, the psychosocial implications of burn rehabilitation. In particular, patients' perspectives and experiences need to be one of the fundamental aspects behind the rehabilitation of those with severe burns.

Acceptance

Humour within tragedy

Reported as an adaptive coping strategy (Samson & Gross, 2012), humour is a natural part of everyday living that is influenced by life experiences (Olsson, Backe, Sorensen, & Kock, 2002). Humour is considered an integral part of an individual's perception of their health, that is believed to be an untapped resource (Astedt-Kurki, Isola, Tammentie, & Kervinen, 2001). Despite this, humour within the healthcare setting has been dismissed as inconsequential and not deserving of scholarly inquiry (Dean & Major, 2008). However, the findings of this study suggest that humour plays a role in the recovery from a traumatic injury. Consequently, there is considerable evidence to suggest that humour facilitates coping, communication, fostering of relationships, the reduction of stress (Astedt-Kurki, et al., 2001; Dean & Major, 2008; Yoels & Clair, 1995) and the up regulation of positive and down-regulation of negative emotions (Samson & Gross, 2012). Additionally, a good sense of humour plays a key role in interpersonal communication that lays the foundations for good relations (Olsson, et al., 2002) that is evident in these findings. Humour assists in reframing traumatic situations through the development of a sense of perspective (Dean & Major, 2008) that contributes to a person's personal growth and development (Astedt-Kurki, et al., 2001). One of the most

challenging adjustments to make after a severe burn, is how to accept help from others in which Edwards (2001) articulates that humour does play a critical role in burn rehabilitation.

The findings of this current study showed that the staff's sense of humour made the rehabilitation journey easier to discuss and accept, concurring with Astedt-Kurki, et al. (2001) results suggesting that staff with a sense of humour allowed for the easier discussion of difficult matters and motivation in patients. As a coping mechanism, humour is used to divert attention away from the visible disabilities (Egan, Harcourt, Rumsey, & Collaboration, 2011; Thompson & Broom, 2009). Humour assists patients to confront and accept difficult circumstances providing the necessary strategies for survival (Astedt-Kurki, et al., 2001). Smith and Kleinman (1989) found that the use of humour was deemed an acceptable manner in which to acknowledge a problem. In particular, humour allows the necessary motivation for rehabilitation that strengthened patients' confidence (Astedt-Kurki, et al., 2001). Furthermore, those who display a high level of resilience, draw from positive emotions to bounce back from traumatic experiences (Egan, et al., 2011; Tugade & Fredrickson, 2004). Although humour has been examined in earlier research, burn survivors' experiences of the use of humour contribute a rich insight and description to existing meanings.

Coping with a severe burn

Adjustment after a severe burn injury is a traumatic process with burn survivors confronted with many physical and psychological challenges. Therefore it is not surprising that those who sustain a severe burn experience difficulties with coping, adapting and accepting an altered body image. However, it has been reported that avoidance and wishful thinking are strategies used to cope with the trauma associated with burns (Patterson, et al., 2006; Tengvall, et al., 2009). Tedstone, Tarrier, and Faragher (1998) found that coping strategies of burn injured patients based on high levels of emotion and poor acceptance was correlated with PTSD. Moreover, Willebrand, Andersson, Kildal, and Ekselius (2002) quantitative study that explored coping patterns in burned adults, identified that those who used avoidance displayed a low health status and were reported to display neurotic and aggressive behaviours while those who adapted displayed optimism and problem solving with favourable outcomes. In fact, Kildal, Willebrand, Andersson, Gerdin, and Ekselius (2005) suggest that the use of avoidance and minimal emotional support are related to poor outcomes. However, the literature to date although limited, suggests that antecedent mental illness and avoidant coping strategies are a predictor of poor outcomes (McLean, et al., 2013, in press). Conversely, positive coping strategies have been related to personality traits as extraversion,

optimism, self-discipline and hope (Gilboa, 2001; Tengvall, et al., 2009; Willebrand, et al., 2002). Therefore, it appears that the response to a severe burn injury is more dependent upon the individual's coping mechanisms and psychosocial adjustment than on medical or demographics as previously believed (Titscher, Lumenta, Kamolz, Mittlboeck, & Frey, 2010). Within this study, some participants expressed that there was no choice but to cope for there were no alternatives and therefore displayed resilient traits. These are critical elements that enable burn survivors to reintegrate and access both social and emotional support from their environment (Gilboa, 2001).

A traumatic injury like a severe burn is known to challenge and potentially change coping strategies (McLean, et al., 2013, in press). Coping strategies used in the short term have been found to differ from strategies used in the long-term (Dahl, et al., 2012) with Kildal, et al. (2005) suggesting that coping strategies used by individuals are actually related to perceived health status a long time after the initial burn injury. Dahl, et al. (2012) in their study of patients' experiences of adaption after a burn injury, interestingly found that those with a small burn of less than five per cent and a shorter hospital stay experienced traumatic memories that were evident long after discharge. Therefore it is fair to say that any burn patient requiring hospitalisation even with a relatively minor injury is at risk of maladaptation. What is of prime importance is the access to social support and maintaining a positive outlook that contributes to adaption and adjustment throughout the rehabilitation journey (Wu, et al., 2009). In terms of adjustment to the effects of a severe burn, one would predict that a secure state of mind might optimise overall coping in the context of the trauma of a burn, by means of encouraging a more direct coping strategy that does not foster avoidance and promotes social support, acceptance and the ultimate resolution of the trauma or loss experienced (McLean, et al., 2013, in press). The Attachment theory describes:

“...the way that human beings develop in relationship and that their early experiences of safety, comfort and loving care (or their absence) lead to the formation of templates or schema that predict the usefulness or harmfulness of care from others, one's own capacity to cope and the strategies required to optimise safety and “organise” one's response”(McLean, et al., 2013, in press, p. 3).

This impacts on help-seeking strategies and a sense of personal competency during the stress response throughout one's life (McLean, et al., 2013, in press). Attachment theory would suggest that those with a secure attachment state of mind will more freely ask for and use help of all kinds and more easily grieve and accept losses and traumas (McLean, et al., 2013, in press).

Suffering and trauma often require change and invite reflection (McLean, et al., 2013, in press) and therefore rationalisation was a means used by participants in this study to facilitate the acceptance of the burn injury and sequelae. Comparing themselves with others who they perceived were in worse circumstances offered participants ways to reframe their experience. This form of coping is also evident collectively in the experiences of being with other burn survivors that offers a form of comfort and compensation which can assist with coping and acceptance (Costa, et al., 2008; Dahl, et al., 2012; Moi & Gjengedal, 2008; Na, 2008; Rossi, et al., 2009; Williams, et al., 2003).

Accepting an altered body image

Living with an altered body image can be a challenging notion in a society where a high premium is placed on physical appearance and neglects and judges the disfigured (Gilboa, 2001). Ultimately, scarring and an altered physical appearance becomes significant during the rehabilitation phase for burn survivors (Martin, Umraw, Gomez, & Cartotto, 2003). Therefore adjusting to a sudden and traumatic change in appearance is a prime challenge for burn survivors (Lawrence, et al., 2004). Undesirable aspects of a burn such as scarring, disfigurement and loss of function may result in continual and subjective body image disturbances (Bernstein, 1990). Rumsey and Harcourt (2004) state that negative self-perception and difficulties with social interaction are frequently experienced by those with disfiguring injuries. Within the domain of burn injury, Fauerbach et al. (2000) highlight that dissatisfaction with body image is related to prolonged difficulties with psychological and physical health related quality of life. The findings of this study reveal that those who endured the trauma of a severe burn were reminded of their injuries every time they look at themselves, which made acceptance and coming to terms with the burn challenging. Participants in this study expressed that acceptance is a gradual process that encompasses acceptance of the physical changes requiring a flexible and dynamic approach. Moi and Gjengedal's (2008) qualitative study of life after a burn injury concurs with this finding concluding that in order to continue living meant that burn survivors need to accept the unchangeable and change what is changeable through the beliefs in their goals and the necessary motivation and determination. However, a visual disfigurement can have a major psychological impact on burn survivors (Rumsey & Harcourt, 2004). Thombs et al. (2008) study of body image after a severe burn, report that burn survivors go through a period in which their perception of body image worsens over a time period due to a personal struggle to accept physical changes that are out of their control. This necessitates the development of

social skills necessary to cope with the reactions of others. Therefore having the ability to adjust to an altered appearance is a key factor in adaption after a severe burn.

The impact of a facial burn is considered far greater, as the face is the principal means of communicating in all face-to-face interactions (Lawrence, et al., 2004). There is however only a small body of literature that investigates the psychological challenges of facial disfigurement related to burn injuries (Rogers, McLean, Streimer, Vandervord, & Kwiet, 2011). Burn survivors have a unique perception about their physical appearance with their self-perception threatened or distorted (Birdsall & Weinberg, 2001). For the participants of this current study, 10 participants sustained a significant facial burn resulting in facial disfigurement. They endured frequent staring, audible comments about their physical appearance and unsolicited questions from the public about their injury as well as behaviours of avoidance and stigmatisation from others. These reactions are also evident in other studies (Birdsall & Weinberg, 2001; Lawrence, Fauerbach, Heinberg, Doctor, & Thombs, 2006; Rumsey & Harcourt, 2004; Thombs, et al., 2008). Furthermore, it has been reported that visible burn scars are associated with poor social adjustment in adults (Browne et al., 1985). For patients looking in the mirror or at their injuries for the first time can be a confronting experience that is ameliorated with social support as demonstrated in this and other studies (Egan, et al., 2011; Redstone, et al., 2011). Participants in Moi, et al.'s (2008) study also report postponing looking at their burns and when they did, found it difficult. Moi, et al. (2008) claim that in their study participants accepted that their bodies would never be the same, however months later the participants' mirror image could elicit a feeling of surprise that indicates that their appearance does not sit well with their inner perception. Interestingly, three quarters of participants from Redstone, et al.'s (2011) study reported that it was the patients who initiated the decision to view their injuries in the mirror for the first time. However, accidental visualisation during dressing changes or through reflections in objects such as windows or mental surfaces is inevitable and requires the appropriate support to cope with an altered body image. As reported in this study, photographs taken by the hospital during different stages of burn survivors' rehabilitation was therapeutic for one participant in particular. Conversely, others identified in Moi, et al.'s (2008) study found that participants looking at their initial pictures showing a swollen body was difficult to view. Perhaps placing less importance on appearance and altering prior values and beliefs, can facilitate adaption and acceptance of an altered body image (Dropkin, 1989). In fact, Egan, et al. (2011) found in their qualitative study of experiences of people who identified themselves as having

adjusted positively to a visible difference, that participants placed little significance on their appearance and greater value on other personal qualities and characteristics.

