



MONASH University

**Outcomes of Free Flap Muscle Transfer Following Traumatic Brachial Plexus Injury:
Impacts on Clients' Engagement in Daily Life**

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Monash University in 2021

Occupational Therapy

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Abstract

Background:

Impairment following brachial plexus injuries (BPI) varies depending on the location and severity of the lesion. Severe BPIs result in on-going, life altering impairment that impacts an individual's ability to engage in daily life. Severe BPIs include the diagnosis pan-BPI which is a nerve injury to the root and/ or trunk levels of C5-T1 (Wali et al., 2017). While the literature reports an exceptionally high cost of BPI in relation to rehabilitation, loss of income, and decreased quality of life (Felici et al., 2014; Wali et al., 2017), outcomes continue to be predominately considered from a biomedical frame of reference. Functional outcomes following brachial plexus injury have been considered in some of the literature, but reported variously as range of movement (Bengston et al., 2008; Dy et al., 2015; Kitajima et al., 2006), activities (Kretschmer et al., 2009) and quality of life measures (Ahmed-Labib et al., 2007). There are few studies that explore long-term outcomes, as well as, few in-depth case series.

Aim:

This thesis aims to better understand long-term outcomes following free functioning muscle transfers (FFMT) reconstructive surgery following traumatic, pan-BPI in Australia. This thesis will contribute to a deeper understanding of this BPI sub-population and aims to inform clinical practice.

Methods:

This thesis utilised a pragmatic paradigm to allow for an in-depth study of individuals that sustained a pan-BPI and FFMT reconstructive surgery. Five key investigations were developed with corresponding aims and questions. The investigations of this thesis

gathered data from the existing literature, the patients, and health care providers. A mixed methods approach including a scoping review, two quantitative, and two qualitative investigations was employed to more deeply understand the objective and subjective experiences and outcomes of this BPI sub-population.

Results:

The results of this thesis are considered using biopsychosocial models, as well as, considered for relevance and recommendation for translation to practice. The scoping review confirmed the lack of consistent measures being used. The patient-reported investigations confirmed the severity of impairment on activity and participation engagement is consistent with other serious life-altering injury (e.g., stroke, spinal cord injury). It also demonstrated while impairment persists, patients successfully use compensation and adaptation to adjust following injury. However, despite their adjustment to injury significant barriers remain that prevent patients from returning to both productive and valued roles, with greatest dissatisfaction in their participation in sports/ physical exercise, work/ education, and household duties. Despite their limitations, patients expressed satisfaction with their relationships and ability to go out and partake in day trips. The findings of this thesis also identified the value of continuity of care with an experienced rehabilitation provider and highlighted the less tangible aspects of the patient-therapist relationship (e.g., knowledge translation, hope, normalisation, unconditional positive regard, and assistance with adjustment to injury).

Conclusion:

In summary, this is a very small, clinically complex population. The literature is predominately biomedical and poorly frames what successful outcomes look like. Treating therapists, often hand therapy OTs in Australia, play a meaningful role in the patient's adaptation and adjustment following injury.

Declaration

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

Signature:

Name: Sara Brito

Date:29/08/2021.....

Thesis Including Published Works Declaration

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

This thesis includes one original paper published in a peer reviewed journal and *four* submitted publications. The core theme of the thesis is outcomes following free functioning muscle transfer for management of pan-brachial plexus injury. The ideas, development and writing up of all the papers in the thesis were the principal responsibility of myself, the student, working within the Department of Occupational Therapy under the supervision of Dr Nikos Thomacos, Prof Ted Brown, and Dr Bridget Hill.

(The inclusion of co-authors reflects the fact that the work came from active collaboration between researchers and acknowledges input into team-based research.)

In the case of Chapters 4-8, my contribution to the work involved the following:

Thesis Chapter	Publication Title	Status	Nature and % of Student Contribution	Co-author Name(s) Nature and % of Co-author's Contribution*
4	Psychosocial outcome measures following free functioning muscle transfer for management of adult brachial plexus injury: A scoping review.	Submitted	70% - Conception of study, collecting data and data analysis, writing complete first draft, subsequent editing, preparation of final manuscript	1) Thomacos, N. – 15% Contributed to the conception of study, supervised data analysis, preparation of manuscript 2) Hill, B. – 15% Contributed to the conception of study, manuscript review and feedback, data analysis, editing of manuscript
5	Measuring activity following free functioning muscle transfer for pan-brachial plexus injury: A case series	Submitted	82% - Conception of study, collecting data and data analysis, and writing complete first draft, subsequent editing, preparation of final manuscript	1) Thomacos, N. – 6% Contributed to the conception of study, supervised data analysis, preparation of manuscript 2) Hill, B. – 6% Contributed to the conception of study, manuscript review and feedback, supervised data analysis, preparation of manuscript 3) McCulloch, M. – 3% Contributed to the conception of study, data gathering, manuscript review and feedback 4) Ferris, S. – 3% Contributed to the conception of study, manuscript review and feedback

6	Participation following brachial plexus injury: An Australian case series.	Submitted	90% - Conception of study, collecting data and data analysis, writing complete first draft, subsequent editing, preparation of final manuscript	1) Brown, T. – 5% Contributed to the conception of study 2) Thomacos, N. – 5% Contributed to the conception of study, supervised data analysis, preparation of manuscript
7	The lived experience following free functioning muscle transfer for management of pan-brachial plexus injury: reflections from a long-term follow-up study.	Published	70% - Conception of study, collecting data and data analysis, and writing complete first draft, subsequent editing, preparation of final manuscript	1) White, J. – 10% Contributed to the preparation of study, data analysis 2) Thomacos, N. – 10% Contributed to the preparation of study, supervised data analysis 3) Hill, B. 10% Contributed to the conception of study, supervised data analysis, reviewed manuscript
8	Effective long-term management of brachial plexus injury following surgery: what is needed from hand therapists' perspectives.	submitted	75% - Conception of study, collecting data and data analysis, and writing complete first draft, subsequent editing, preparation of final manuscript	1) White, J. – 10% Contributed to the conception of study, data analysis, preparation of the manuscript 2) Thomacos, N. – 10% Contributed to the conception of study, supervised data analysis, preparation of the manuscript 3) Hill, B. 5% - Contributed to the conception of study, supervised data analysis, preparation of the manuscript

*If no co-authors, leave fields blank


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

Student signature:

Date: 23/Aug/2021

The undersigned hereby certify that the above declaration correctly reflects the nature and extent of the student's and co-authors' contributions to this work. In instances where I am not the responsible author, I have consulted with the responsible author to agree on the respective contributions of the authors.

Main Supervisor signature:



Date: 23/Aug/2021

Spelling and Layout

The American Psychological Association (APA) 7th Edition *Publication Manual* has been used as a guiding reference for writing this thesis (American Psychological Association, 2020). In accordance with APA7 guidelines, this thesis has been written in past tense. Australian spelling has been used throughout the text except in quotations and names of organisations, etc. where the original spelling has been maintained. Footnotes have been used sparingly in accordance with APA7 guidelines.

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Abbreviations

BPI = brachial plexus injury

BrAT = Brachial Assessment Tool

Brief COPE = Brief Coping with Problems Experience

COPM = Canadian Occupational Performance Measure

CMOP-E = Canadian Model of Occupational Performance-Engagement

DASH = Disability of the Arm, Shoulder and Hand

FFMT = free functioning muscle transfer

ICF = International Classification of Functioning, Disability, and Health

Pan-BPI = pan-brachial plexus

MHQ = Michigan Hand Outcomes Questionnaire

mSWAP = Modified Satisfaction with Appearance Scale

SAS = Self Rating Anxiety Scale

SDS = Self-rating Depression Scale

SF-36 = Medical Outcomes Study: 36-Item Short Form Health Survey

UEFI = Upper extremity functional index

WHO = World Health Organization

Chapter 1 - Introduction and Overview

1.1 Chapter Introduction

This chapter provides an overview of this thesis and introduces the frameworks that have been used to operationalise the various investigations that make up this thesis. The focus and scope of the thesis emerged from the author's clinical work, as an occupational therapist working in hand therapy, with individuals who had sustained brachial plexus injuries (BPIs). Hand therapists, in Australia, are registered occupational therapists or physiotherapists who have gained additional education and clinical experience in the area of upper limb conditions (Australian Hand Therapy Association, 2015). Hand therapists routinely treat musculoskeletal conditions of the upper quadrant (i.e., tendon injury/ repair, distal radius fractures, carpal tunnel syndrome, tendon injuries, joint pathologies) (Takata et al., 2017).

The majority of the author's case load (non-BPI) in the private practice was managed with treatment programs that commonly lasted 4-6 months, with most patients returning to pre-injury / pre-surgical activities. However, clinical observation of patients following BPI indicated that these patients are commonly involved in many years of rehabilitation, with the injury resulting in significant and on-going disruption to their daily life, roles, and routines – often with minimal physical gains noted. Working with these patients in rehabilitation following discharge from hospital and witnessing both the challenges they experienced, and resilience demonstrated by them, led to questions about the therapeutic management and outcomes of these patients. The most severely impacted were individuals who underwent free functioning muscle transfer (FFMT) surgery for

management of pan-BPI. Additional information about this sub-population of BPI will be explored in Chapter 2.

1.2 Theoretical Framework

Hand therapy aims to enable patients “to execute tasks and to participate fully in life situations” (Dimick et al., 2009, p. 374) by incorporating goals that focus on health, well-being, function, wellness and activity-participation (Lucado et al., 2018). The research literature acknowledges that upper extremity injuries negatively impact patients’ ability to participate in daily life (Takata et al., 2017). A theoretical framework provides a structure through which one can consider a concept, specific relationships between them, and provide a way of thinking about a concept (Baum et al., 2015). This thesis will utilise a biopsychosocial framework as this is congruent with the author’s area of practice as an occupational therapist working in the field of hand therapy.

A biopsychosocial perspective of health goes beyond physical health (disease or injury) and considers mental health, social participation, environmental factors and the resulting impact on participation in life situations, activities, and occupations (Peterson et al., 2010; Reed & Sanderson, 1999; Turpin & Iwama, 2011). The development and analysis of this thesis were guided by two biopsychosocial models: the International Classification of Functioning, Disability, and Health (ICF; World Health Organization, 2001) and the Canadian Model of Occupational and Engagement (CMOP-E; Canadian Association of Occupational Therapists, 1997; Townsend & Polatajko, 2007). Both the ICF and occupational therapy models (including the CMOP-E) consider health and well-being through a biopsychosocial lens and are composed of similar concepts (Stamm et al., 2006). Both models contain a number of health-related factors that focus on the: person,

execution of tasks, involvement in life roles, and environmental and personal factors (Polatajko et al., 2013) (Table 1).

Table 1

Relationship of ICF and CMOP-E Concepts

	Person factors	Execution of tasks	Involvement in life roles	Environmental and personal factors
ICF (World Health Organization, 2001)	Body function and structure	Activity	Participation	Contextual factors
CMOP-E (Townsend & Polatajko, 2007)	Affective, cognitive, physical, & spirituality	Activities are composed of tasks, which are composed of voluntary movement and/ or mental processes	Performance and engagement of occupational roles	Physical, institutional, cultural, social

Note: ICF= International classification of health and disability; CMOP-E = Canadian Model of Occupational Performance.

A biopsychosocial theoretical perspective is the foundation for this thesis and has shaped the development of the research questions and methodology. This theoretical foundation has been operationalised through two models: the ICF (World Health Organization, 2001) and the CMOP-E (Townsend & Polatajko, 2007). The ICF (World Health Organization, 2001) and its terminology were applied in the methodology and manuscripts (Chapters 4-8). The rationale for using the ICF framework and terminology in the manuscripts is two-fold. It provides a common language that can be understood across health professions and the resulting publications will be made available to a broader

audience of health care professionals who may come into contact with the population group focussed on in this thesis. The discussion (Chapter 9), will then synthesise and consider the results of all the investigations in this thesis using an occupational therapy model – the CMOP-E (Townsend & Polatajko, 2007). Taking an occupationally-grounded perspective is both beneficial for occupational therapists working with this population, but is also reflective of this thesis being conducted in the Department of Occupational Therapy.