The impact and ongoing trauma experienced

Pain

Pain remains a significant and challenging aspect in the management of severe burns (Esfahlan, Lotfi, Zamanzadeh, & Babapuor, 2010; Tengvall, et al., 2009; Yuxiang et al., 2012). From the time of the burn occurring and throughout rehabilitation, burn pain invades all aspects of care. Despite the use of analgesia, sedation and distraction techniques as virtual reality (Morris, et al., 2009) hypnosis (Gilboa, Borenstein, Seidman, & Tsur, 1990) and music (Prensner, Yowler, Smith, Steele, & Fratianne, 2001; Protacio, 2010), burn pain continues to be undertreated (Carrougner et al., 2003; Carrougner et al., 2006; Choiniere, Melzack, Girard, Rondeau, & Paquin, 1990; Yuxiang, et al., 2012) with patients experiencing significant amounts of pain during burn care procedures. Additionally, those experiencing post-traumatic stress have been associated with higher pain scores during dressing changes and burn therapy (Corry, et al., 2010; Taal & Faber, 1998; Taal & Faber, 1997). Consequently, acute and prolonged experiences of pain are a significant characteristic of those rehabilitating from a severe burn injury that impacts on the quality of life (Gonçalves, et al., 2011). Browne, et al. (2011) suggest that those with severe burns repeatedly exposed to painful procedures for prolonged periods, are at risk of developing chronic pain due to multiple episodes of acute pain.

For the participants in this study, pain is a stark reality that permeated through all aspects of their rehabilitation journey and beyond. These findings are echoed by Williams, et al. (2003), Tengvall, et al. (2009), Yuxiang, et al. (2012) and Dahl, et al. (2012) who established through qualitative analysis of burns survivors' experiences, that extreme pain was a reality in the burn survivors' experience. It is well established that patients with severe burns describe their dressing changes as the most painful experience endured during their rehabilitation. As evident with the participants in this study, much of the apprehension and anxiety is related to pain experienced from dressing changes and ongoing therapy creating feelings of depression and fear. This is in concordance with Ashburn (1995) and Geisser, Bingham, and Robinson (1995) who report that burn survivors experience high anxiety associated with burn care procedures. Ulmer (1997) who investigated pain, coping and depressed mood in burn injured patients establishing that a depressed mood was significantly correlated with pain intensity.

Furthermore, exposure to chronic pain is linked to developing depression, anxiety and suicidal thoughts (Edwards et al., 2007; Yuxiang, et al., 2012) as demonstrated by some participants in this current study. In fact, Yuxiang, et al. (2012) in their qualitative study on burns patients' experiences of pain management, state that all participants in their study described the pain as a result of burn care as psychologically taxing and physically, the worst pain imaginable. Na (2008) aptly highlights that these issues have a tendency to take second place or may even be neglected by burn clinicians that results from the primary objective of preserving life.

Severe pain is correlated with poor physical functioning that affects functioning many years after the initial injury (Corry, et al., 2009; Dauber, Osgood, Breslau, Vernon, & Carr, 2002) with reports that burn pain is underestimated and often ignored by health professionals (Morris, et al., 2009; Patterson, et al., 2006). Choiniere, Melzack, Girard, Rondeau, and Paquin's (1990) comparison between patients' and nurses' assessment of pain and medication efficacy in severe burn injuries, found that nurses frequently either overestimated or underestimated patients' pain as well as displaying a tendency to overestimate the degree of pain relief. Consequently, poor management of burn pain can facilitate increased discomfort, dissatisfaction, a prolonged hospitalisation coupled with delayed wound healing (Heiser, Chiles, Fudge, & Gray, 1997), poor adherence to burn care and therapy, an increased incidence of chronic pain (Yuxiang, et al., 2012) and has a significant impact on patients' adjustment (Patterson, et al., 2006). This is concerning as the long-term pain experienced by those with severe burns has been identified as up to seven years after the initial injury (Choinière, Melzack, & Papillon, 1991; Malenfant et al., 1996) with others reporting pain 12 years after sustaining a severe burn (Dauber, et al., 2002). In fact Dauber, et al. (2002), found that 66% of their participants reported that pain interfered with their burn rehabilitation, and 55% reported that pain interfered with their daily lives. The participants in this current study were interviewed up to eight years after their burn injuries and still continued to experience pain on a daily basis that affected their activities of daily living. Tengvall, et al. (2009) note that over the last decade, the average length of stay has decreased from 13 to eight days; this has implications for the outpatient setting in relation to the management of patients' pain.

Experiences of despair, loss and trauma

A traumatic injury such as a burn injury has a significant impact with severe pain and long-term physical and psychological problems. Such an injury can render a person significantly disfigured and disabled therefore unable to return to their former lifestyle despite the

rehabilitation process. The findings in this study suggest that participants with severe burns experience and for some continue to experience physical and emotional losses that result in feelings of hopelessness, despair and depression. Both Nolte (2007) and Maher (2009) provide clear insights into how they experienced their rehabilitation journey in which the feelings of depression, despair and loss, are fundamental themes in their biographies. Participants in this current study as with other studies, express that their loss encompassed both physical and emotional entities such as their independence, dignity, hope, physical functioning, income and productivity and sadly, family and friends. Abrams (2012), Williams, et al. (2003) and Na (2008), reiterate that loss was a fundamental concept experienced by the participants in their research. In fact, Williams, et al. (2003) state that losses are a significant part of post burn reality that manifest as both physical and intangible forms.

As a result of the trauma experienced from the burn injury itself and sequelae, survivors often experience flashbacks, sleeplessness and trauma related to burn care (Low et al., 2003). There have been many studies that investigate the phenomenon of PTSD in patients with severe burns (Lawrence & Fauerbach, 2003; Mason et al., 2012; Quinn, Wasiak, & Cleland, 2010; Schneider, et al., 2009; Schneider, Bassi, & Ryan, 2011). Although not within the scope of this study, Corry, et al. (2010) indicate that those who suffer from PTSD have decreased physical and social functioning. Furthermore, it has been reported that the presence of PTSD soon after discharge is related to poorer physical, social functioning and psychosocial disability (Corry, et al., 2009). Depression and anxiety are experienced among those who sustain severe burn injuries (Patterson, Ptacek, Cromes, Fauerbach, & Engrav, 2000; Ptacek, et al., 2002; Tedstone, et al., 1998; Tengvall, et al., 2009; Willebrand, et al., 2004). In fact, Browne, et al. (2011) found that participants in their study experienced significant depressive and post-traumatic stress symptoms up to 11 years after sustaining a severe burn injury highlighting that experiencing depression influences the physical and psychological functioning of the burn survivors. This is echoed by Williams, et al. (2003) who affirm that depression was universal in all participants in their study. Additionally, Bras, Loncar, Brajkovic, Gregurek, and Mickovic (2007) found in their study of burn survivors early in their admission, that there was a statistically significant relationship between levels of depression and anxiety and levels of hopelessness and depression. However, Ptacek, et al. (2002) indicate that few burn survivors in their study rated their depression as severe with depression scores decreasing significantly from admission to discharge. One explanation for

this is related to decreasing painful intervention as the patients' progress through their rehabilitation. The intensity of burn pain varies over the rehabilitation journey therefore the estimation and treatment of patients' pain remains difficult (Summer, Puntillo, Miaskowski, Green, & Levine, 2007). There is evidence to suggest that the coping responses of individuals to stressors plays an important role in adjustment (Billings & Moos, 1981) as depression can escalate as a result of increasing adjustment. Although it must be dually noted, that the patients' pre-injury health status would have a significant impact on the psychosocial well-being as it is well documented that the pre-injury psychiatric history has a bearing on their rehabilitation (Fauerbach, Lawrence, Haythornthwaite, McGuire, & Munster, 1996; Patterson et al., 2003; Tarrier, Gregg, Edwards, & Dunn, 2005; Tedstone, et al., 1998). The strong impact of mental health on rehabilitation speaks to the need for close psychological and psychiatric care and liaison in the rehabilitation journey.

Maintaining inner strength and resilience

Significance and influences of goal setting

The notion of developing patient-centred goals assisted the participants of this study with the tenacity and motivation necessary to endure the long road of burn rehabilitation. In particular, these findings highlight the importance and significance of goal setting during the rehabilitation journey. Goal setting has been identified as a key element in the rehabilitation process that engages patients to actively participate in their rehabilitation (Holliday, Antoun, & Playford, 2005; Holliday, Ballinger, & Playford, 2007; Wade, 2009) and has been reported as a fundamental component of a contemporary rehabilitation program (Siegert & Taylor, 2004). Goal setting assists in reducing anxiety and increases insight and acceptance of the rehabilitation process (Holliday, et al., 2007; Playford, Siegert, Levack, & Freeman, 2009; Young, Manmathan, & Ward, 2008). In recent years, there has been a shift in how goals are formulated in the rehabilitation environment (Holliday, et al., 2005). Guidelines advocate goal setting as a collaborative effort between the patient and therapist (Turner-Stokes, Williams, Abraham, & Duckett, 2000). However, the research concerning teaching patients the usefulness and benefits of goal setting is sparse (Holliday, et al., 2007). Furthermore, the literature concerning goal setting in burn rehabilitation to the researcher's knowledge is very limited with even less known about the patients' perception of goal setting in the area of burn rehabilitation. This has resulted in non-uniform methods of goal setting that vary across

rehabilitation settings and often reflect the therapists' and not the patients' needs (Holliday, et al., 2005).

Significant to the findings in this current study is the notion of mutual collaboration between the multidisciplinary team and the patient. This is seen as instrumental in participants realising and owning their rehabilitation. Holliday, et al.'s (2007) study reinforces this notion stating that burn survivors involved with the development of their own goals enables them to feel a sense of ownership. Fundamentally, interactions with therapists is pivotal to understanding the broad sense of rehabilitation (Holliday, et al., 2007). Goal setting meetings are a motivational experience for both staff and patients valuing the collaborative environment of working together towards a common goal (Young, et al., 2008). Participation in regular meetings for goal setting assisted participants in Young, et al.'s (2008) study to appreciate that rehabilitation is a step by step journey. Case conferences are a time to consolidate progress and for patients to express their concerns in a supportive environment. Young, et al. (2008) suggest that goal setting meetings are a useful coping strategy to express their emotions and to compartmentalise problems experienced. In fact, Klinge, Chamberlain, Redden, and King (2009) state that goal setting could equip patients with the necessary tools to cope with the trauma of a burn injury. Furthermore, goal setting has given cause for patients to reappraise strategies utilised to manage their day to day lives (Holliday, et al., 2007).

As Wade (2009) highlights, linking goals so patients can perceive the relationship between short term and long term goals is of importance. This is reflected in this current study with the development of a central long term goal deemed imperative to assist with remaining focused throughout the rehabilitation journey. However, the notion of shifting goal posts and remaining flexible in relation to goal setting is a key element in the rehabilitation journey. The achievement and recognition of small goals increases patients' confidence and reinforces the notion of progress providing appropriate direction and timing. The development of realistic achievable goals within an appropriate timeframes is necessary to foster realistic outcomes and expectations (Young, et al., 2008). Further to this, it is critical that goals developed are not only realistic but reflect the patient's natural environment. Too often there is limited relevance to patients' everyday life with difficulties encountered when transitioning through the rehabilitation process (Holliday, et al., 2007). This notion is also expressed by Siegert and Taylor (2004) stating that when a patient is discharged back into the community

setting, goals are likely to be broader with a greater emphasis on social functioning and reintegration.

Resiliency in the severely burned

The identification of resilient behaviours has emerged through the phenomenological identification of characteristics of survivors of trauma (Richardson, 2002). Resilience has been defined as the capacity of an individual to positively adjust and adapt to adversity (Jackson, Firtko, & Edenborough, 2007) reflecting the ability to maintain a stable equilibrium (Bonanno, 2004). In essence, it is the ability for flexible and resourceful adaptation to external and internal stressors (Klohen, 1996). Developmentally as opposed to behaviourally, Benard (2004) states that “resilience strengths are critical survival skills, intrinsically motivated or biologically driven, and culturally expressed” (p. 39). Furthermore, a resilience viewpoint recognises the dynamic and adaptational qualities of resilient strengths, acknowledging that these characteristics are not fixed (Benard, 2004). Interestingly, both Fredrickson, Tugade, Waugh, and Larkin (2003) and Campbell-Sills, Cohan, and Stein (2006) clearly refer to resilience as a personality trait. However, Walsh (2003) claims that people are not born resilient; instead resilience is acquired through exposure to adversity. Therefore this implies that resilience develops over a period of time, indicating that it is a process and not a personal trait (Cameron & Brownie, 2010; Gillespie, Chaboyer, & Wallis, 2007). Resilience can be perceived to be an adaptive state (Luthar & Cicchetti, 2000) that can be nurtured and developed throughout one’s life. In fact, Gillespie, et al. (2007) state that the growth of resilience is influenced by the individuals’ environment and experiences. Furthermore, attachment theory suggests that the templates for organising cognitive, emotional and behavioural responses and meaning-making can rest out of conscious control, but have been formed as a result of how past lived experience is appraised (McLean, et al., 2013, in press). The previous acquisition of a secure state of mind helps adjustment to adversity and additively trauma can offer an opportunity for others who have not been previously secure to gain support to move towards reappraisal and resolution of past experience (McLean, et al., 2013, in press).

Resiliency after a traumatic injury has received attention in the healthcare literature (Bonanno, 2004; Bonanno, Kennedy, Galatzer-Levy, Lude, & Elfstrom, 2012; Norris, Tracy, & Galea, 2009). Most papers reviewed concerning resilience; focus on other areas of trauma. Additionally, few studies focus on the resilience of adult burn survivors with much of the literature tending to represent the paediatric and adolescent population (Holaday &

McPhearson, 1997; Holaday & Terrell, 1994; Lau & van Niekerk, 2011). Despite this, resilience plays a key role in why people are able to survive both physically and emotionally against devastating adversity (Holaday & McPhearson, 1997). Studies which focus on adult resilience demonstrate a paradigm shift. They acknowledge the experience of adversity that does not equate to poor adaptation; however, may be representative of adaptive resilience (Abrams, 2012). Importantly, resilience is necessary throughout the acute burn phase which enables survivors to endure the rehabilitation journey (Abrams, 2012) providing an increase in self-efficacy that allows for more control and less reliance on medications and external support (Richardson, 2002). Although, Wallis, et al. (2006) and Lee and Swenson (2005) argue that resources such as social support can instil remarkable resilience on the patients' behalf, when faced with an injury such as a severe burn that results in substantial psychological and physical trauma clearly evident in this current study.

Importantly, Wallis, et al. (2006) point out that studies have focused on the psychological problems and distress among burn patients, but it is the resourcefulness and strengths of these patients that have unfortunately received much less attention as it is these factors that can assist burn survivors to face the challenges of a burn injury and its sequelae. This is aptly identified by Abrams (2012), who states that the literature stops short of addressing any long-term interventions to promote resilience in burn survivors. The participants in this current study demonstrated a positive attitude, determination and enduring motivation that have been identified as key attributes in resilient individuals (Askay & Magyar-Russell, 2009). Furthermore, these findings and others (Abrams, 2012; Holaday & McPhearson, 1997; Portman, 1989) suggest that these characteristics and qualities are pivotal to coping and accepting the traumatic nature of a burn injury. Egan, et al. (2011) who explored patients' experiences of adjustment with a visible injury, found that patients felt that they had changed in numerous positive ways as a result of living with a visible injury which included becoming more resourceful and resilient. Resilient behaviours enable burn survivors to adapt to the environment that is critical for successful long term adjustment (Gilboa, 2001). In fact, Willebrand, et al. (2002) state that adaptive people identified in their study of burn survivors used strategies as emotional support, optimism and problem solving and were also reported to have the highest health status rating. Therefore, understanding the concept of resilience can assist in providing support to burn survivors that encourage positive coping strategies fostering the development of resilient behaviours.

Progression, reintegration and beyond

Transition and reintegration

Transition through the rehabilitation journey has been described by Richard, et al. (2008) as consisting of three components: acute, immediate and long term rehabilitation. The findings in this study suggest that the phases of burn rehabilitation are a challenge both physically and psychologically for burn survivors with reports of difficulties transitioning from the burn unit to the rehabilitation facility and beyond. During the acute phase, patients are commencing to comprehend the extent of their injury and the realisation that their life as they knew it has changed dramatically forever (Blakeney, Rosenberg, Rosenberg, & Faber, 2008) which is typically characterised by uncertainty concerning their survival. Once medically stable, the patients transition to the burns unit where they continue to undergo painful procedures. Consequently, there is now an increased awareness both physically and emotionally of the impact of the injury (Patterson et al., 1993). Furthermore, the rehabilitation and reintegration phase is a demanding and disruptive period. As observed in this study, some participants transitioned back to the burns unit due to complications experienced. Transfer to the acute care setting from the rehabilitation facility is an interruption in a patients' recovery and represents deficiencies in the quality of care for those with severe burns (Schneider, et al., 2012). The primary reasons for the transfer back to the acute care setting are an inappropriate level of care, insufficient resources at the rehabilitation facility, issues with communication and a medically unstable patient (Schneider, et al., 2012). Patients are required to take command of their continuing rehabilitation with a focus on an increasingly autonomous regime with a major objective of reintegration into everyday life comprised of reengaging socially with family, friends and the greater community (Blakeney, et al., 2008). A smooth transition is facilitated by the instigation of an organised community integration program prior to discharge from the inpatient rehabilitation setting (Goggins, et al., 1990). However as this study demonstrates, this is very little in the way of programs that facilitate burn survivors post discharge.

Among the burn literature, there appears to be a belief that those affected by a severe burn experience severe functional and psychological issues. However, it has been reported that compared to the greater population, most people who have sustained a burn injury adapt well (Altier, et al., 2002; Cochran, Edelman, Saffle, & Morris, 2004; Moi, Wentzel-Larsen, Salemark, Wahl, & Hanestad, 2006) and are able to make that transition from burn victim to burn survivor (Abrams, 2012). Results from Altier, et al.'s (2002) study demonstrate that

burn survivors enjoy a quality of life comparable to that of the non-burned healthy population, with only 25% of those sustaining a severe burn experiencing psychological disturbances. However, Pallua, et al. (2003) state that social integration of burn survivors with limited physical functioning is poor, experiencing social isolation and feelings of marginalisation. Although what must be taken into consideration is that there is a diverse reaction that patients exhibit to a burn injury and the psychosocial problems that influence adjustment, making it difficult to predict functional outcomes (Klinge, et al., 2009). Surprisingly, Yohannan, Ronda-Velez, et al.'s (2012) exploration of burn survivors' perception of rehabilitation found that it was the intervention of physiotherapy and occupational therapy that contributed positively to burn survivors reintegration into society. In particular, 80% of Yohannan, Ronda-Velez, et al.'s (2012) participants said that they either 'strongly agreed' or 'agreed' that physiotherapy and occupational therapy prepared them for going home and functioning within the family. Furthermore, 76% of participants in their study felt that physiotherapy and occupational therapy successfully facilitated with reintegration into their community. The perceptions and experiences of burn survivors' rehabilitation journey as portrayed in this current study are significant given the psychological risks associated with severe burn injuries (Sveen, Ekselius, Gerdin, & Willebrand, 2011; Willebrand, et al., 2004; Wilson et al., 2011).