The ICF has the following domains related to an individual's health: body function and structure, activity, participation, and contextual factors (environmental and personal) (World Health Organization, 2001). The CMOP-E has domains that are congruent with the ICF and they are: person, occupation, environment, and occupational performance and engagement (Townsend & Polatajko, 2007). While these two models overlap conceptually, the CMOP-E includes key considerations not well considered in the ICF. One limitation of the ICF is that it does not adequately acknowledge the subjective experience of the individual which is key in occupational therapy models that prioritise a client-centred philosophy (Ennals & Fossey, 2017). This subjective experience is captured in the CMOP-E by the person domain. It has also been discussed that the ICF domains for activity and participation are poorly conceptualised (Bakas et al., 2012; Hemmingsson & Jonsson, 2005), however these are concepts that thoroughly developed in the CMOP-E (Polatajko et al., 2004).

In line with the decision to use the ICF across the publications of this thesis, the term *patient* will also be used to refer to the individuals with BPI. It is acknowledged here that this term is not commonly used by occupational therapists as it implies the person is sick and can be stigmatising (Herzberg, 1990), but will be used in this thesis so that what is

included the manuscripts (Chapters 4-8) is both in line with the ICF and consistent with the current literature (Cole et al., 2020; Kahn & Moore, 2016).

1.3 Frames of Reference

Frames of reference are used to make explicit a set of assumptions and values. This research applies principles of both a biomedical and rehabilitation (restorative and compensatory) frames of reference to explore the post-operative recovery of patients following traumatic, pan-brachial plexus injury (pan-BPI). They have been used to direct inquiry and understand findings included in this thesis. The biomedical framework views health as the absence of illness/ impairment, with interventions focussed on remediation of limitations (e.g., weakness, reduced range of motion, oedema, etc.) (Curtin et al., 2013). Remediation is clearly a priority and necessary to maximise physical outcomes following reconstructive surgeries and this biomedical frame of reference predominates BPI outcomes reporting (Hoang et al., 2018), BPI therapeutic interventions (Cole et al., 2020; Kahn & Moore, 2016), and the broader hand therapy literature (Robinson et al., 2016). A rehabilitative approach, by comparison, emphasises the individual's strengths and maximises occupational performance through adaptation, compensation and environmental modification (Gillen, 2013). The biomedical/ remediation approach following pan-BPI is needed for maximising gains following reconstructive surgery, while individuals experience a slow recovery with on-going physical impairment that will require adaptation and compensation for them to complete everyday tasks that are better addressed using the rehabilitative approach (Liu et al., 2013).

While biomedical and rehabilitative perspectives are appropriate frames of reference for management of BPI, they do not capture some key aspects observed in the pan-BPI population. One approach that may better accommodate this sub-population that

experienced permanent impairment and adjustment to injury following pan-BPI is the recovery model. The recovery approach is most commonly used in mental health care, but has been applied to physical rehabilitation (Bennett et al., 2013). The recovery model is a strength-based approach that focusses on promoting personal adaptation and adjustment, promoting social inclusion, and empowering the individual (Repper & Perkins, 2003).

Treatment and assessment can be approached using a top-down or bottom-up approach (Brown & Bourke-Taylor, 2021). A bottom-up approach aligns with the biomedical/ rehabilitative frames of reference and considers the body function and structure components of an individual's ability (Brown & Bourke-Taylor, 2021). A top-down approach is focussed on physical and social components and daily participation outcomes (Khetani et al., 2012). The recovery model of care takes a top-down approach to assessment and treatment to that focusses on meaningful participation and social connectedness that may otherwise be missed in a bottom-up approach (Hocking, 2010). Considering the impact and course of pan-BPI injury and therapy, the recovery model has been used to examine the findings from the studies included in this thesis (Chapter 10).

1.4 Thesis Rationale

There are few BPI studies that evaluate long-term outcomes or focus on quality of life (Miller et al., 2019). The findings from the investigations in this thesis will contribute to the existing literature by reporting long-term outcomes in a holistic manner that will provide a more nuanced examination of this small, but distinct population. This thesis will explore factors related to patients' return to meaningful daily occupations and subsequently consider the rehabilitation priorities that would enhance patients' post-injury outcomes. The research contained in this thesis aims to do more than just identifying objective outcomes; and considers and reflects on the client-centred care currently being provided

post-operatively. By reviewing the existing literature, patients' perspectives, and the insights of therapists that work with this population, the current research aims to provide a deeper understanding of the experience of this type of injury and subsequent outcomes. Although each individual patient must have a rehabilitation program that is specifically tailored to them, identifying common themes for this cohort will assist health care practitioners working with this diagnostic group.

1.5 Thesis Aim and Question

This thesis utilised a pragmatic methodology that informed the nature and scope of the investigations undertaken in order to address the thesis' overall question:

What are the experiences and psychosocial outcomes following free functioning muscle transfer reconstructive surgery for management of pan-brachial plexus injury in Australia?

This question facilitated the planning of five investigations that aimed to better understand long-term outcomes following free functioning muscle transfers (FFMT) reconstructive surgery following traumatic, pan-BPI in Australia. The pan-BPI population and FFMT reconstructive surgery are more thoroughly explored in the next chapter.

1.6 Overview of Thesis Structure

The purpose of the current research was to describe the health outcomes for individuals following BPI in Australia. A number of investigations employing a mixed methods design were planned using a pragmatic paradigm (Creswell & Poth, 2018; Johnson & Onwuegbuzie, 2004; Morgan, 2007). The use of a mixed methodology is based on a belief that knowledge is best generated from diverse theories and sources (Creswell & Poth, 2018). As stated, this research was borne from questions arising from clinical practice, and key principles of pragmatism are congruent with the current investigations in

that this methodological approach allows selection of methodology to be dictated by the purposes of each investigation, as well as, the recognition that research occurs in a social political and cultural context (Creswell & Poth, 2018; Liamputtong, 2017). The latter principle aligns with the biopsychosocial models of the ICF (World Health Organization, 2001) and occupational therapy (Townsend & Polatajko, 2007) and therefore is in keeping with the aim of this thesis. The thesis structure is described below.

Chapter 1 aims to provide an introduction and overview of the thesis. This chapter provides the theoretical foundations used in this thesis, explores frames of reference relevant to the identified population of interest (pan-BPI), and briefly outlines the content of the chapters in the thesis.

Chapter 2 is a literature review about traumatic BPI that provides background information on the anatomy, aetiology, and management following injury. Specific BPI diagnoses are not well researched; instead, regardless of level of lesion or severity of injury, this population is often discussed in the literature as a singular population – traumatic, BPI. Chapter 2 discussed pan-BPI, where the literature allows, and BPI more broadly where this is the only literature available. The chapter outlines the variations of injury diagnosis and presentation; explores common surgical procedures performed, reviews therapeutic approaches to rehabilitation, and identifies existing gaps in the literature.

Chapter 3 outlines the methodology of each investigation that make up this thesis. The chapter also outlines the links between the included investigations and the theoretical foundation of the thesis.

Chapters 4-8 contain manuscripts for publications related to the five investigations included in this thesis. These chapters include the peer-reviewed manuscripts that have been submitted for peer-review (one manuscript has been published and the other four are currently under review). The corresponding abstracts and manuscripts are formatted as required by the journal to which they were submitted. Chapter 4 is a scoping review aimed at locating literature related to the population and identifies what psychosocial outcomes are currently being reported. This serves multiple purposes. First, it illustrates what outcomes the current literature prioritises in measuring and reporting. Second, it identifies studies for descriptive comparison with the investigations in this thesis.

Chapter 5 and 6 are manuscripts that relate to two quantitative, case series investigations that report on the long-term outcomes of activity and participation following traumatic, pan-BPI. These two domains were selected for a few reasons. Firstly, the scoping review (Chapter 4) identified that an activity-based outcome measure was the most used following FFMT surgery following strength and range of movement measures. Secondly, no studies were identified by the scoping review that assessed participation using a reproducible measurement tool. Finally, the domains of activity and participation are central to occupational therapy (Polatajko et al., 2013), the practice area of the researcher. Chapter 5 contains a manuscript that examines two patient reported outcome measures of activity, comparing the most commonly used measure and a new measure of activity validated for use with a BPI population. Chapter 6 is a quantitative investigation that reports on the long-term, participation outcomes of patients following traumatic, pan-BPI using a participation-specific outcome measure.

The next two chapters are qualitative investigations. These chapters aim to better understand the subjective experiences of recovery following pan-BPI. Chapter 8

investigates the experience of individuals following traumatic, pan-BPI. This investigation aims to better understand recovery from the perspective of the patient and the factors that impact their engagement in daily life following injury. Chapter 9 uses focus groups to explore the concept of rehabilitation and recovery following traumatic, BPI from the perspective of allied health service providers. This final investigation aims to gather data from clinicians and thus offer a different perspective on life post pan-BPI to what was reported on and explored with patients. It also provides the opportunity for the triangulation of data and findings from the investigation involving patients (Chapter 6). To help illustrate the structure of the investigations (Chapters 4-8), the five investigations undertaken are mapped below in Table 2.

The final chapters of this thesis (9 & 10) discuss the results of all the investigations and highlights key findings. Chapter 9 is an integrated discussion of all the above-mentioned investigations, and the thesis concludes with practice implications, limitations, and recommendations for future research (Chapter 10).

Table 2*Investigations in This Thesis*

		Questions	Aims	Methodology
Theory & evidence	Investigation 1 (Chapter 4)	What psychosocial outcomes are currently reported for individuals following FFMT surgery for management of traumatic BPI?	To identify outcome measures used to report psychosocial outcomes following FFMT surgery for the management of traumatic, BPI.	Scoping Review
Activity and Participation	Investigation 2 (Chapter 5)	1) What are long-term, activity-related outcomes for individuals with pan-brachial plexus injuries following FFMT reconstructive surgery in Australia? 2) How do these outcomes relate to other similar populations?	To report long-term, activity outcomes of individuals following pan-BPI following FFMT reconstructive surgery in Australia.	Quantitative, case series Methodology: Descriptive analysis, One-sample t-tests
	Investigation 3 (Chapter 6)	1) How do individuals report objective and subjective experiences of participation in life situations following surgery for management of a BPI? 2) What frequency, restriction, and satisfaction outcomes are reported for participation?	Report on the objective and subjective experience of participation following FFMT surgery for management of complete, TPBI.	Quantitative, case series Methodology: Descriptive analysis, One-sample t-tests
Patients' lived experiences	Investigation 4 (Chapter 7)	What are patients' experiences following pan-BPI and FFMT surgery?	To explore the experience following FFMT reconstructive surgery for management of flail limb, traumatic BPI to better understand the issues that occur during recovery and the implications for improving health services when managing this type of injury.	Qualitative Methodology: Interpretative phenomenological analysis

Health professionals' perceptions	Investigation 5 (Chapter 8)	<p>1) What outcomes do health professionals aim to achieve following FFMT for management of pan-BPI?</p> <p>2) What are health providers thoughts on factors related to outcomes following surgery for pan-BPI?</p> <p>3) Identify factors perceived to support/ challenge rehabilitation</p>	Explore health professionals' experience of rehabilitation following FFMT for management of pan-BPI?	<p>Qualitative</p> <p>Methodology: Thematic analysis</p>
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1.7 Definitions of Key Terminology

The following is a list of key terms that will be used throughout this thesis.

Activity – “execution of a task or action by an individual” (World Health Organization, 2001, p. 193).

Brachial plexus – the anatomical name given to the nerves arising from spinal roots C5-T1 that travel through the neck, axilla and upper limb to provide innervation to our shoulder, arm and hand (Wilbourn, 2006).