Occupational implications

A fundamental goal of burn rehabilitation is the promotion of participation in the community which includes returning to work (Mason, et al., 2012; Schneider, et al., 2009, 2011). Returning burn survivors back into the work force delivers immense benefits not only for patients, but also their families and the greater community (Mackey, et al., 2009). Therefore returning to work is often utilised as an outcome measure for functional recovery (Schneider, et al., 2009). The capacity to return to work is a critical factor in the quality of life of burns survivors that is representative of the return to a normal life and community reintegration (Rossi, et al., 2009). There are a multitude of factors that influence the ability to return to work for those who have sustained a severe burn (Fauerbach et al., 2001). In particular, the severity of the burn seems to be a significant factor (Dyster-Aas, Kildal, & Willebrand, 2007; Mason, et al., 2012; Moi, Wentzel-Larsen, Salemark, & Hanestad, 2007; Quinn, et al., 2010). However, the pre-injury employment status of burn survivors has been flagged as considerably influential (Fauerbach, et al., 2001; Oster, et al., 2010) although this was refuted by Quinn, et al. (2010). The findings of this current study found that of the 21 participants,

only six returned to their previous employment, 8 participants were unable to return to work and one needed to find alternative employment due to their disabilities. Some participants experienced a loss of income and the inability to return to their prior employment status due to the injury sustained, while others returned to work accepting their limitations. Three participants that were unemployed prior to the injury remained unemployed. This is consistent with Mackey, et al.'s (2009) findings that explored 23 burn survivors' experiences of returning to work after a severe burn of which 12 participants were employed in the same position, five were employed in a different job and six were unemployed of which three were unemployed prior to the injury. Mackey, et al.'s (2009) study found that burn survivors who remained unemployed were either defeated or burdened and those who returned to work were thematically grouped as affected, unchanged or stronger. However other studies have shown that only a small percentage return to the same employment with the same employer (Brych et al., 2001) clearly demonstrating how a severe burn can disrupt one's life.

Barriers to employment

The identification of barriers to employment after a severe burn is a fundamental area that guides clinical care (Schneider, et al., 2011). Other studies have investigated barriers impacting employment after a severe burn injury (Fauerbach, et al., 2001; Mason, et al., 2012; Quinn, et al., 2010; Schneider, et al., 2009, 2011). Despite the fact that these studies are of a quantitative nature and do not explore the burn survivors' perspective or experiences, they do highlight the fundamental issues that impact on burn survivors returning to work. The findings of this study are comparable to those of Oster's (2010) phenomenological study exploring burn survivors perceptions of barriers and facilitators in returning to work. Oster, et al. (2010) found that the individuals' characteristics, in particular resilience and motivation, having specific rehabilitation goals and the ability to adjust and adapt to their disability and environment, facilitate the return to work, whereas barriers are perceived as a lack of a rehabilitation plan, social support and limited knowledge and education concerning their burn care. Additionally, such factors as TBSA, depth and location of injury, length of stay, significant psychiatric history, age, marital status and their employment status at the time of the burn, have all been identified as predictors that play a role in returning to work (Dyster-Aas, et al., 2007; Esselman et al., 2007; Mason, et al., 2012; Moi, et al., 2007; Quinn, et al., 2010). A recent study by Schneider, et al. (2011) identified pain, neurological issues, limited mobility and burn wounds as barriers to employment for those burned outside the work setting. Furthermore, a recent literature review identified TBSA as the fundamental barrier of

returning to work (Mason, et al., 2012; Quinn, et al., 2010) with those who sustained higher TBSA's more likely to be delayed in returning to work compared to a small burn (Quinn, et al., 2010).

Ongoing rehabilitation services

Patients with severe burns are among the most complex, resource intensive and costly medical conditions to treat and manage with the expenditure of acute care alone rising into the millions (Dimick, et al., 2005; Klein et al., 2009). With the necessity for burn care over long extended periods, the decreasing length of stay combined with an existing overstretched health system, creates multiple challenges for burn clinicians in addressing the needs of patients with severe burns in the outpatient setting (Badger & Royse, 2010a; Farrell, et al., 2006). Burn care is highly dependent on the integrated multidisciplinary burn team that requires a high level of care after discharge (Farrell, et al., 2006). Despite many burn units having integrated comprehensive outpatient care facilities (Sagraves et al., 2006), the findings of this study suggest that patients discharged from the burn service struggle with finding appropriate care that meets their ongoing burn rehabilitation needs and in particular are those from rural and regional Australia. This is substantiated with Dimick, et al. (2005) stating that a lack of reliable coordinated long-term follow-up of burn survivors occurs routinely that has led to significant variations in outcomes. Outpatient services at regional burn centres is, at times, fraught with issues concerning follow-up due to the distance patients are required to travel that is not only an inconvenience but a costly adventure that jeopardises clinical outcomes and facilitates poor patient compliance (Sagraves, et al., 2006). Van Loey, et al.'s (2001) study that looked at the needs of outpatient burn care, found that of the participants who sought help after discharge, 65% were dissatisfied with the care received with 87% of dissatisfied participants opting for a burn specific outpatient clinic. However, Kleve and Robinson (1999) study investigating psychological needs of adult burn patients, found that 66% of patients in their study reported receiving support after discharge with a majority of patients finding the support received to be helpful.

Many patients are physically unable to attend routine clinic appointments for dressing changes and therefore utilise the services of district home nurses unfamiliar with burn care practices and consequently experience difficulties with complex burn dressings (Yurko, et al., 2001). Furthermore, few multidisciplinary burns specific outpatient services are provided, with a lack of attention directed towards the psychosocial issues (Van Loey, et al., 2001). Sagraves, et al. (2006) study that assessed the feasibility of providing outpatient burn care at

a rural level one trauma centre in collaboration with regional burn centres, found that outpatient burn care can be a viable option and achieved at a non-burn facility with the necessary dedicated personnel such as burns nurses providing wound care, continuity of care and follow up via telephone for those unable to attend scheduled appointments. Additionally, physiotherapists and occupational therapists can assist with local rehabilitation with the regional burn centre providing appropriate and timely assistance via email or phone (Sagraves, et al., 2006). It must be noted that collaboration between burn centres and district and rural hospitals remains a controversial issue with the case in point for collaboration made in relation to patient travelling times, cost and the benefit to patients' outcomes and adherence to therapy.

Summary of chapter

Chapter seven has discussed the findings of this descriptive phenomenological study that addressed the 'lived experience' of rehabilitation for those with severe burns in the context of the current and relevant research. The discussion commenced with consideration given to the role of burn peer support in psychosocial rehabilitation with the importance of family support and the influence of health professionals examined. This was followed by the continuing challenge for burn survivors with respect to adherence and the continuity of care throughout rehabilitation. Of significance was the acceptance of the burn injury itself along with an altered body image in which such strategies as the use of humour and rationalisation were adopted to facilitate acceptance, adaption and adjustment after a tragedy as a severe burn. The impact of the burn injury was also discussed in relation to the pain, despair and loss experienced throughout the rehabilitation journey. Motivation, resilience and goal setting were fundamental in adapting to life after a severe burn injury. The transition through the rehabilitation journey was explored, with consistency and continuity of care and access to ongoing burn rehabilitation of particular significance. Finally, the discussion concluded with consideration given to occupational implications with particular reference to return to work and barriers to seeking employment. The following and final chapter of this thesis presents the recommendations and conclusion which address the study's significance for clinical practice, recommendations, limitations and the prospects for further research.

CHAPTER EIGHT

RECOMMENDATIONS AND CONCLUSION

Overview of the research

This thesis has explored patients' 'lived experience' of rehabilitation after a severe burn injury.

The research question asked:

- What is the 'lived experience' of patients' rehabilitation after a severe burn injury?

This study has been informed and guided by a descriptive phenomenological approach derived from the workings of Husserl and Colaizzi. Twenty one participants with severe burn injuries volunteered to participate in this current study. Participants were required to discuss their unique experiences of burn rehabilitation that commenced from the time of admission and for some participants, their rehabilitation journey still continues. The data collected through semi structured face to face interviews, were transcribed verbatim and analysed using Colaizzi's seven step approach of data analysis.

From the data analysis, seven emergent themes were identified describing burn survivors' perspective and experiences of rehabilitation: *Vital supports, Spatial environment, Challenges, Acceptance, Impact, Endurance, and Progression*. These emergent themes are reflective of the participants' experiences of rehabilitation that incorporates both the physical and psychosocial impact after a severe burn injury. The exploration of participants' stories highlights the physical and psychosocial challenges that burn survivors and their families encounter. Burn survivors' 'lived experience' of rehabilitation has previously been a neglected area of research with only certain elements explored. Most studies have utilised a quantitative approach that overlooks the patients' experiences and perceptions that are fundamental to an improved understanding of the rehabilitation process as experienced and understood by the participants in this qualitative inquiry. The narratives voiced in this study may assist to better understand the phenomena of burn rehabilitation and the diversity in the individuals' experiences that warrants greater recognition.

Significance for burn rehabilitation

This thesis presents a broader and more in depth exploration of burn survivors ‘lived experience’ of rehabilitation than has been previously been published or reported. Meaningful and comprehensive perspectives with which to comprehend and appreciate patients’ experiences of burn rehabilitation were discussed in the terms of the significant viewpoints providing a rich and detailed insight, highlighting burn rehabilitation in the Australian setting perceived from the viewpoints of burn survivors.

The findings of this study have captured the diverse problems experienced by burn survivors highlighting the complexity of care involved in burn rehabilitation. Crucial to the process of burn rehabilitation, is the ongoing educative support burn clinicians provide to health professionals, burn survivors and their families as this is a significant and vital element in the burn rehabilitation journey. There is a necessity for appropriate knowledge and education based programmes for burn survivors with consideration given to the timing and delivery of education. Finally, this research informs a broader understanding of burn survivors’ experiences and perceptions, both in the physical and psychological context of rehabilitation. Creating opportunities for collaborative research lends itself to possible education and research development aimed primarily at improving patients outcomes.

Recommendations

Recommendation 1: Development of a national inpatient clinician based formalised burn peer support program.

While there are several burn support foundations and charities in Australia, there currently is no national formalised clinician based burn peer support program for inpatients with burn injuries. A peer-based support program has the capacity to engage burn survivors providing hope and reassurance (Acton, et al., 2007; Badger & Royse, 2010a) and facilitating their psychosocial adjustment (Acton, et al., 2007; Badger & Royse, 2010a; Sproul, et al., 2009; Williams, et al., 2002). Speaking to another burn survivor is often a key aspect in the rehabilitation of those with severe burn injuries (Sproul, et al., 2009). It has been reported that an encounter with a burn survivor is a meaningful experience for a person who is rehabilitating from a severe burn injury (Sproul, et al., 2009).

Currently, the Agency for Clinical Innovation Statewide Burn Injury Service in NSW is the only Australian State trialling a formalised inpatient burn peer support program. This

program is championed by volunteers based on the fundamental premise of a shared experience. Burn survivors are selected following a comprehensive recruitment, screening and training process to ensure appropriateness. A national network based on this structure could provide burn survivors across Australia, and in particular remote access locations, with the necessary peer support needed to endure the rehabilitation journey.

Recommendation 2: Provision of services that mutually engage health professionals, employers and survivor in the process of transition and returning to work.

Improved integration between the burn units and the rehabilitation setting may improve the patient's experience and facilitate for a smooth transition period during an often disruptive period. This could be achieved by purposeful collaboration between the acute and rehabilitation services whereby the rehabilitation nurses responsible for the care of the patient, come to the burns unit and engage with both the patient and the multidisciplinary burn team and partake in burn care practices. In addition, patients should be offered structured visits to the rehabilitation facility prior to discharge to familiarise themselves with the rehabilitation setting and impending routine. Further to this, the burn Clinical Nurse Consultants should follow up with the patient at regular set intervals to monitor issues as wound breakdown, scarring and contracture development as this may reduce the incidence of unplanned readmissions. Finally, to facilitate the return to work, liaising with employers early in the rehabilitation process may provide for better communication and understanding between the employee and employer. This could assist with providing both the employee and employer with the necessary support and resources to enable burn survivors to return to the workplace environment.

Recommendation 3: Development of a multimedia education based programme directed towards adherence to burn therapy and continuum of burn care.

With patients increasingly requesting and accessing information via different mediums, they are becoming active participants in their own healthcare (Lo, et al., 2010). The development of a multimedia education based program would provide those with severe burns greater knowledge and understanding of their injury. Multimedia programs have been shown to not only increase patients' confidence and reinforce critical elements of burn care (Finlay et al., 2012), they have been reported to significantly improve the knowledge base of patients that in turn reduces anxiety and enhances adherent behaviours (Lo, et al., 2010; So, et al., 2003).

The Telstra Burns Reconstruction and Rehabilitation Unit at the Royal Perth Hospital in Western Australia, has recently developed and evaluated an instructional burns digital video disc (DVD) for the education of burn patients who were not admitted to hospital. This study reported that patients' confidence in the self-management of burn care improved after viewing the DVD and was deemed a useful adjunct to current practices in burn care (Finlay, et al., 2012). A multimedia package could contain such products as a DVD, audio compact disc (CD), still images, animation, traditional text or interactive media directed at ongoing burn care and therapy. Given that participants in this study state that more information concerning their injury and sequelae would have been beneficial, this raises questions of the timing and delivery of education and information. Utilising a multimedia format could overcome some of these issues experienced during burn rehabilitation. Additionally, using DVDs and CDs to provide survivors with information on their burn care and therapy would facilitate those who have poor literacy skills. Furthermore, producing a multimedia package in several languages would be beneficial for those with a non-English speaking background.

Recommendation 4: Formation of an accredited burn rehabilitation training program directed at community and rehabilitation health professionals across all Australian states.

The Australian and New Zealand Burn Association provide training for the emergency management of severe burns (EMSB) that requires all participants to successfully complete a multiple choice examination and a short clinical scenario utilising a simulated patient and management strategies in order to fulfil the course requirements. The EMSB is held numerous times a year across all Australian states and New Zealand with 17 EMSB courses being held in 2013. However, there remains no accredited rigorous training in the area of burn rehabilitation. In fact, nationally in Australia, there are no burns specific rehabilitation courses available for health professionals working within rehabilitation or the community setting. This is surprising since rehabilitation commences at the time of injury and extends beyond discharge. In NSW, the Agency for Clinical Innovation Statewide Burn Injury Service conducts a two day burn rehabilitation series held annually and in Western Australia, the Royal Perth Burns Unit conducts a regional\rural burns management course which is a four hour event. This lack of clinician based burn rehabilitation education is grossly insufficient given the findings within this study highlight the inadequacies experienced by burn survivors concerning the management of burn injuries in rehabilitation and community

facilities in Australia. The development of an accredited burn rehabilitation training program would allow health professionals with the necessary knowledge and training to be confident and competent in managing burn patients in the rehabilitation and community settings. As with the EMSB, such a course should require all participants to successfully complete the course with an examinable component to ensure that those working in the area of burn rehabilitation are competent clinicians.

Study limitations

Recognising the limitations of this study offers the reader an understanding and the capacity to evaluate the implications of these findings. The limitations are principally derived from a methodological standpoint due to a lack of transparency in qualitative methodologies (Higginbottom, 2004). As a result, a descriptive phenomenological approach is recognised as having numerous intrinsic limitations.

The lack of generalisability is often a criticism of qualitative research (Higginbottom, 2004). However, whilst the findings of this study contribute to the growing body of knowledge related to burn rehabilitation, the applicability and transferability of the results may be limited. Despite this, the aim of the research was to highlight and offer a rich description allowing understanding and provides a valuable insight to the ‘lived experience’ of burn survivors’ rehabilitation.

Qualitative research is quality not quantity dependent. The focus is on the richness and quality of data rather than the quantity of data gathered (Patton, 2000) and therefore does not correlate to the participant numbers. In qualitative research, the sampling strategy utilised is determined by the methodology selected (Higginbottom, 2004). The use of purposeful sampling for the selection of the participants does introduce the element of bias. Although, phenomenology focuses on the meaning of the phenomenon encompassed in the ‘lived experience’ of the individual participants who have specific characteristics of interest (Guimond-Plourde, 2010). Therefore utilising probability sampling methods would be deemed incompatible as the primary purpose of probability sampling is to attain transferability (Higginbottom, 2004).

The study included only participants from Australia and included three Australian states (New South Wales, Victoria and South Australia). The inclusion of all Australian states and territories that have existing burn units and burn rehabilitation facilities would have given a

more holistic perspective on the Australian experience. However, due to circumstances beyond the control of the researcher this was not possible. On a global scale, this study was conducted in Australia, although, according to the World Health Organisation, 90% of burns occur in developing or underdeveloped countries (Potokar, Prowse, Whitaker, Ali, & Chamania, 2008). Therefore the experiences explored in this study may not be representative of the global population. This may impact on the applicability and transferability of the finding reported in the study to the global setting.

The study incorporated 20 males with only one female participant. This may be viewed as a limitation although, it is consistent with the incidence of burn injury due to occupational risk factors leaving the male population prone to industrial accidents (Wasiak, et al., 2009). The inclusion of a larger female population may unearth differing aspects of burn rehabilitation compared to the male population and may warrant further investigation. Additionally, the ethnicity of the participants was generally Caucasian and not representative of other cultures.

The time period after the initial injury occurred ranged from one year up to eight years. This may be viewed as a potential for recollection bias as it has been suggested that memories can be influenced by the passage of time, causing recall biases (Roberts, Rickard, Rajbhandari, & Reynolds, 2007). However despite the extended time since the injury, the emotion and recollection of their experiences were vividly expressed. The presence of a family member during the interview may have influenced participants' response as the relatives' experience of the burn may differ from the patient (Phillips, Fussell, & Rumsey, 2007; Rossi, Vila, Zago, & Ferreira, 2005). The focus of the study was the burn survivors' experience of rehabilitation; therefore all efforts were made to explain this to the participants and family members. Despite these limitations, the findings of this study may assist policy makers, health professionals, burn survivors and their families guide the management of burn rehabilitation.

Further research

This study suggests that there are several aspects within this research that warrants further consideration. Any research that endeavours to develop the awareness and understanding of burn survivors' needs would be deemed as beneficial and valuable to the rehabilitation journey. The following areas may potentially provide greater insight into the diverse and multidisciplinary nature of rehabilitation for those with severe burn injuries.

The participants in this study were principally male, therefore the exploration of female burn survivors' experiences of rehabilitation would add greater depth to the understanding the experiences of burn rehabilitation. Likewise, this study focused primarily on adults and excluded paediatric and adolescence patients. There was a wide age range between 21 and 65 years with a mean age of 44 years. Consequently, it may be well worthwhile exploring specific age groups that may identify specific requirements and needs.