Brachial plexus injury – Closed, traumatic injuries caused by closed, stretch injuries variable lesion pattern and variable potential for spontaneous recovery (Hems, 2015).

Biomechanical – Biomechanics refers to the “application of mechanical principles in the study of living organisms” (Hall, 2019, p. 495). Biomechanical in this thesis is contextualised to capture a biomedical perspective of the upper limb and includes movement, strength, and sensation. These factors demonstrate the muscular and neurological consideration of biomechanics.

Occupation – “groups of activities and tasks of everyday life, named, organized and given value and meaning by individuals and a culture” (Townsend & Polatajko, 2007, p. 377).

Pan-BPI – nerve injuries to the root and/ or trunk levels of C5-T1, sometimes referred to as a flail limb, complete-, total-, or global-BPI (Wali et al., 2017).

Participation – “involvement in a life situation” (World Health Organization, 2001, p. 193).

Psychosocial – This term refers to a group of theories, models, and interventions that recognise the influence of personal and environmental factors as they relate to an individual’s functioning, participation in everyday life, and quality of life (Chan et al., 2009). Psychosocial refers to “human psychological, emotional, and social function and experience that occurs within daily occupations carried out in context” (Krupa, 2016).

1.8 Chapter Summary

This chapter has provided an outline of the research project. This thesis consists of five investigations, and each has been included here as a submitted manuscript or published paper. It has detailed the theoretical underpinnings of the project and identified and defined key terminology relevant to this thesis. The next chapter is a literature review of brachial plexus injuries and patient care.

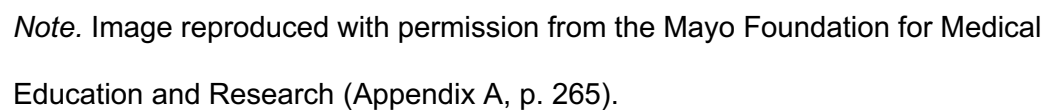
Chapter 2 - Background

2.1 Introduction

The purpose of this chapter is to review and summarise the existing literature related to the anatomy, aetiology, surgical management, and post-operative care following traumatic, pan-BPI. This review will establish what is currently known about this population and identifying gaps in knowledge. The subpopulation of pan-BPI will be explicitly reviewed where the literature is available as they are the focus of this research.

A plexus is a complex network of nerves and there are a number of spinal plexuses (Kelly & Leonard, 2012). The term brachial denotes the anatomical location and innervation of the plexus related to the arm. Therefore, the brachial plexus is the anatomical name given to the nerves arising from spinal roots C5-T1 that travel through the neck, axilla and upper limb to provide innervation to our shoulder, arm and hand (Wilbourn, 2006) (Figure 1). BPIs have a variety of sensory and motor presentations depending on the mechanism, level, and pattern of injury (Kang & Wolfe, 2011). Closed, traumatic injuries are most commonly caused by road traffic injuries, especially motorcycle accidents, and frequently result in serious injury (Hems, 2015). These closed, stretch injuries can cause severe lesions with variable potential for spontaneous recovery (Hems, 2015). Brachial plexus injuries commonly present with weakness, sensory changes, pain, and difficulty completing daily tasks (Kelly & Leonard, 2012). Knowledge of the type and extent of injury to the neuroanatomy of the nerve is essential for planning appropriate management.

Image of the Left Brachial Plexus



The degree of injury is classified on the extent of nerve damage. The severity of nerve pathology is categorised based on a classification, such as, *Seddon's classification of nerve injury* (Smith, 2011). This well-known classification system describes graded levels of nerve injury related to the type and extent of injury to the neuroanatomy of the nerve. Seddon's classification grades from neurapraxia (temporary conduction block, likely to resolve spontaneously), to axotomesis (axonal loss, variable potential for

spontaneous recovery), to neurotmesis (nerve divided and no conduction, surgical repair required for recovery) (Hems, 2015). Injury to the brachial plexus can occur in a number of ways and is discussed below.

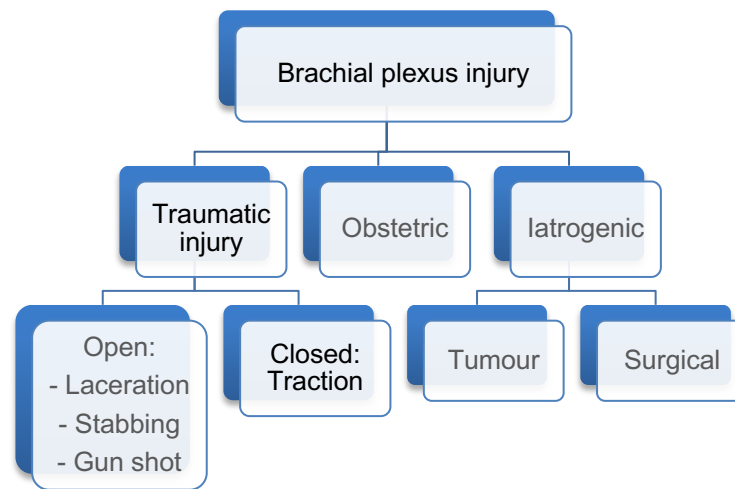
2.2 Epidemiology of BPI

Injury to nerves of the brachial plexus can occur in a myriad of ways (

Figure 2). Obstetric brachial plexus palsy occurs during birth. Some BPIs can also be acquired secondary to surgery or compression due to a tumour (Wilbourn, 2006). BPI can be a result of a closed or open injury (Wilbourn, 2006). An open injury frequently occurs as a result of laceration, stabbing, or gunshot injury (Wilbourn, 2006). A closed, traction injury is the most common plexopathy (Marzouk et al., 2006). It can result from a variety of mechanisms including road traffic injuries as well as leisure activities (i.e., cycling, snow mobile riding and water skiing) (Kaiser et al., 2018; Midha, 1997; Tonkin et al., 1996). Damage from a traction injury results from over-stretching of the plexus, generally when the head and neck move in one direction and the arm and shoulder move in the opposite direction (Moran et al., 2005).

Figure 2

Main Mechanisms of Injury to the Brachial Plexus



Note. Adapted from Wilbourn (2006).

There has also been an increase in the number of traumatic BPis in the past few decades linked to life saving advances in health care and increased legislation for compulsory helmet use on motorbikes (Agarwal et al., 2021; Wilbourn, 2006). Most adults with brachial plexus injuries are young men who survive high-speed accidents and have sustained closed traction injuries (Moran et al., 2005; Yang et al., 2012). It has been reported that motorcycle accidents account for 67% of closed BPI (Kaiser et al., 2018). It is unknown if the mandated use of helmets for motorcyclists has directly increased the incidence rate of traumatic BPI, but it is likely that motorcyclists who have sustained a BPI would have died without a helmet are now surviving (Ciaramitaro et al., 2010).

Geography and culture influence the prevalence and severity of injuries. In Southeast Asia there is a high incidence rate of BPI as motorbikes

are frequently used for transportation (Jain et al., 2012). While the prevalence in the general population of Australia is lower, BPI injuries are linked to road traffic accidents - with one study reporting that 53% of the patients with BPI sustained them in road traffic accidents (Cole et al., 2020). While BPIs are commonly accompanied with fractures, soft tissue injuries, and brain trauma (Midha, 1997; Narakas, 1985 as cited in Moran et al., 2005), some locations outside the Western world report less severe concomitant injuries based on the decreased travelling speed of vehicles (Jain et al., 2012). Severe or life-threatening co-morbid conditions can sometimes delay BPI diagnosis because patients are either unconscious or sedated. These co-morbid conditions, combined with the variable injury pattern of BPI, are factors that contribute to the heterogeneous symptom presentation of this patient population (Giuffre et al., 2010; Krishnan et al., 2008; Moran et al., 2005).

When considering a BPI, there are a number of factors that must be acknowledged including the level and pattern of lesion (Kang & Wolfe, 2011). Anatomical location is often used and references the location of injury within the brachial plexus (i.e., at the level of the roots, trunks, divisions, and/or cords – Figure 1). An alternative classification of injury uses anatomical position of damage by describing the injury relative to the clavicle: supraclavicular (plexopathies of the roots and trunks) or infraclavicular (injury to the cords and/or terminal branches) (Wilbourn, 2006). Supraclavicular BPI can be further classified based on the level of lesion: upper-plexus, lower-plexus, or pan-plexus injury (Kaiser et al., 2018). An upper-plexus injury (C5, C6 +/- C7) results in impairment of the shoulder and elbow (Hems, 2015). A lower-plexus injury (C8-T1) results in an impairment of the wrist and hand

(Hems, 2015). A pan-plexus injury (C5-T1), sometimes referred to as a total plexus injury or flail limb, results in motor impairment of the shoulder, elbow, wrist, and hand, as well as a global upper limb deficit (Hems, 2015). As noted by Bentolila et al. (1999), a pan-BPI may have “partial or fully active trapezius, levator scapulae, rhomboids and serratus anterior” (p. 21). Pan-BPI patients generally have an injury to the root or trunk.

This thesis focuses on individuals who have sustained injury that resulted in a functional deficit consistent with a pan-BPI (C5-T1). Both in this chapter and across the thesis, some information will be discussed that is general to BPI, while some will be specific to pan-BPI. This is because many of the treatment and management approaches for BPI apply to the pan-BPI sub-population. However, pan-BPI is being considered explicitly in this thesis because of its severity results in more significant and global deficits involving the whole upper limb.

Reporting the prevalence and incidence of pan-BPI is challenging for multiple reasons. Firstly, as demonstrated above the classification of BPI can vary between authors (Welbourne, 2006; Kaiser et al., 2018; Hems, 2015; Chuang, 2008a). The second reason is that often studies report a range of lesion patterns as one population (Cole et al., 2020). It is likely that this is done to provide larger sample sizes for statistical analysis and data reporting. As a result the authors were not able to locate any published prevalence or incidence figures for this specific pattern of lesion.

2.3 Surgical Management for BPI

Reconstruction of the plexus has been revolutionised over the last few decades with advances in microsurgery (Moore & Novak, 2014). Prompt repair of nerves (e.g., direct repair or nerve transfer) is key, as prolonged absence of innervation results in irreversible atrophy of muscles (Smania et al., 2012; Yang et al., 2012). It is generally accepted that motor end plates cannot survive without nerve stimulation beyond 18 months (Lee & Wolfe, 2012; Smania et al., 2012). It is also preferable that surgery is performed between 3-6 months post-injury to allow the opportunity for signs of spontaneous nerve recovery (Kang & Wolfe, 2011).

Brachial plexus surgery consists of primary and secondary reconstruction (Shin et al., 2005). Primary reconstruction typically involves nerve surgery and secondary reconstruction includes soft tissue procedures such as tendon/ muscle transfer and bony procedures (e.g., arthrodesis) (Brophy & Wolfe, 2005). Priorities for surgical restoration are generally agreed on as follows (Brophy & Wolfe, 2005; Giuffre et al., 2010; Lee & Wolfe, 2012; Shin et al., 2005; Vekris et al., 2008):

- Elbow flexion
- Shoulder - abduction, external rotation, scapular stabilisation
- Elbow extension
- Sensory to the median nerve distribution

While restoration of ulnar and median nerves can be problematic following pan-BPI, sensation of the median nerve distribution should be attempted where possible, as it has been shown to relieve pain (Brophy & Wolfe, 2005).

Surgical options vary depending on many factors including time since injury, degree of nerve injury and availability of viable donor nerves (Chuang, 2008b; Kline & Tiel, 2005; Lee & Wolfe, 2012; Moore & Novak, 2014). This last point is particularly significant following pan-BPI as there are fewer available donor nerve options than with partial BPIs (Dodakundi et al., 2013; Lanier et al., 2020). Donor nerves are used during nerve transfers, and represent expendable nerves or fascicles that are transferred to an injured nerve to reinnervate and restore function to a denervated, recipient muscle (Midha & de Villiers Alant, 2012). Nerve transfers are also used to reinnervate the transferred muscle following FFMT.