This study specifically examined the patients' experiences and perspectives. Investigation of health professionals involved in the treatment and ongoing care of patients with severe burn injuries would perhaps serve as a valuable and constructive area of research in light of the findings presented in this thesis. Additionally, this study incorporated burn survivors from three Australian States: New South Wales, Victoria and South Australia. The general goals of burn rehabilitation are the same globally. However, practices vary significantly between burn centres. Consequently, a study encompassing all states within Australia may provide a greater diversity of experiences. Furthermore, exploration of an international perspective with the inclusion of low and middle income countries, would prove worthwhile, valuable and of great significance and augment the existing understanding. Moreover, a comparison between high income and middle to low income countries could identify unique and varied experiences.

Nearly half of the participants in this study sustained a facial burn with significant scarring, further exploration of the unique experiences of those with significant facial burns is a critical area in burn rehabilitation. Additionally, a principal finding in this study was the significance of burn survivor peer support. There is limited research that addresses the significance of peer support for burn survivor. Hence, there is potential to further investigate the benefits and detriments of peer support programmes within the burns community as further debate on this particular issue is required.

Finally, burn rehabilitation within the community setting warrants further investigation as the findings of this study suggest that burn survivors have limited access to specialised burn care in the community and rural setting. As a result, these settings may not receive appropriate educational management and guidelines unlike large tertiary teaching hospitals. One point that is very clear is research into burn rehabilitation is crucial to identify, develop and evaluate practices that improve outcomes for this unique group of patients.

Conclusion

In concluding, this thesis has presented an in-depth exploration of patients' 'lived experience' of rehabilitation after a severe burn injury within the Australian context. Informed by Husserlian phenomenology, seven themes emerged that formed and encompassed burn survivors experience of rehabilitation: *Vital supports, Spatial environment, Challenges, Acceptance, Impact, Endurance and Progression.*

In relation to the significance for burn rehabilitation, the findings from this study offer rich and detailed insight into the lived experiences of burn survivors' rehabilitation that vividly highlight their rehabilitation perceived from the viewpoints of those who have endured a severe burn injury and survived.

The recommendations set forth were presented in light of the findings of this study. The limitations of the study have been considered mainly in relation to the methodology and participant population. It is a recommendation of this study that future research concerning experiences and perceptions of burn survivors' rehabilitation encompass a diverse and international population incorporating low and middle income countries.

Finally, this study has unearthed fundamental aspects of burn rehabilitation that span across a diverse and multidisciplinary sector of healthcare including nursing, social work, psychiatry, occupational therapy, physiotherapy, speech pathology, dietetics and medicine. In essence, these findings provide a valuable and unique insight into the patients' perspective and experiences of burn rehabilitation that may provide for the further development of health policy in relation to management of severe burn injury; principles and guidelines for best practice; and both survivor and health professional education so as to improve outcomes for burn survivors, their families and the community.

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APPENDICES

APPENDIX 1

Search strategy

Database	Search Terms
<p>Pubmed</p> <p>(burns [mh]OR burn [tiab]OR burns [tiab]OR burned [tiab]OR burnt [tiab] OR cicatrix, hypertrophic [mh] OR hypertrophic cicatrix [tiab])AND(rehabilitation [mh]OR rehabilitation [sh]OR rehabiltat* [tiab]OR rehabilitation nursing [mh]OR activities of daily living [mh]OR activities of daily living [tiab]OR Length of stay [mh] OR length of stay [tiab] OR Return to work [tiab] OR living skills* [tiab]OR recovery of function [mh]OR recovery of function [tiab]) AND (social Support [mh]OR social support* [tiab] OR Life change events [mh] OR life events [tiab] OR life change events [tiab]OR adaptation, psychological [mh] OR psychological adaptation [tiab] OR patient satisfaction [mh]OR satisfaction [tiab]OR quality of life [mh] OR quality of life [tiab] OR body image [mh]OR Body image [tiab]OR social perception [tiab]OR patient perception* [tiab] OR patients perception* [tiab] OR Social adjustment [mh]OR social adjustment [tiab]OR resilience, psychological [mh]OR resilienc* [tiab] OR adaptation [tiab]OR psychosocial [tiab]) NOT (Burnout [tw] OR Child* [tiab]OR pediatric* [tiab] OR self-emollition [tiab]OR suicide [tiab] OR Burn* [au])</p> <p>Filters: published in the last 10 years; English; Adult:19+ years [mh] = mesh heading, [tiab] = title and abstract, [tw] = text word</p>	
<p>CINAHL</p> <p>(MH cicatrix, hypertrophic OR TI,AB hypertrophic cicatrix OR MH burns OR TI,AB burn OR TI,AB burns OR TI,AB burned OR TI,AB burnt)AND(MH rehabilitation OR TI,AB rehabiltat*OR MH rehabilitation nursing OR MH activities of daily living OR TI,AB activities of daily living OR MH Length of stay OR TI,AB length of stay OR TI,AB return to work OR TI,AB living skill*OR MH recovery OR TI,AB recovery)AND MH Life experiences OR TI,AB Experience* OR MH perception OR TI,AB patients perception* OR TI,AB patient perception* OR MH Patient attitudes OR TI,AB attitude* OR MH health status OR MH quality of life OR TI,AB quality of life OR MH survivors OR MH support, psychosocial OR TI,AB psychosocial OR MH coping OR TI,AB coping OR MH life change events OR TI,AB life change events OR TI,AB life events OR MH adaption,psychological OR TI,AB adapt* OR MH patient satisfaction OR TI,AB satisfaction OR MH social adjustment OR TI,AB social adjustment OR MH body image OR TI,AB body image OR MH self-concept OR TI,AB self-concept OR MH hardiness OR TI,AB resili*) NOT (TI,AB Burnout OR AU burn* OR TI,AB child* OR TI,AB pediatric* OR TI,AB suicide OR TI,AB self-emollition)</p> <p>Limiters - Published Date from: 2002-2012; Language: English; Age Groups: All Adult. MH = main heading, TI = title, AB = abstract</p>	

Database	Search Terms
EMBASE	<p>burn'/exp OR burn OR burn:ab,ti OR burns:ab,ti OR burned:ab,ti OR burnt:ab,ti OR 'hypertrophic cicatrix':ab,ti)AND('rehabilitation'/exp OR rehabilitation OR rehabilitat*:ab,ti OR 'daily life activity':de OR 'activities of daily living':ab,ti OR 'rehabilitation nursing':de OR 'rehabilitation center':de OR 'vocational rehabilitation':de OR 'length of stay':ab,ti OR'return to work':ab,ti OR 'recovery of function':de) AND ('quality of life'/exp OR 'quality of life' OR 'patient satisfaction':de OR 'patient attitude'/exp OR 'patient attitude' OR 'perception'/exp OR perception OR 'patients perceptions':ab,ti OR 'patients perception':ab,ti OR'patient perception':ab,ti OR 'personal experience':de OR experience:ab,ti OR experiences:ab,ti OR'psychosocial care':de OR 'life event':de OR 'adaptive behavior':de OR'body image':de OR'coping behavior'/exp OR 'coping behavior' OR 'social support':de OR support:ab,ti) NOT (burnout:de OR children:ab,ti OR child:ab,ti OR pediatric:ab,ti OR burn:au OR burns:au OR suicide:de OR:'self-emollition':de)</p> <p>Limiters - Published Date from: 2002-2012; Language: English; Age Groups: All Adult exp = explode, ab = abstract, ti = title, de = index term</p>

Scopus

(TITLE-ABS-KEY(burn OR burns OR burned OR burnt OR hypertrophic OR scar)) AND (TITLE-ABS-KEY(rehabilitation OR rehabilitat* OR "Rehabilitation nursing" OR "activities of daily living" OR "Length of stay" OR "Return to work" OR "living skills" OR "recovery of function")) AND(TITLE-ABS-KEY("Social Support" OR "Life change events" OR "life events" OR "psychological adaptation" OR "Patient Satisfaction" OR satisfaction OR "Quality of life" OR "Body image" OR "Social perception" OR "Patient perception*" OR "Patients perception*" OR "social adjustment" OR resilience OR resilienc* OR psychosocial)) AND NOT (burnout OR child* OR pediatric* OR suicide OR self-immolation OR self-burning OR AUTHOR-NAME burn*) AND (LIMIT-TO(PUBYEAR, 2012)OR LIMIT-TO(PUBYEAR, 2011) OR LIMIT-TO(PUBYEAR, 2010) OR LIMIT-TO(PUBYEAR, 2009) OR LIMIT-TO(PUBYEAR, 2008) OR LIMIT-TO(PUBYEAR, 2007) OR LIMIT-TO(PUBYEAR, 2006) OR LIMIT-TO(PUBYEAR, 2005)OR LIMIT-TO(PUBYEAR, 2004) OR LIMIT-TO(PUBYEAR, 2003) OR LIMIT-TO(PUBYEAR, 2012)OR LIMIT-TO(PUBYEAR, 2011)OR LIMIT-TO(PUBYEAR, 2010) OR LIMIT-TO(PUBYEAR, 2009) OR LIMIT-TO(PUBYEAR,2008) OR LIMIT-TO(PUBYEAR, 2007) OR LIMIT-TO(PUBYEAR, 2006)OR LIMIT-TO(PUBYEAR, 2005)OR LIMIT-TO(PUBYEAR, 2004) OR LIMIT-TO(PUBYEAR, 2003) OR LIMIT-TO(PUBYEAR, 2002))AND (LIMIT TO(SUBJAREA, "MEDI") OR LIMIT-TO(SUBJAREA, "NURS") OR LIMIT-TO(SUBJAREA, "PSYC") OR LIMIT-TO(SUBJAREA, "MEDI") OR LIMIT-TO(SUBJAREA, "NURS") OR LIMIT-TO(SUBJAREA, "HEAL") OR LIMIT-TO(SUBJAREA, "PSYC") OR LIMIT-TO(SUBJAREA, "MULT")) AND (LIMIT-TO(DOCTYPE, "ar") OR LIMIT-TO(DOCTYPE, "re") OR LIMIT-TO(DOCTYPE, "cp") OR LIMIT-TO(DOCTYPE, "ip")) AND (LIMIT-TO(LANGUAGE, "English"))AND EXCLUDE(EXACTKEYWORD, "Surgical technique") OR EXCLUDE(EXACTKEYWORD,"Adolescent")OR EXCLUDE(EXACTKEYWORD, "Clinical trial") OR EXCLUDE(EXACTKEYWORD, "Operation duration"))AND(LIMIT-TO(EXACTKEYWORD, "Adult") OR LIMIT-TO(EXACTKEYWORD, "Burns") OR LIMIT-TO(EXACTKEYWORD, "Rehabilitation"))

TITLE-ABS-KEY = tile and abstract

Database	Search Terms
PsycINFO	((burn OR burns OR burned OR burnt OR hypertrophic OR scar)AND rehabilitation OR rehabilitat* OR rehabilitation nursing OR activities of daily living OR Length of stay OR Return to work OR living skills OR recovery of function)AND Social Support OR Life change events OR life events OR psychological adaptation OR patient satisfaction OR satisfaction OR quality of life OR body image OR Social perception OR patient perception* OR patients perception* OR social adjustment OR resilience OR resilienc* OR psychosocial))NOT((Burnout OR child* OR pediatric* OR suicide OR self-immolation OR self-burning OR AU burn*))
Limiters - Publication Year from: 2002-2012; Language: English; Age Groups: Adulthood (18 yrs & older)	
Trove	(burn OR burns) AND (rehabilitation) AND (perception OR experiences) NOT (burnout OR child* OR pediatric* OR self-immolation) date:[2002 TO 2012]

All results were limited to articles in English, only adults between 2002 to 2012

APPENDIX 2

Key personnel information sheet

Project title:

Severe burn injury patients' 'lived experience' of rehabilitation.

Principal researcher:

Rachel Kornhaber: PhD candidate, Discipline of Nursing, the University of Adelaide.

Purpose of the study:

The purpose of this study is to describe the experiences and difficulties of adult severe burn injury patients' rehabilitation and gain an in-depth understanding of patients' experiences.

Your involvement:

The reason for this request is to ask you if you could speak to patients recently discharged with severe burn injuries and provide them with a copy of the patient information sheet outlining the details of this study. If the patient expresses an interest to participate in this study, could you firstly gain verbal consent from the patient and then obtain their details providing a name and a contact telephone number. It would be appreciated if you could forward them to me via the email address listed below. Please note that no payment is involved with the recruitment of patients into this study. However your efforts will be acknowledged in any publication related to this study.

Ethics:

This study has been ethically approved by both the University of Adelaide Human Research Ethics Committee.

Rachel Anne Kornhaber,

Phone: (02) 9452 4554 or 0418 646 592 (mobile)

Email: Rachel.kornhaber@adelaide.edu.au

If you wish to discuss any aspect of this study with someone not directly involved in the research, you can contact Ms Sabine Schreiber the Research Ethics Officer at the University of Adelaide.

Phone: (08) 8303 6028

Email: sabine.schreiber@adelaide.edu.au

APPENDIX 3



Patient information and consent form

Project title:

Severe burn injury patients' 'lived experience' of rehabilitation.

Principal researcher:

Rachel Kornhaber: PhD candidate, Discipline of Nursing, the University of Adelaide.

Purpose of the study:

The purpose of this study is to describe the experiences and difficulties of adult severe burn injury patients' rehabilitation and gain an in-depth understanding of patients' experiences.

The possible benefits to you from this research:

You may not directly benefit from this study; however the findings of this study will offer significant insight into this phenomenon and therefore inform healthcare professionals about critical issues in the rehabilitation of severe burn injury patients. Future practice may incorporate issues identified in this study which could potentially translate into improve healthcare outcomes for patients with severe burn injuries.

Your participation:

Your participation is voluntary and therefore receives no payment for your participation. You can withdraw from the study at anytime without repercussions to your medical care now or in the future. Participation involves a face to face, digitally audio recorded interview of approximately 45 minutes, to be conducted in a place and time suitable to you. Questions will be asked regarding your experiences of rehabilitation after a severe burn injury. You may decline to answer any question, request to stop recording or terminate the interview. The interview will be transcribed by a professional transcription service and a copy of the transcript will be made available to you so that you can check that the information is correct and if necessary request alterations to the transcript. In addition, a comprehensive description of the experiences of rehabilitation of severe burn injury patients will be sent to you at the later stage of the study. You will be asked to validate this description stating whether you believe that the description provided is congruent with your own experience. Furthermore, it will be necessary to access your medical records in order to collect data pertaining to your injury such as the depth and percentage of burn sustained and length of stay on the burn unit and whilst in rehabilitation.

What are the possible risks that I will encounter?

There are no known risks involved in the participation of this research; however, if you become upset or distressed as a result of your participation in the research, the researcher is able to arrange for a referral to be made to the social worker or psychiatric team at the burns unit with your permission. Any counselling or support will be provided by staff who are not members of the research team.

Confidentiality:

All information and documents containing your personal information will be kept strictly confidential. Any identifying information about you or the hospital will not be transcribed. Anonymity will be maintained in any reports or publications produced from this research. No one other than myself will have access to information that links you to the research.

Contacting the researcher:

If you wish to discuss your involvement in this research, or have any further questions you can contact me at anytime point in time.

Note: This study has been approved by the University of Adelaide Human Research Ethics Committee. If you wish to discuss any other aspect of this study with someone who is not directly involved or have any complaints or reservations about the ethical conduct of this research, you may contact the Research Ethics Officer at the University of Adelaide Ms Sabine Schreiber **Phone:** (08) 8303 6028 **Email:** sabine.schreiber@adelaide.edu.au. Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.

If you wish you can also contact my academic supervisors listed below:

Primary Academic Supervisor: Dr Anne Wilson

The University of Adelaide, South Australia

Phone: (08) 83033595

Email: anne.wilson@adelaide.edu.au

Academic Co Supervisor: Dr Jacqueline Baker

University of Technology, Sydney

Phone: (02) 9514 5072

Email: Jacqueline.Baker@uts.edu.au

Academic Co Supervisor: Dr Ma'en Zaid Abu – Qamar

Mu'tah University, Mu'tah- AL-Karak, Jordan

Phone: 0011962785777524

Email: maen@MUTAH.EDU.JO

I look forward to hearing from you,
Yours sincerely

Rachel Anne Kornhaber,

Phone: (02) 9452 4554 or 0418 646 592 (mobile)

Email: Rachel.kornhaber@adelaide.edu.au

Informed consent form

Project Title: Up out of the ashes: Severe burn injury patients’ ‘lived experience’ of rehabilitation.

Researcher: Rachel Anne Kornhaber

1. The name and purpose of the research project has been explained to me. I understand it and agree to take part.
2. I understand that while information gained during the study may be published, I will not be identified and my personal details will remain confidential.
3. I understand that I may not directly benefit from taking part in the study.
4. I understand that I may decline to answer particular questions and ask for the recording to be ceased during the interview or withdraw from the study at any stage if I so wish and this will not affect any medical care now or in the future.
5. I understand the statement contained in the participant information sheet concerning receiving no payment for participation in this study.
6. I understand that the conversation will be audio digitally recorded and deleted at the end of the study.
7. I consent to the researcher accessing my patient medical records for the collection of data in connection with this study only.
8. I understand that any material from my patient records will be used in such a way that I am not identified in the study.
9. I understand that, while information gained during the study may be published, I will not be identified and my personal results will remain confidential.
10. I have had the opportunity to discuss taking part in this study with a family member or friend.

Name of Subject: _____

Signature of the subject: _____

Dated: _____

I certify that I have explained the study to the volunteer and consider that he/she understands what is involved

Researcher’s Name: _____

Signature of researcher: _____

Dated: _____

APPENDIX 4

Interview guide

1. Tell me about your experience of rehabilitation after a severe burn injury?
2. What difficulties were you confronted with during your rehabilitation?
3. What factors enhanced your journey during rehabilitation?

Prompts:

- How do you think you coped with this event?
- Can you elaborate on that point some more.
- Can you describe in more depth how this made you feel.
- What did this mean for you?
- How did you feel when that happened?

APPENDIX 5

Ethics approval



RESEARCH BRANCH
RESEARCH ETHICS AND COMPLIANCE UNIT

SARAH DE RUITER
SECRETARY
HUMAN RESEARCH ETHICS COMMITTEE
THE UNIVERSITY OF ADELAIDE
80, GLEN
ADELAIDE
SOUTH AUSTRALIA

TELEPHONE: 48 3 8837 9225
TELEFAX: 48 3 8837 9225
E-MAIL: sarah.de.ruiters@adelaide.edu.au
CH2281-4044 (number 33128)

13 December 2010

Associate Professor A Wilson
Discipline of Nursing

Dear Associate Professor Wilson

PROJECT NO: H-202-2010

Up out of the ashes: severe burn injury patients' lived experience of rehabilitation

I write to advise you that the Human Research Ethics Committee has approved the above project. Please refer to the enclosed endorsement sheet for further details and conditions that may be applicable to this approval.

Approval is current for one year. The expiry date for this project is: 31 December 2011.

Where possible, participants taking part in the study should be given a copy of the Information Sheet and the signed Consent Form to retain.

Please note that any changes to the project which might affect its continued ethical acceptability will invalidate the project's approval. In such cases an amended protocol must be submitted to the Committee for further approval. It is a condition of approval that you immediately report anything which might warrant review of ethical approval including (a) serious or unexpected adverse effects on participants (b) proposed changes in the protocol; and (c) unforeseen events that might affect continued ethical acceptability of the project. It is also a condition of approval that you inform the Committee, giving reasons, if the project is discontinued before the expected date of completion.