Table 3, below, summarises possible reconstructive procedures in order of surgical priority following pan-BPI. It is not meant to be an exhaustive list of options or even a reflection of best practice, as the discussion is still ongoing regarding the benefits and risks of some procedures (Giuffre et al., 2010); however, it does provide an overview of the current surgical options for the management of pan-BPI.

Table 3*Reconstructive Procedures for Restoring Function Following Pan-brachial Plexus Injury*

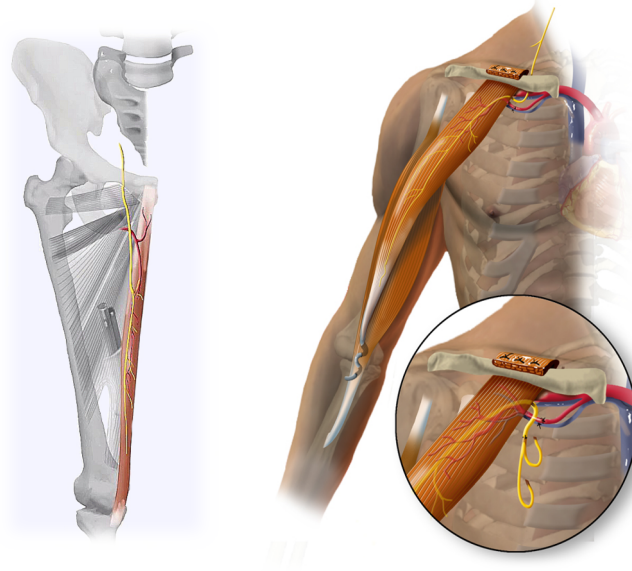
Action	Procedure	Donor	Recipient
Elbow flexion	Nerve transfer (Ruch et al., 1995)	Intercostal nerve	Musculocutaneous (biceps and/or brachialis)
		Donor nerves - Intercostal motor nerves or spinal accessory nerve	
Elbow flexion	Free functioning muscle transfer (Doi et al., 2000; Shin et al., 2005)	Donor muscles- Gracilis (anterior division of the obturator nerve or Latissimus dorsi (thoracodorsal nerve) (Doi et al., 2000)	The transferred muscle is often secured proximally at the clavicle and distally to the distal biceps tendon.
Shoulder movement	Nerve transfer	Spinal accessory nerve (Colbert & Mackinnon, 2008) or Phrenic nerve (Gu, 1996)	Suprascapular nerve
Shoulder stability	Glenohumeral arthrodesis (Doi et al., 1995)	Not applicable	Not applicable
Shoulder abduction	Nerve transfer (Leechavengvongs et al., 2003)	Spinal accessory nerve or triceps branch of radial nerve	Axillary nerve

Elbow extension	Free functioning muscle transfer (Doi et al., 1995)	Intercostal nerve (if not already used for elbow flexion)	Radial nerve (triceps branch)
Hand sensibility	Nerve transfer (Berman et al., 1996)	Intercostal nerve	Median nerve
Wrist and hand function	Free functioning muscle transfer (Doi et al., 2000; Giuffre et al., 2010)	As above for elbow flexion, but the distal end is attached to finger flexor tendons or finger extensor tendons.	
Wrist and hand function	Contralateral C7 (CC7) (Gu et al., 1998)	Uninjured contralateral C7 (partial or whole)	Median nerve

Patients who have sustained a pan-BPI often have poor outcomes for hand re-animation due to the physiological distance between healthy nerves and the location the injured muscles of the hand (Aszmann et al., 2015). There are two free functioning muscle transfer (FFMT) surgical techniques discussed in the literature (Doi et al., 2000; Giuffre et al., 2010) and described in Table 3 under the actions elbow flexion and extension. Doi et al. (2000) described a double gracilis transfer which uses the first FFMT to restore elbow flexion and finger extension and the second to restore finger flexion (Doi et al., 2000). Subsequently, Giuffre et al. (2010) have modified this technique using a single FFMT to restore elbow flexion combined with finger reanimation to enable key pinch and grasp. As both surgical techniques involve the transfer of muscles that cross multiple joints including the shoulder, this is an important consideration in terms of post-operative care as well as biomechanically with respect to rehabilitation. Figure 3 illustrates the gracilis muscle in situ anatomically (image on left) and an image of the muscle following an FFMT procedure (image on right).

Figure 3

Single Free Functioning Muscle Transfer Image (Left) with the Gracilis Muscle, a Common Donor Muscle Used for FFMT Reconstructive Surgery (Right).



Note. Images used with permission from Penn Clinical Briefings™ (Appendix A, p. 267).

Subsequent surgeries then consider maximising function by providing stability or improved positioning of the upper limb. Wrist fusion surgery often occurs to stabilise the otherwise flaccid wrist joint (Terzis & Barmptsioti, 2009). To improve reanimated hand movement, intrinsic replacement surgery, such as the Zancolli-Illasso, is considered (Dodakundi et al., 2013). Finally, shoulder arthrodesis is another option that is considered to provide proximal stability to enhance function of reanimated elbow and/or hand movement (Doi et al., 2000). As one would expect, such complex procedures require intensive rehabilitation following surgery.

2.4 Therapeutic Management of Patients Following FFMT

Specialised rehabilitation following BPI and reconstructive surgeries is recommended (Frampton, 1986; Kahn & Moore, 2016; Kinlaw, 2005); and the

literature has stressed the role of a certified upper extremity rehabilitation therapist to provide appropriate assessment and treatment. Despite this, there is a paucity of published articles regarding post-operative therapy interventions for the pan-BPI group. The absence of such studies has been noted by authors who publish in this area (Novak & von der Heyde, 2013).

The lack of published studies regarding post-operative care following FFMT may be attributed to the fact that this injury does not affect a large number of individuals combined with the unique and individual nature of the rehabilitation procedures utilised. Instead, established rehabilitation concepts of post-operative care (i.e., wound healing/care, passive ranging, oedema management, scar management, tendon transfer and nerve transfer) are considered along with sound clinical reasoning (Scott et al., 2013) when providing post-operative care following BPI and reconstructive surgery. Clinicians integrate therapeutic interventions designed to maximise functional return of the injured limb (Scott et al., 2013). Then once outcomes have been maximised, if independence has not been reached, interventions are aimed at adaptation to meet client goals (Scott et al., 2013). The key rehabilitation principles following FFMT surgery for pan-BPI are considered below using the BPI literature available.

Several authors have contributed to the broader BPI-related therapeutic literature (Cole et al., 2020; Frampton, 1986; Kahn & Moore, 2016; Kinlaw, 2005). Although, they do not address FFMT specifically, they do consider many of the salient issues that apply to both partial and pan-BPI care and rehabilitation including:

- patient education (injury, surgery, prognosis)
- wound care

- range of motion (passive, active-assist and finally active)
- protection of healing tissue (patient education, orthosis fabrication, sling use)
- cortical retraining (maintain sensory-motor cortex, neuroplasticity: neuromuscular re-education, biofeedback)
- sensory education (precautions for in-sensate areas, desensitisation, re-education)
- pain management education/ referral
- assessment (initial and on-going).

Pan-BPI patients undergo multiple reconstructive surgeries, and each will have unique post-operative considerations (Doi et al., 2000). Frampton (1986) states this succinctly,

Reconstructive surgery in brachial plexus lesions is more complicated than in peripheral nerve injuries because of the complex nature of the injuries, poor proprioception, weakness of the muscle for transfer and the need on occasions to plan a series of operations (p. 7).

The following will consider rehabilitation following pan-BPI from a biopsychosocial perspective. This is consistent with the theoretical models outlined in Chapter 1, the ICF (World Health Organization, 2001) and the CMOP-E (Townsend & Polatajko, 2007), and consider health as involving a range of biomedical and non-biomedical domains.

2.4.1 Biomedical

A biomedical model conceptualises health in terms of the presence or absence of illness or impairment, with interventions focussed on curing these states (Curtin et al., 2013).

2.4.1.1 Nerve Surgery. Novak (2008; 2013) has written comprehensive post-operative recommendations on the topic of nerve injury and transfer rehabilitation. Rehabilitation following nerve transfer strongly influence post-operative FFMT care as a nerve transfer is required as part of an FFMT operation. Post-operative care following nerve repair or transfer involves a period of immobilisation for 1-3 weeks depending on the tension of the repair and any specific instructions given by the surgeon (Novak & von der Heyde, 2013). One key difference with rehabilitation following nerve transfer, as opposed to nerve repair, is the need for patient education regarding activation of the donor muscle initially in order to activate the recipient muscle (Novak, 2008). This is a similar process to re-education following tendon transfer (Novak, 2008).

2.4.1.2 Cortical Retraining. The continuity of brain to fingertip is critical during rehabilitation. "Next to the brain, the hand is man's greatest asset and to it is due the development of man's handiwork. The hand begins in the opposite cerebral cortex and extends from there to the tips of the nails." (Stirling Bunnell, as cited by Sabapathy & Soucacos, 2013, p. 282). As such, cortical retraining is required following nerve transfer surgery and the FFMT procedure. During nerve transfers, surgeons take some of a healthy nerve's motor and/or sensory fibres and transfer them to the injured (recipient) nerve distal to the site of the pathology (Lee & Wolfe, 2012). Chen et al. (2003) investigated neuroplastic changes following muscle transfer and concluded that there is evidence of plasticity. Neuroplasticity refers to the brains ability to make changes to neural connections and occurs normally to everyone through their life span (Anastakis et al., 2008); and assists recovery following injury to the nervous system. Rehabilitation following FFMT requires the brain, given its neuroplasticity, to retrain the activation of transferred muscle via a

new nerve pathway to activate the transferred muscle. For example, if nerve fibres from the intercostal nerve are transferred to the FFMT, the nerve fibres that activated the intercostal muscle (respiration) pre-operatively, will activate the transferred muscle (e.g., gracilis muscle) to enable elbow flexion.

Cortical retraining following nerve transfers is recommended as it influences the return of muscle function following nerve transfer surgery (Kahn & Moore, 2016; Sturma et al., 2019). The key strategies for cortical retraining following nerve transfer include: pre-operative training of the donor muscle, repetition, early activation post-operatively in gravity reduced positions, therapist supervised practice, and strengthening and endurance up to 2 years following reconstructive surgery (Anastakis et al., 2008).

Beisteiner et al. (2011) conducted a small, but informative study which found that in the two patients studied, following end-to-side coaptation of the phrenic nerve to the musculocutaneous nerve, patients were able to activate their diaphragm (phrenic nerve) and bicep muscle (musculocutaneous nerve) independently. This ability to isolate the recipient muscle without activating the donor muscles is sometimes referred to as uncoupling. Clinical observations by the author have been inconclusive, with some patients successfully uncoupling the donor activation from the recipient muscle. However, even those that do successfully uncouple, some patients still report spontaneous activation with involuntary activation – for example, a sneeze (activation of intercostal muscles) will cause involuntary elbow flexion (recipient muscle activation). The use of cortical retraining and neuroplasticity following BPI deserves clinical consideration for inclusion in the rehabilitation of patients post-BPI until further research is conducted.

2.4.1.3 Biofeedback. Biofeedback is a therapeutic technique that provides feedback to a patient when they “gain volitional control over a physiological response” (Bracciano, 2011, p. 543). In the case of FFMT reconstructive surgery biofeedback provides visual or auditory feedback when the patient activates the surgically re-innervated muscle. This progresses from a conscious effort to activate the newly innervated action to a more natural pattern of the action that automatically happens when using an upper limb. Biofeedback in a clinical setting is often a valuable addition in BPI recovery (Novak, 2008). Biofeedback can also be done without the use of an electronic device and involves teaching the patient to apply pressure over the muscle he/ she is trying to activate and feeling for a flicker or contraction of the muscle, which indicates its activation.

2.4.1.4 Electrical Stimulation. Therapists use electrical stimulation (e-stim) during rehabilitation for a variety of purposes including oedema, hemiplegia, wound management, pain management, and muscle strengthening (Bracciano, 2011; Skirven et al., 2011). However, the use of e-stim post-surgery during rehabilitation following BPI is contentious (Smania et al., 2012). E-stim is included in some BPI rehabilitation literature despite a lack of conclusive research supporting its use following surgery for BPI (Kahn & Moore, 2016; Kinlaw, 2005; Scott et al., 2013; Smania et al., 2012). Although e-stim does not assist with the patient establishing new motor patterns (Novak, 2008), it can be used as part of biofeedback training, by activating the muscle to contract and teaching the patient what the muscle contraction feels like. This can then be used when the patient is completing biofeedback exercises (discussed above).

2.4.1.5 Pain Management. Pain and pain management are two important considerations following nerve injury and thus, BPI. Smania et al. (2012) stated that “there are no sufficient and conclusive data regarding the effects of various pain treatments in patient with brachial plexus lesion” (p. 495). Rehabilitation for traumatic BPI patients inevitably includes pain education and management strategies. Bertelli et al. (2011) reported that approximately 75% of the patients with total palsy injuries (pan-BPI) experienced pain. Pain is frequent following root injury and “when it is present for more than three years after injury, it usually persists indefinitely” (Wilbourn, 2006, p. 357). Unfortunately this form of chronic, neuropathic pain does not respond well to medicinal or surgical interventions (Wilbourn, 2006), and many patients require medication for the management of pain (Frampton, 1996). Rehabilitation therapists support their patients with pain management through patient education, distraction techniques, and the use of transcutaneous electrical stimulation (Frampton, 1996).

2.4.1.6 Sensory Considerations. Following pan-BPI, patients have varying levels of an insensate upper limb. Lack of sensation in one’s hand affects grasp and release, pleasurable touch (e.g., holding a loved one’s hand), and places it at risk of injury (Bentzel, 2011). During rehabilitation there is a need for ongoing assessment and monitoring of patients’ sensation. If sensory return is noted, sensory re-education needs to commence. This may involve desensitisation (frequent, small bursts of stimulation to increase patient tolerance to sensory input), stereognosis (developing patients’ ability to recognise an object from tactile information only), and/or proprioception (patients’ monitoring of perception of their body position and/or movement) (Bentzel, 2011; Hattori et al., 2009). Unfortunately, there is considerably less reporting on sensory outcomes compared to motor outcomes in the existing BPI

literature (Dy et al., 2015). As part of rehabilitation patients need to be educated regarding awareness of their sensory deficit in order to protect them from extreme temperatures, friction and sharp objects (Bentzel, 2011). Patients need to become cognisant of such risks and adopt protective strategies.

2.4.1.7 Compensatory. Compensation strategies should be employed when an individual is unable to perform a function without external assistance (Tipton-Burton 2017). Compensation strategies following pan-BPI are predominately either activity modification (e.g., adoption of one-handed techniques) or equipment prescription. These compensatory strategies enable patients to complete meaningfully daily tasks one-handed. There are many common occupations (e.g., cooking, dressing, driving, etc.) that require such modification and/or the use of adaptive equipment.

2.4.2 Psychosocial

Pan-BPI results in permanent loss of upper limb function (Sachar et al., 2020), and as such is considered to be a chronic condition. This is significant, as it is acknowledged that chronic conditions (regardless of age or aetiology) present a set of challenges including: dealing with symptoms, emotional impact, and lifestyle adjustments to name a few (Kellezi et al., 2017; Wagner et al., 2001). Despite this, many people living with chronic conditions do not receive the required psychosocial care to effectively self-manage their illness or condition (Wagner et al., 2001).

Psychosocial perspectives following BPI have been considered recently in the literature (Franzblau & Chung, 2015; Landers et al., 2018). Psychosocial frames of reference consider an individual's psychological, emotional, and social functioning

and experiences in daily life (Krupa, 2016). Other severe injuries such as multi-trauma and spinal cord injury have a large body of literature that considers psychosocial outcomes and management (Chen et al., 2008; Frieden & Winnegar, 2012; Post et al., 2012), and these findings are also relevant when considering pan-BPI outcomes. Holmes et al. (2014), for example, found that patients with spinal cord injury were commonly diagnosed with a mood or anxiety disorder more than 12 months after their injury, drawing attention to the need for both short and longer term psychological follow up after serious injury. However, the BPI rehabilitation literature is primarily biomechanical and does not meaningfully explore psychosocial management following BPI. It is common to see recommendations in the literature recommending appropriate psychological support and referral (Franzblau & Chung, 2015; Gray, 2016; McDonald & Pettigrew, 2014), however, no articles specific to the psychosocial management of pan-BPI patients were located as part of the current research.

That said, two recent studies explored the psychosocial factors that impact patients' recovery post-BPI. One study examined online support groups for BPI and identified that BPI disease, BPI treatment, recovery after BPI, and the process of seeking care for BPI are topics that patients wished to better understand (Morris et al., 2016). A more recent study by Sachar et al. (2020) explored differences in perceived social support and coping strategies employed between patients with BPI and uninjured control subjects. This study concluded that there were no significant differences between the two groups with respect to perceived social support or number of people in their social support groups compared to healthy volunteers that were age- and sex-matched (Sachar et al., 2020). However, this study identified the following coping strategies employed more by the BPI group: active coping, self-

distraction, denial, behaviour disengagement, venting, planning, self-blame and acceptance (Sachar et al., 2020). Franzblau and Chung (2015) also reported that the most frequently used coping strategies employed following BPI were: acceptance, active coping, planning, and obtaining emotional support. These studies inform health care providers delivering care to patients with BPI regarding coping strategies favoured and the potential for maladaptive coping.

The above review of literature introduced pan-BPI and discussed current management strategies. It highlights the dominance of surgical and biomedical approaches post-injury with less consideration of the rehabilitation needed over time. A consideration of pan-BPI outcomes and contextual healthcare information will now be considered as this will provide a summary of what outcomes are currently being reported in the literature.

2.5 Outcomes Following Pan-BPI

A pan-BPI has a devastating impact on the arm's ability to move (Hébert-Blouin et al., 2012) and those who sustain this injury will have poorer overall outcomes (Moore & Novak, 2014; Stevanovic & Sharpe, 2014; Terzis & Kostopoulos, 2009). Clinically, patients that have a flail limb need to wear a sling to protect the arm and stop it flopping around. However following FFMT patients regain enough stability of the upper limb to cease wearing a sling and gain the ability to bend the elbow and if procedures include the finger flexor tendons they can make a hook grip with their fingers.

The elbow flexion and hook grip allow patients to carry bags (either in the hook grasp or over the forearm) or to stabilise an object while the other hand manipulates

(e.g., the reconstructed limb can hold a wallet, while the unaffected limb manipulates items in or out of the wallet). While surgical techniques including FFMT surgery have improved the management, many pan-BPIs still result in permanent disability (Cohen & Marino, 2000; Dijkers et al., 2000; Livneh & Antonak, 2005). As such, a top-down approach to issues including adjustment to post-injury level of functioning, psychosocial functioning, and general well-being are as important as physical and biomechanical capacity in understanding and measuring outcomes in this population is required (Dijkers et al., 2000; Livneh & Antonak, 2005; Martz et al., 2005).

A recent systematic review of outcome following FFMT to restore elbow flexion following BPI reported on the incidence of flap failure, muscle power, elbow range of motion, sensory recovery, pain, return to work/ study, and functioning (Yi Lee et al., 2019). This systematic review provides a snapshot of some of the key outcomes post-BPI including 87% of patients achieved medical research council grade of strength of ≥ 3 , a mean of arc of elbow flexion between 58° - 116° , pain reduced following surgery (but persisted for many), variable rates of return to work or study, and that the majority were satisfied with the surgery (Yi Lee et al., 2019). Findings from this systematic review of outcomes following FFMT post-BPI indicate that the focus continues to be biomechanical, but some studies are reporting functional (e.g., ability to undertake self-care, productive engagement, etc.) and psychosocial outcomes (e.g., life satisfaction, depression, etc.) (Yi Lee et al., 2019).

The reporting of psychosocial outcomes following BPI have experienced increased attention in recent years (Landers et al., 2018; Wilson et al., 2016; Yannascoli et al., 2018). Psychosocially-grounded studies following BPI have focused on the psychological impact (Landers et al., 2018; Wilson et al., 2016) and

quality of life (Dy et al., 2021; Gray, 2016; Rasulić et al., 2017) of patients post-BPI. Patients who sustain traumatic BPI have been compared to patient groups that experience significant physical impairment following trauma such as spinal cord injury (Franzblau & Chung, 2015). These populations also share common characteristics with the BPI population, in particular they tend to involve young men involved in road accidents that face ongoing “physical, financial, occupational, and psychosocial consequences” (Franzblau & Chung, 2015, p. 135). It is therefore beneficial to consider how the psychosocial consequences are managed following other traumatic injuries. For example, the broader trauma literature has considered adaptation (Grob et al., 2008), social participation (Barclay et al., 2017), and community reintegration (Sloan et al., 2009). Given the severity of pan-BPI, long rehabilitation, and permanent impairment, such broader psychosocial outcomes of this sub-population need to be more fully considered and more consistently discussed across the rehabilitation/ management literature.

McDonald and Pettigrew (2014) found that many patients following traumatic BPI experienced changes in their life roles and identity, expressed as changed role involvement within the family, role loss as the primary wage earner in the home, decreased participation in social groups and body image concerns (being self-conscious of affected limb). Psychosocial considerations cannot be adequately explored using either the biomedical or the compensatory approaches discussed. Instead, a broader psychosocial approach, the recovery model, may offer an alternative way of conceptualising a more fulsome consideration of rehabilitation and outcomes following FFMT for pan-BPI. The recovery model which aims to restore well-being and health, consists of three elements: facilitating personal adaptation,

promoting inclusion, and developing hope-inspiring relationships - and may be well suited for this purpose (Repper & Perkins, 2003).

Psychosocial outcomes are poorly understood for pan-BPI patients. Franzblau and Chung (2015) completed a mixed methods study with 12 patients that examined psychosocial outcomes and coping following severe BPIs. The authors identified a number of themes that summarised patients' experiences. They found that patients report low satisfaction with the appearance and function of their affected upper extremity and that the discrepancy between patients' and health professional's expectations led to low satisfaction of post-surgical outcomes (Franzblau & Chung, 2015). While surgeons may be achieving results they feel are good, and therapists are maximising objective physical functioning through rehabilitation, it is clinically relevant that therapists who work with this diagnostic group understand the patient's subjective experience of outcomes. Psychosocial outcomes (e.g., activity and participation) and the challenges and opportunities these patients experience following the injury need more research (Franzblau & Chung, 2015). Accordingly, gaining a fuller understanding about outcomes and measures being used following reconstructive surgery will facilitate a better understanding of the impact of BPI and subsequent surgery on people's lives. Such knowledge can inform practice and service planning, that are both important issues for this population.

While some reviews of the broader BPI literature have identified how outcomes have been measured in the recent BPI literature (Dy et al., 2015; Hill et al., 2011), knowledge and research gaps remain. A systematic review of outcomes reported by Dy et al. (2015) found a strong preference for a bottom-up approach to reporting with 94% of the identified studies reporting muscle strength with 59% of these reporting

no other measures of patient outcome. The same study reviewed 88 articles to find the following patient outcomes were measured: 27% active range of motion, 17% pain, 6% function/ disability 5% quality of life, 3% patient satisfaction, and only one study included psychosocial health (Dy et al., 2015). Another systematic review that aimed to identify activity measures used following traumatic BPI found that only 13% of measures evaluated upper limb activity and of those only two had an overall score attributed to upper limb activity (Hill et al., 2011). More recently Yi Lee et al. (2019) completed a systematic review that reported outcome measures following FFMT for elbow flexion in BPI. The authors (Yi Lee et al., 2019) found that of the 19 identified studies the following percentage of outcomes measures were reported: 84% reported muscle power, 68% range of motion, 21% pain (using a pain specific measure), and 42% used a multidimensional measure (a measures that assess more than one construct) the Disability the Arm, Shoulder, and Hand (Hudak et al., 1996).