A reporting form is available from the Committee's website. This may be used to renew ethical approval or report on project status including completion.

Yours sincerely

 PROFESSOR GARRETT CULLITY
Convenor
Human Research Ethics Committee



RESEARCH ETHICS
 RESEARCH ETHICS COMPL. ACCOUNT
 SARAH SCULLIVAN
 SECRETARY
 HUMAN RESEARCH ETHICS COMMITTEE
 THE UNIVERSITY OF ADELAIDE
 SA 5005
 AUSTRALIA
 TELEPHONE: +61 8 8303 3030
 FACSIMILE: +61 8 8303 3055
 EMAIL: sarah.scullivan@adelaide.edu.au
 GPO BOX 496 Adelaide SA 5001

13 December 2010

Associate Professor A Wilson
 Discipline of Nursing

Dear Associate Professor Wilson

PROJECT NO: H-202-2010
Up out of the ashes: severe burn injury patients' lived experience of rehabilitation

I write to advise you that the Human Research Ethics Committee has approved the above project. Please refer to the enclosed endorsement sheet for further details and conditions that may be applicable to this approval.

Approval is current for one year. The expiry date for this project is: 31 December 2011.

Where possible, participants taking part in the study should be given a copy of the Information Sheet and the signed Consent Form to retain.

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A reporting form is available from the Committee's website. This may be used to renew ethical approval or report on project status including completion.

Yours sincerely

 PROFESSOR GARRETT CULLITY
 Convenor
Human Research Ethics Committee

Sabine Schreiber

From: Sabine Schreiber [sabine.schreiber@adelaide.edu.au]
Sent: Thursday, 18 June 2011 12:31:21 PM
To: 'Rachel Kornhaber'
Subject: RE: EXTENDING RECRUITING PERIOD TO 8 YEARS FROM 4

Dear Rachel

Thank you for notifying the HREC of the change to the recruitment period. The HREC Convenor has been notified and we will update our records accordingly.

Regards
 Sabine

Sabine Schreiber
 Secretary, Human Research Ethics Committee Research Ethics and Compliance Unit Research Branch,
 Level 7, 115 Grenfell St
 The University of Adelaide, AUSTRALIA 5005
 Ph : 8303 6028 (Mon - Thurs)
 Fax : 8303 7325
 e-mail: sabine.schreiber@adelaide.edu.au <http://www.adelaide.edu.au/ethics/human/>

CRICOS Provider Number 00123M

IMPORTANT: This message may contain confidential or legally privileged information. If you think it was sent to you by mistake, please delete all copies and advise the sender. For the purposes of the SPAM Act 2003, this email is authorised by The University of Adelaide.

Think green: read on the screen.

-----Original Message-----

From: Rachel Kornhaber [mailto:rachel.kornhaber@adelaide.edu.au]
Sent: Thursday, 2 June 2011 9:31 AM
To: sabine.schreiber@adelaide.edu.au
Subject: EXTENDING RECRUITING PERIOD TO 8 YEARS FROM 4

Dear Sabine,

As per telephone conversation this morning it is necessary to extend the recruitment period from the original 4 years to 8 years due to low participant numbers. This is the only amendment I am requesting and have applied for amendments through the correct channels at the other hospital HREC involved in the study.


Regards

Rachel

Rachel Anne Kornhaber MN, BN, RN
 PhD candidate
 School of Nursing
 The University of Adelaide, AUSTRALIA 5005
 Ph: 02 9452 4554
 Mob: 0418 646 592
 Email: rachel.kornhaber@adelaide.edu.au

APPENDIX 6

Scientific review


 Northern Sydney Central Coast Health
HUMAN RESEARCH ETHICS COMMITTEE
SCIENTIFIC REVIEW

Assessor Number 3

Protocol 1011-386M(Other) (Other)

The attached proposal, entitled **Up out of the ashes: Severe burn injury patients' 'lived experience' of rehabilitation.** (AU RED Ref. HREC/10/HAWKE/153) has been received from - **R Kornhaber**, - and will be considered at the HREC meeting on the **14 December 2010**.

Scientific assessment of the proposal is required to assist the HREC in its consideration of this project. It would be appreciated if you could review the proposal and forward your assessment no later than the 1 December 2010 to the Research Office.

RATING:

Scientific Validity

Concept: *Excellent* *Very Good* *Good* *Fair* *Poor*
 Design: *Excellent* *Very Good* *Good* *Fair* *Poor*

Successful completion of project? Likely Unlikely

GENERAL COMMENTS:

THIS PROJECT HAS THE FULL SUPPORT OF THE ADULT BURNS SERVICE, ROYAL ADELAIDE HOSPITAL AND IS SEEN AS AN AREA OF NEED.

Are you willing to be identified to the investigator? Yes No

Name of assessor: SHELLA KAVANAGH Signature: _____ Date: 29/11/10

Date circulated 18/11/10

06-DEC-2010 06:27 From:

To:61 2 9926 6179

P.2/2

Northern Sydney Central Coast Health
HUMAN RESEARCH ETHICS COMMITTEE
SCIENTIFIC REVIEW

Assessor Number__2

Protocol 1011-386M(Other) (Other)

The attached proposal, entitled **Up out of the ashes: Severe burn injury patients' 'lived experience' of rehabilitation.** (AU RED Ref, HREC/10/HAWKE/153) has been received from - **R Kornhaber**, - and will be considered at the HREC meeting on the **14 December 2010**.

Scientific assessment of the proposal is required to assist the HREC in its consideration of this project. It would be appreciated if you could review the proposal and forward your assessment no later than the 1 December 2010 to the Research Office.

RATING:

Scientific Validity

Concept: *Excellent* *Very Good* *Good* *Fair* *Poor*
 Design: *Excellent* *Very Good* *Good* *Fair* *Poor*

Successful completion of project? Likely Unlikely

GENERAL COMMENTS:

*Thank you
 This is an interesting and worthwhile project. Design is appropriate.
 The researcher has a good track record and I expect the study will be completed successfully.*

Are you willing to be identified to the investigator? Yes No

Name of assessor: *R Kornhaber* Signature

Date: *4/12/10*

Date circulated 25/11/10

NORTHERN SYDNEY
 CENTRAL COAST
 Northern Sydney Central Coast Health
NSW HEALTH
 HUMAN RESEARCH ETHICS COMMITTEE
 SCIENTIFIC REVIEW
 Assessor Number 1

Protocol 1011-386M(Other) (Other)

The attached proposal, entitled **Up out of the ashes: Severe burn injury patients' 'lived experience' of rehabilitation.** (AU RED Ref. HREC/10/HAWKE/153) has been received from - **R Kornhaber**, - and will be considered at the HREC meeting on the **14 December 2010**.

Scientific assessment of the proposal is required to assist the HREC in its consideration of this project. It would be appreciated if you could review the proposal and forward your assessment no later than the 1 December 2010 to the Research Office.

RATING:

Scientific Validity
 Concept: Excellent Very Good Good Fair Poor
 Design: Excellent Very Good Good Fair Poor
 Successful completion of project? Likely Unlikely

GENERAL COMMENTS:

The lived experience of severe burn injury patients in rehabilitation has not previously been investigated in any depth. The methodology as described is most appropriate and in particular all necessary ethical issues have been addressed. As a component of a PhD program the study objectives are certainly achievable.

Are you willing to be identified to the investigator? Yes No

Name of assessor: Rick Niechula, DN Signature: _____ Date: 30/11/10
 Date circulated 25/11/10

APPENDIX 7

Demographic data

Participant	Age at time of injury (years)	Total burn surface area (TBSA)	Significant facial burns	Returned to work	Causality	ICU LOS (days)	BU LOS (days)	Rehabilitation LOS (days)	Total LOS (days)
1	42	50%	Yes	No	Motor vehicle accident	21	134	69	224
2	59	35%	No	No	Work place accident	47	23	41	111
3	21	70%	No	Yes	Work place accident	22	141	80	243
4	30	20%	No	Unemployed	Motor vehicle accident	5	30	62 (Multiple admissions)	97
5	61	70%	Yes	Retired prior to injury	Accident	22	128	73	223
6	62	45%	No	Retired prior to injury	Accident	58	118	56	232

Participant	Age at time of injury (years)	Total burn surface area (TBSA)	Significant facial burns	Returned to work	Causality	ICU LOS (days)	BU LOS (days)	Rehabilitation LOS (days)	Total LOS (days)
7	33	80%	Yes	Unemployed	House fire	32	52	57	141
8	42	60%	No	Yes	Work place accident	79	223 (Multiple admissions)	146 (Multiple admissions)	448
9	32	52%	Yes	Unemployed	Motor vehicle accident	55	141	248 Multiple admissions	444
10	38	80%	No	No	Accident	4	118	49	171
11	43	70%	Yes	Yes	Work place accident	39	36	31	106
12	49	27%	No	No	Work place accident	15	16	24	55
13	55	60%	No	No	Work place accident	22	77	54 (Multiple admissions)	153
14	38	40%	Yes	Yes	Accident	51	58	45 (Multiple admissions)	154

Participant	Age at time of injury (years)	Total burn surface area (TBSA)	Significant facial burns	Returned to work	Causality	ICU LOS (days)	BU LOS (days)	Rehabilitation LOS (days)	Total LOS (days)
15	65	40%	No	Retired prior to injury	Accident	15	25	25	65
16	45	90%	Yes	No	Work place accident	86	119 (Multiple admissions)	158 (Multiple admissions)	363
17	59	30%	No	No	Accident	5	41	27	73
18	37	40%	No	Yes	Work place accident	32	39	40	111
19	40	55%	Yes	No	Accident	39	170	42	251
20	34	60%	Yes	Yes	Work place accident	40	119	59 Multiple admissions	218
21	36	78%	Yes	Yes *	Accident	38	65	42	145

*Returned to different workplace and position.