Previous research of outcomes following other traumatic injuries has investigated the influence of an array of outcomes: secondary health conditions (Hitzig et al., 2013), environmental factors (Wong et al., 2017), and biopsychosocial factors on quality of life and participation (Walter et al., 2016). Consideration of how a more holistic, top-down approach to the measurement of outcomes following FFMT for management of BPI has not been reported in the literature and is therefore warranted.

2.6 Australian Healthcare System and BPI

To understand how care following BPI occurs, it is important to consider the Australian health care system. The Australian health care system is based on the

principle of universal access, which provides equal access to health services for all citizens and permanent residents (Krassnitzer, 2020) and is a hybrid of public and private health services. Public health is based on the Welfare State model and is funded by taxation (Krassnitzer, 2020). The Australian government is responsible for some health care and social services, with other services being provided by private providers. While this dual system creates tensions among stakeholders (Krassnitzer, 2020), Australia delivers some of the best health outcomes in the world when compared with similar countries (Australian Institute of Health and Welfare, 2018).

In addition to the private and public health care provided, some Australian states and territories offer a compensable insurance scheme that assists with financial support and personal medical expenses for people involved in road accidents. This thesis is being conducted in the Australian state of Victoria. In Victoria, the Transport Accident Commission (TAC) provides compensation for individuals who are in road traffic accidents either in Victoria, or for Victorian residents driving Victorian registered vehicles interstate (Transport Accident Commission, 2021).

The author of this thesis is an occupational therapist who works with patients with BPI as part of her role in the area of hand therapy. Occupational therapists in Australia are registered with the Australian Health Practitioner Regulation Agency (AHPRA)(Occupational Therapy Board, 2021). Occupational therapists work in a range of settings including, but not limited to, hospitals, rehabilitation centres, community health centres, aged care, schools and prisons/ detention centres (Mortimer & Kortman, 2020). The concept of occupation is defined as “groups of activities and tasks of everyday life, named, organized and given value and meaning

by individuals and a culture” (Townsend & Polatajko, 2007, p. 377). As such, occupational therapists support individuals, groups, or populations to engage in meaningful occupations of everyday life to support and maximise health and well-being (World Federation of Occupational Therapy, 2012). As this thesis is being completed with the Department of Occupational Therapy, there will be direct links drawn to this health profession in the discussion (Chapter 9).

One area of practice that occupational therapists work in is hand therapy. Hand therapists are recognised internationally as being either registered occupational therapists or physiotherapists who have gained additional education and clinical experience in the area of upper limb conditions (International Federation of Society of Hand Therapists, 2021). In Australia, hand therapists are professionals trained in upper limb rehabilitation with 73% being occupational therapists and 27% physiotherapists (Dixon, personal communication April 19, 2021). Hand therapy “is the art and science of rehabilitation of the upper limb” and commonly involves treating: fractures, dislocations, sprains, scars, tendinopathies, et cetera (Australian Hand Therapy Association, 2021). While hand therapists’ work is predominately informed by a medical model of health, there is a growing awareness that occupational therapists working in this area need to consider the application of an occupational perspective to their work (Burley et al., 2018; Colaianni et al., 2015).

Client-centred practice that prioritises the opinions, experiences, and values of the client is a central tenet of occupational therapy practice (Mortimer & Kortman, 2020). In practice, occupational therapists prioritise the goals of their clients when planning and delivering rehabilitation programs. This thesis aims to inform the

practice of therapists and other health professionals working with patients that have had FFMT reconstructive surgery for the management of pan-BPI.

2.7 Chapter Summary

This chapter has introduced and explained how the existing literature has researched and thus conceptualised BPI. As this thesis aims to take a holistic view of outcomes following pan-BPI, this chapter provides an overview of the complexity of BPI. It has also provided an overview of the surgical and rehabilitative management, while highlighting the biomedical focus in the existing literature. In summary the research into management of BPI and its sequelae was from a predominately biomedical frame of reference, with gaps from the psychosocial perspective. Additionally, a gap in the literature related to the needs and outcomes of a distinct population of pan-BPI and FFMT reconstruction for the management of BPI has been identified. The findings in this chapter have guided the development of this thesis' research questions which are outlined along with the methodology in the next chapter.

Chapter 3 - Methodology

3.1 Chapter Introduction

Pan-BPIs, while rare, are associated with poor recovery outcomes (Bertelli et al., 2011). As discussed in Chapter 2, health care delivery for this population remains biomedically-focussed with substantially less consideration of psychosocial management or outcomes. A biopsychosocial approach, such as the International Classification of Functioning, Disability, and Health (ICF; World Health Organization, 2001), which aims to take into account the complex interaction between physiological, psychological, environmental, and social factors provides a more holistic consideration of outcomes (Bekkers et al., 2014). The ICF has been applied to inform the design of this thesis's methodology. This chapter will provide an overview of the research design, participants, materials and procedures used in this thesis.

This thesis aims to report on long-term outcomes following free functioning muscle transfer reconstructive surgery for management of traumatic, brachial plexus injury in Australia. Better understanding of long-term outcomes following brachial plexus injury is needed and has been noted in the literature (Wang et al., 2016). In the existing BPI literature, long-term is used to describe a follow up time of between 2.5-11.5 years (Chuang & Hernon, 2012; Dickson & Biant, 2010; Suzuki et al., 2007; Wang et al., 2016). Currently long-term, follow up studies are scarce and predominately report strength, range of movement and sensory outcomes (Chuang & Hernon, 2012; Dickson & Biant, 2010; Suzuki et al., 2007; Wang et al., 2016).

A pragmatic inquiry paradigm was applied to address the aims and for planning this research. Pragmatic inquiry aims to “seek practical and useful answers that can

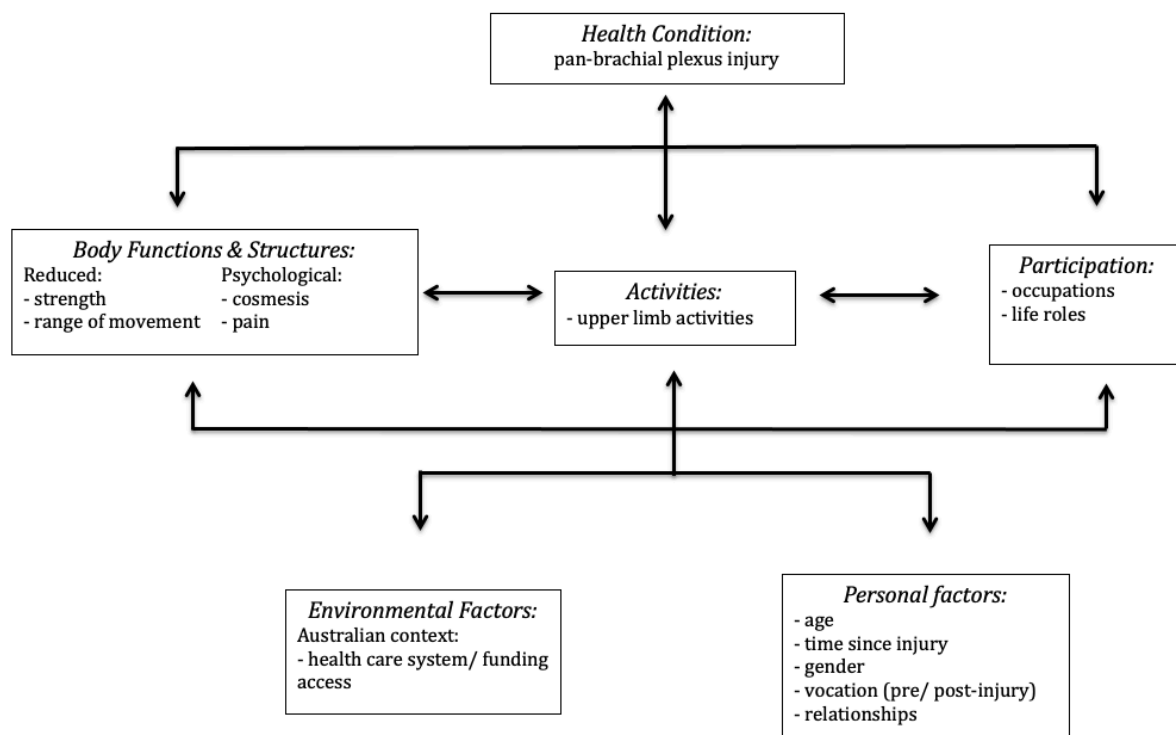
solve, or at least provide directions in addressing, concrete problems” (Patton, 2002, p. 152). Pragmatic studies are commonly used in health care research and allow the researcher to investigate the human experience and human adjustment (Salkind, 2010). A pragmatic design does not require a linear investigation, but rather embraces the human experience, and seeks to improve a problematic situation (rather than examine a narrow hypotheses) in order to lead to broader social benefits (Salkind, 2010). Given that this thesis originated while the author was working with people with BPI in a hand therapy clinic, the current inquiry aims to consider practical questions with the aim to produce useful and clinically relevant conclusions. This use of pursuing practical questions in order to better understand real-world issues is consistent with a pragmatic inquiry (Patton, 2002).

The two biopsychosocial frameworks introduced in the introduction (Chapter 1), one from occupational therapy’s holistic view of health (Crepeau et al., 2003) and the other the World Health Organization’s International Classification of Functioning (World Health Organization, 2001), were used when generating the research questions and planning the research design. This approach of both multi-factorial and subjective/ objective outcome gathering is supported in the BPI literature (Smith et al., 2019). Following a review of the BPI literature, the research’s aims and questions were organised into five investigations. Concepts to be measured were selected to investigate a range of biopsychosocial factors. Given that the investigations were planned to be written as manuscripts for a multidisciplinary audience, these concepts were mapped using the ICF framework as illustrated in Figure 4 (World Health Organization, 2001). This was done as the ICF has been found to encourage a person-centred outcome approach that considers the

biopsychosocial factors related to health and well-being that can be understood across health disciplines (Alford et al., 2015).

Figure 4

Concepts to be Explored by This Thesis Organised by the International Classification of Functioning, Health and Disability Model 1 (World Health Organization, 2001)



Note. Reproduced with permission (Appendix A, p. 262).

3.2 Research Approach

Reporting health outcomes is complex. Accordingly, a mixed methods approach was chosen, as such an approach provides the opportunity to analyse outcomes that validate multiple perspectives from a variety of stakeholders to gain a more thorough understanding (Greene, 2015; Liamputtong, 2017). A mixed methods approach is commonly used when a single-method design would not adequately

answer the research question (Taket, 2017), such as the complex range of outcomes reported following permanent disability (Liamputtong, 2017; Morse & O'Brien, 1995; Yang et al., 2016). Data in this thesis provided scope to gather and analyse outcomes utilising multiple methodologies (i.e., quantitative/ qualitative) and multiple perspectives (i.e., patients and health care clinicians), therefore yielding a more fulsome reporting and consideration of the findings. This chapter outlines the methodology for this thesis that is made up of five investigations: a scoping review, two quantitative studies, and two qualitative studies. The following provides an overview of each of the investigations, their research questions and aims, and a detailed methodology for each investigation.

3.3 Investigation 1: Scoping Review

Included as Chapter 4.

3.3.1 Research Question

What psychosocial outcomes are currently reported for individuals following FFMT surgery for management of traumatic BPI?

3.3.2 Aim

To identify outcome measures used to report psychosocial outcomes following FFMT surgery for the management of pan-BPI.

3.3.3 Methodology

A scoping review is a rapid review that can be used to identify gaps in the existing literature (Arksey & O'Malley, 2005). The purpose of the scoping review prepared as part of this thesis was to examine and summarise the existing literature to consolidate what is already known about the measurement of psychosocial

outcomes following FFMT for management of pan-BPIs. Biomechanical outcome measures (e.g., range of movement, strength) have been frequently applied following brachial plexus reconstructive surgeries (Bengston et al., 2008; Kay et al., 2010; Kim et al., 2003). The scoping review aimed to identify and explore which non-biomechanical outcomes have been reported for this population. By looking beyond biomechanical outcomes, the objective of this investigation was to gain a more holistic understanding of patient health outcomes in keeping with biopsychosocial ideas of health and wellness as defined in the ICF (World Health Organization, 2001).

The search strategy was developed in consultation with university librarians and used two main themes “FFMT reconstruction following BPI” and “psychosocial outcomes” (Appendix C, p. 271). References identified from the search strategy were exported to an Excel database and reviewed independently by two reviewers. Differences of opinion were resolved through discussion. The complete methodology used for the scoping review is detailed in Chapter 4.

3.3.4 Reporting Results

Data extraction was done by one reviewer and checked by another to ensure accuracy. Data extracted included: sample size, location of participants, demographics, study design, diagnosis, follow-up time, outcome measures applied, outcomes reported, results, and conclusions.

3.4 Investigation 2: Activity Outcomes

Included as Chapter 5.

3.4.1 Aim

To report long-term, activity-related outcomes of individuals with pan-brachial plexus injuries following FFMT reconstructive surgery in Australia.

3.4.2 Research Questions

This investigation aimed to address two research questions:

- 1) What are the long-term activity outcomes for individuals with pan-brachial plexus injuries following FFMT reconstructive surgery in Australia?
- 2) How do these outcomes relate to other similar populations?

3.4.3 Methodology

A descriptive, cross-sectional design was used in Investigation 2. A descriptive methodology is an approach commonly used to provide cross-sectional data on a specific population (World Health Organization- Regional Office for the Western Pacific., 2001). This methodology is consistent with the research question and paradigm as it gathers the objective data representing the participants' engagement in activity following injury and surgery (Offredy & Vickers, 2010). This investigation filled gaps in existing literature (identified in Investigation 1) and contributed to existing knowledge by reporting patient outcomes from a patient-centred perspective. Two instruments that measure activity, one identified in Investigation 1, were used to assess a range of variables following pan-BPI.

3.4.3.1 Sample and Procedure. The study utilised a convenience sample of participants who had undergone FFMT surgery between the years of 2007 and 2017. All patients were recruited from a private clinical practice that specialises in managing people with BPI. Inclusion criteria were: a diagnosis of traumatic, pan-BPI

confirmed by magnetic resonance imaging; nerve conduction studies or clinical findings; had undergone their first FFMT surgery between 2007 and 2015; were 18 years or older, with no prior dysfunction of the upper limb; and were at least 1-year post first FFMT surgery. Participants were excluded if they had sustained a partial BPI or did not provide informed consent (Chapter 1Appendix D , p. 279). Information packs were posted to 23 patients that met the inclusion criteria. Eight provided written informed consent, four declined, and 11 did not reply. In an attempt to recruit more participants, ethical approval was obtained to contact therapists in public hospitals to inform them of the study and their assistance sought to recruit additional participants (Chapter 1Appendix E p. 275). Specifically, therapists invited patients that met the inclusion criteria and distributed information about the study to interested patients. However, no additional participants were able to be recruited.

3.4.3.2 Outcome Measures. Demographic data was gathered from each participant. This demographic data included injury specific data: diagnoses, injury mechanism, time post injury, time from injury to FFMT surgery, time since FFMT surgery(ies) to time of study, concomitant injures, and BPI-related surgeries. Demographic data collected also included personal information such as: age, highest level of education completed, job prior to and following injury, the length of time from injury to return to work, and hand dominance. Participants completed the Disability of Arm, Shoulder, and Hand (DASH; Hudak et al., 1996) and the Brachial Assessment Tool (BrAT; Hill et al., 2016).

The DASH is a *30-item* questionnaire *that asks* individuals to rate their perceived ability to complete daily activities, symptoms, social function, sleep and confidence on a five-point Likert scale (1 = *no difficulty* and 5 = *unable*) (Hudak et al.,

1996). Answers are summed and a score out of 100 is calculated, with 0 indicating “no disability” and 100 “complete disability”. Beaton et al. (2001) reported that the DASH had good psychometric properties. Specifically, they found that the DASH has a strong test-retest reliability of 0.96 (Pearson correlation) and good construct validity with large correlations with other measures of disability (the Shoulder Pain and Disability Index and the Brigham questionnaire). Kolber et al. (2014) conducted a systematic review of the DASH’s clinimetric properties, with the measure’s internal consistency being between 0.92 to 0.98. The authors state, however, that this may indicate a degree of item redundancy in the instrument. While it is acknowledged that the DASH has many limitations for people with BPI, the DASH has been retained for comparison to existing research and a new activity measure, the Brachial Assessment Tool (BrAT; Hill et al., 2015), designed for use with individuals following BPI.

The BrAT is a valid and reliable patient-reported measure, that assesses day-to-day activity limitations in people with BPI (Hill et al., 2016). It was developed in collaboration with both health professionals and people with BPI. The BrAT consists of 31-items with responses being rated on a 4-point Likert scale (0 = *cannot do now*; 3 = *easy to do now*). It has high retest reliability (0.90 for subscale 3; 0.97 total score) and high internal consistency ($\alpha=0.90-0.98$) (Hill et al., 2017). Hill et al. (2018) examined the construct validity using the DASH (Hudak et al., 1996) and the Upper Extremity Functional Index (UEFI; Stratford et al., 2001) and found the BrAT demonstrated a moderate to low correlation with the DASH (-0.48 - 0.69) and a large correlation with the UEFI (0.6 - 0.8). These results suggests that the BrAT and DASH are likely to be measuring different constructs, while the BrAT and UEFI are more likely to be assessing similar constructs.

3.4.3.3 Data Analysis. Data were analysed using Statistical Package for Social Sciences (SPSS) version 25 for Windows (IBM, 2017). Demographic information was tabled. Categorical data were described as percentages and continuous data as a mean and standard deviation. One-sample t-tests were used for comparing results from this study to other studies' populations.

3.5 Investigation 3: Participation Outcomes

Included as Chapter 6.

The World Health Organization (2001) defines participation as involvement in a life situations and acknowledges its role in health and well-being (e.g., social inclusion). Reduction in, and limitation to, participation following traumatic injury is known to negatively impact a person's life satisfaction (Powell et al., 2007; Wise et al., 2010). Participation is embedded in the practice of hand therapy and occupational therapy (Fenton et al., 2003; Radomski & Trombly Latham, 2008; Schoneveld et al., 2009). However, measurement of participation and activity in hand therapy practice remains under-utilised (Schoneveld et al., 2009; Weinstock-Zlotnick & Bear-Lehman, 2012).

This investigation was designed to gather information on participation for individuals following traumatic BPI. Engagement in meaningful roles and occupations is central to occupational therapy practice (Fenton et al., 2003; Weinstock-Zlotnick & Bear-Lehman, 2012). Occupational therapy models consider participation to encompass subjective meaning, satisfaction, and performance (Taylor & Kielhofner, 2017; Townsend & Polatajko, 2007). However, participation and engagement in occupations cannot be considered interchangeable (Doble & Santha, 2008). The following patient-rated measure, the Utrecht Scale for Evaluation of Rehabilitation -

Participation (USER-Participation; van der Zee et al., 2008), attempts to provide information regarding both an objective and subjective view of participation and engagement in occupations.

3.5.1 Research Questions

This investigation aimed to address three research questions:

- 1) How do individuals report objective and subjective experiences of participation in life situations following surgery for the management of a BPI?
- 2) What frequency, restriction, and satisfaction outcomes are reported for participation?
- 3) What influence does pain have on how individuals experience participation?

3.5.2 Aim

Report outcomes related to participation in daily life following BPI.

3.5.3 Methodology

This study involved an exploratory, case series. It included descriptive data to report participation outcomes following BPI and compared this data with other diagnoses of similar severity that resulted in physical impairment.

3.5.3.1 Sample and Procedure. Participants were recruited, using a convenience sampling method, from a hand therapy service that specialised in the management of participants who presented with traumatic BPI. Broader recruitment was used for this investigation and included all injuries classified as BPI, since there was no existing reporting of participation following any type of BPI and that additional recruitment of patients with pan-BPI was not successful as part of Investigation 2.

Inclusion criteria for this study were: a diagnosis of traumatic BPI, ≥ 18 years old, no prior dysfunction of the upper limb, and at least 1-year post-injury.

Information packs were emailed (or posted if no email was available) to patients that met the inclusion criteria. A total of 72 participants met these criteria that had undergone surgical repair for BPI between the years of 2007 and 2015. Two follow up calls were made to participants that did not reply. Data was collected online using Google Forms, with participants being sent a hyperlink to the Google Form upon receipt of their signed consent forms.

3.5.3.2 Measures. The USER-Participation (van der Zee et al., 2008) was designed for use as a community-based rehabilitation measure. The items were created using the ICF to incorporate both the objective and subjective dimensions of participation. The measure consists of 31 items that make up three domains of participation: frequency (objective measure), restriction, and satisfaction (subjective measures) (van der Zee et al., 2010). The measure takes approximately 15-20 minutes to administer as an interview.

The scale has been used with a range of populations including brain injury, neuromuscular disease, spinal cord injury (van der Zee et al., 2010; van der Zee et al., 2013a; van der Zee et al., 2013b). When the USER-Participation was used to review participation in chronic stroke patients, it was concluded that subjective participation was determined predominately by physical and cognitive independence, fatigue and mood whereas objective participation was more linked to physical and cognitive independence, age and education. van der Zee et al. (2010) conducted a study to establish the test/ retest reliability of the USER-Participation and reported a

correlation of ≤ 0.65 for the frequency domain, ≤ 0.85 for the restriction domain, and ≤ 0.84 for the satisfaction domain. The USER-Participation's reliability was reported as satisfactory ($\leq 0.70-0.91$) (Post et al., 2012). The authors also reported that the measure was valid when rating both objective and subjective participation in persons with physical disabilities with strong concurrent validity of its frequency scale to the Frenchay Activities Index (Holbrook & Skilbeck, 1983) ($r = 0.59$) and its restriction scale to the ICF Measure of Participation and Activities Screener (IMPACT-S; Post et al., 2008) ($r = -0.73$) (Post et al., 2012).

3.5.3.3. Data Analysis. Data was analysed using *t*-tests as per recommendations by Pallant (2016). The USER-Participation scores are presented as means with accompanying standard deviations and ranges. The current investigation's findings were compared to that of other relevant studies (de Ruijter et al., 2018; Mader et al., 2016; van der Zee et al., 2013b). All analyses were carried out using SPSS 25 (IBM Corp., Released 2017).

3.6 Investigation 4: The Lived Experience

Included as Chapter 7.

3.6.1 Research Question

What are patients' experiences following pan-BPI and FFMT surgery?

3.6.2 Aim

To explore the experience following FFMT reconstructive surgery for management of flail limb, traumatic BPI to better understand the issues that occur during recovery and the implications for improving health services when managing this type of injury.

3.6.3 Methodology

A qualitative methodology was selected to allow patients to freely express their thoughts and feelings. As discussed in Chapter 2 (p. 36), studies that consider the psychological and social aspects of BPI are needed. This study aims to explore the experience following injury from the perspective and voice of the patient. The intention of this investigation aligns with phenomenological research in that it aims to better understand the experiences of several individuals following injury and reconstructive surgery; therefore, this investigation employed an Interpretative Phenomenological Analysis (IPA) design (Smith, 1996).

3.6.3.1 Participants. The study included a purposive sample of participants who underwent FFMT surgery between the years of 2007 and 2015. All patients were recruited from a clinical practice that specialises in that traumatic BPI diagnostic group. The participants from this study were recruited by indicating their interest in participating in an interview when participating in Investigation 2. Therefore, the inclusion criteria for this investigation were the same as that outlined for Investigation 2 (pp. 46-47).

3.6.3.2 Data Collection. Data for this study were collected by semi-structured interviews. All interviews were conducted by the author, using a series of open-ended questions and corresponding prompt questions that were developed specifically for this study. Interview questions are listed in Chapter 7 (p. 145). Only one interview was conducted with each participant and interviews lasted approximately one to one and a half hours.

3.6.3.3 Data Analysis. Interpretative Phenomenological Analysis (IPA) was used to analyse the data and information. IPA is an inductive form of analysis that is designed for analysing the phenomena of experiences and their associated meanings (Smith, 1996). As IPA has been recognised as an excellent philosophical match for occupational therapy research (Clarke, 2009), it is well aligned with the theoretical foundations of this thesis.

3.7 Investigation 5: Therapists' Perspectives

Included as Chapter 8.

3.7.1 Research Questions

This investigation aimed to address three research questions:

- 1) What outcomes do health professionals aim to achieve following FFMT for management of pan-BPI?
- 2) What are health providers thoughts on factors related to outcomes following surgery for pan-BPI?
- 3) What are the factors perceived to support/ challenge rehabilitation?

3.7.2 Aim

To describe health professionals' experience and thoughts of rehabilitation following traumatic BPI.

3.7.3 Methodology

This study took a qualitative approach and sought to identify and understand experiences and thoughts of health professionals related to working with individuals following traumatic BPI. Thematic analysis was used to explore the experience of health professionals as they relate to rehabilitation aims in order to evidence key

aspects of service delivery in the health care systems that impact individual's with BPI (Braun & Clarke, 2006).

3.7.3.1 Participants. Participants in this study were occupational therapists or physiotherapists involved in the post-operative care and rehabilitation of patients following traumatic BPI. Inclusion criteria for this investigation were that participants needed to be occupational therapists or physiotherapists, aged 18+ years old, fluent in conversational English, and has met one of the following BPI treatment criteria a) have been involved directly with rehabilitation of a patient following BPI for >1 year or b) have treated ≥ 5 patients with BPI.

A purposive sampling approach was used to recruit participants. Purposive sampling allows for selection of participants based on certain characteristics (Offredy & Vickers, 2010), in this case, their experience in treating patients with BPI. The author used her professional networks to contact therapists known to her and invited them via email to participate. This email also encouraged these senior clinicians working with clients following adult BPI to forward the invitation to other therapists who they believed might have suitable experience and potentially be interested in participating in the investigation - this process is known as snowball sampling (Offredy & Vickers, 2010). Prior to participation in a focus group, participants had returned a signed consent form and completed a demographic survey.

3.7.3.2 Data Collection. Information for this investigation was collected through focus groups with individuals who met the inclusion criteria stated above. The focus groups were conducted using videoconferencing (Zoom®) as participants were located in different parts of Australia. An experienced qualitative researcher

(Jennifer White) moderated the focus groups. The moderator was not a hand therapist. This was designed to reduce bias and encourage participants to share their thoughts openly. The moderator opened the focus group by reminding the group of the confidentiality of information and opinions shared in the focus group. The second facilitator (Sara Brito) took field notes during the focus groups. Guided questions were used and can be found in Chapter 8 (pp. 176-177). The focus groups were recorded and lasted between 50-60 minutes.

3.7.3.3 Data Analysis. Data collected were analysed using inductive thematic analysis (Braun & Clarke, 2006; Elo & Kyngäs, 2008). This approach was chosen as it is flexible in terms of the theoretical framework being employed, data being collected, and sample size (Braun & Clarke, 2013). This is not to say that the knowledge and standpoint of the researchers were absent from analysis, as these factors always have some degree of influence on analysis (Braun & Clarke, 2013).

The six phases of analysis outlined by Braun and Clarke (2006) guided the process of thematic analysis used with this data set. The following process was completed by the author and an additional author (JW) independently for discussion and agreement. The first phase involved familiarisation with the data. Transcripts were read and notes were made by two researchers (SB & JW) in response to participant statements that related to the research questions. The next phase involved generating initial codes across the entire data set. This was done independently and discussed between the author and the second author (JW) of the included manuscript. The next two phases involved searching for and reviewing themes. This involved repeating the process multiple times, to review and re-review the data and codes and to consider how the codes related to one another and to the

data set as a whole. This process involved mind mapping concepts in many different configurations to conceptualise what the participants were saying and how their comments related to one another and to broader ideas. The analysis was finished using the final two phases of thematic analysis: 'defining and naming the themes' (see the results of the manuscript in Chapter 8) and 'producing the report' (writing the manuscript) (Braun & Clarke, 2006).

To improve the trustworthiness of this investigation several considerations were made. The dependability, a trustworthiness criteria proposed by Lincoln and Guba (1985), of data collection and analysis was demonstrated through a well-documented and clear audit trail that included a logical, traceable process. Member checking of data during data analysis was also utilised to ensure the credibility of findings (Braun & Clarke, 2013; Guba & Lincoln, 1989).

3.8 Ethical Considerations

All investigations that involved participants were approved by the Monash University Human Research Ethics Committee (MUHREC) (Appendix B, p. 269). Participants voluntarily agreed to participate in the above-described investigations having signed a consent form prior to any data being collected (Appendix D, p. 279). There was minimal risk to the participants. Participants were informed of this in their consent letter and encouraged them to speak with the author or other health care providers detailed in the participant statement if they had any questions or concerns (Appendix D, p. 275). Participants were also provided with information about the storage and strict confidentiality of data gathered.

3.9 Data Management

All data were stored in a way to ensure participant anonymity. To maintain confidentiality and anonymity of participants, data and other investigation-related documentation were stored on a secure computer drive at Monash University. Access to the data and any other study-related documentation was restricted to the author and research team. Participants were informed that the data gathered may be presented by the author at conferences, professional meetings, journal articles, and will be included in the author's Ph.D. thesis. Findings have only been presented in this thesis in a manner that ensures that no individual participant can be identified. All data and investigation-related documentation will be stored for a period of 7 years, then deleted.

3.10 Chapter Summary

This chapter has laid out the methods for the five investigations that make up this thesis and outlined the associated methodologies utilised in each. The next chapter contains the manuscript from Investigation 1.

Chapter 4 - Psychosocial Outcome Measures Following Free Functioning Muscle Transfer for Management of Adult Brachial Plexus Injury: A Scoping Review

4.1 Chapter Introduction

Chapter 3 outlined the methodology for each investigation in this thesis. This chapter is the first of five manuscripts that form part of this thesis, and is a scoping review designed to identify psychosocial outcomes reported for BPI patients who underwent FFMT reconstructive surgery. Specifically, the population focused on includes people who have sustained pan-BPIs (C5-T1 injury) and/or avulsion BPIs. Simply put, people who sustain such injuries have poorer overall outcomes than other BPI lesion patterns (Moore & Novak, 2014; Stevanovic & Sharpe, 2014; Terzis & Kostopoulos, 2009). This scoping review aimed to identify current measures, beyond biomechanical measures (e.g., range of movement and strength) that have been used with this population. It has been proposed that measuring quality of life, function, and satisfaction would improve understanding of outcomes following BPI (Ciaramitaro et al., 2010), but little is known about how this is being operationalised in the literature. This study's results also informed the selection of outcome measures used in subsequent investigations included in this thesis.

4.2 Manuscript 1 Information

Brito, S., Thomacos, N., Hill, B., & Brown, T. (manuscript under review). Psychosocial outcome measures following free functioning muscle transfer for management of adult brachial plexus injury: A scoping review. *International Journal of Rehabilitation Research*.

Date submitted: 2 September 2021

4.3 Abstract

4.3.1 Objective

This study aims to identify and explore psychosocial outcome measures for this population.

4.3.2 Data Sources

This search was across key databases (AMED, Cinahl, Embase, OvidMedline, PsychInfo, Scopus, and a range of grey literature databases) published in English from 1990 to 2021.

4.3.3 Study Selection

An electronic search was performed for any studies that reported psychosocial outcomes following brachial plexus injury and free-functioning muscle transfer for elbow flexion. Articles were independently reviewed by the two reviewers and then discussed in order to reach agreement.

4.3.4 Data Extraction

Data extracted included: sample size, location of study, participant demographics, study design, diagnosis, and outcome measures applied.

4.3.5 Data Synthesis

Fourteen studies were located with the most frequently used measures being the Disability of the Arm, Shoulder, and Hand (79%) followed by the SF-36 (36%) and the Modified-SWAP (14%). The other measures were only used once: Upper Extremity Functional Index, Canadian Occupational Performance Measure, Self-rating Anxiety Scale, Self-rating Depression Scale, Michigan Hand Outcomes Questionnaire, Brief-Coping with Problems Experienced. In addition to patient

reported questionnaires, three studies also collected data using study-specific questions.

4.3.6 Conclusion

This review found that while outcomes are being considered in a holistic manner, none of the measures used have been validated for use with individuals with BPI, and the method of measurement varies among studies. The applicability of some of the measurement tools used with this population have been questioned. Further research is required to ensure appropriate measurement tools are used.

4.4 Investigation 1 Manuscript 1

The manuscript below, linked to Investigation 1.

4.5 Manuscript 1 Introduction

Physical impairment following traumatic BPI varies depending on the location and severity of the injury (Brophy & Wolfe, 2005) and a number of surgical procedures have been used to reanimate the upper limb. The most commonly reported outcomes following brachial plexus injury (BPI) relate to physical impairment (i.e. motor or sensory deficits)(Chuang, 2008; Moran et al., 2005). While such an emphasis on physical impairment following trauma aligns well with a medical model of health (Yang et al., 2012), it does not holistically consider all of the outcomes of such a life-changing injury. Consequently, it has been proposed that a fuller consideration of outcomes following BPI is needed (Ciaramitaro et al., 2010). This review focuses on examining psychosocial outcome measures used following free functioning muscle transfer (FFMT)(Hébert-Blouin et al., 2012; Stevanovic & Sharpe, 2014; Terzis & Kostopoulos, 2009; Vekris et al., 2008), an increasingly used procedure for severe BPI or where nerve transfers have been delayed. FFMT

involves harvesting a viable donor muscle (e.g. gracilis), including its neurovascular bundle, and using it to reanimate the upper limb(Akasaka et al., 1991). Despite the use of FFMT, the management of severe adult BPI still results in permanent disability(Cohen & Marino, 2000; Dijkers et al., 2000; Livneh & Antonak, 2005). As such, issues such as post-injury adjustment and general well-being are as important as physical and biomechanical capacity and functioning in understanding and measuring outcomes in this population(Dijkers et al., 2000; Livneh & Antonak, 2005; Martz et al., 2005).

To date, three systematic reviews have considered functional and clinical outcomes following BPI(Dy et al., 2015; Hill et al., 2011; Yi Lee et al., 2019). While all three are timely and needed, a gap in the literature remains in respect to a fuller appraisal of the range of psychosocial outcome measures that have been used in respect to this specific population. The purpose of this scoping review is to identify and explore psychosocial measures used following FFMT surgery for BPI. The findings will illustrate current outcome domains being measured and inform future research studies of common measures used with this population.

4.6 Manuscript 1 Methods

This scoping review does not have a registered protocol, but has followed the recommended process of Arksey and O'Malley (2005): 1) Identify the research question, 2) Identify relevant studies, 3) Study selection, 4) Chart the data, and 5) Collate, summarize and report the results. The included articles were critically appraised using tools developed by the Joanna Briggs Institute(The Joanna Briggs Institute, 2016)(Appendix F, p. 285). While this is customarily completed as part of reviews to assist with making inferences regarding the results of studies, this was completed here to more comprehensively review the included articles. The PRIMSA

Extension for Scoping Reviews (PRISMA-ScR) checklist provided guidance during the reporting of this study (Tricco et al., 2018) (Appendix G, p. 289).

4.6.1 Identify the research question

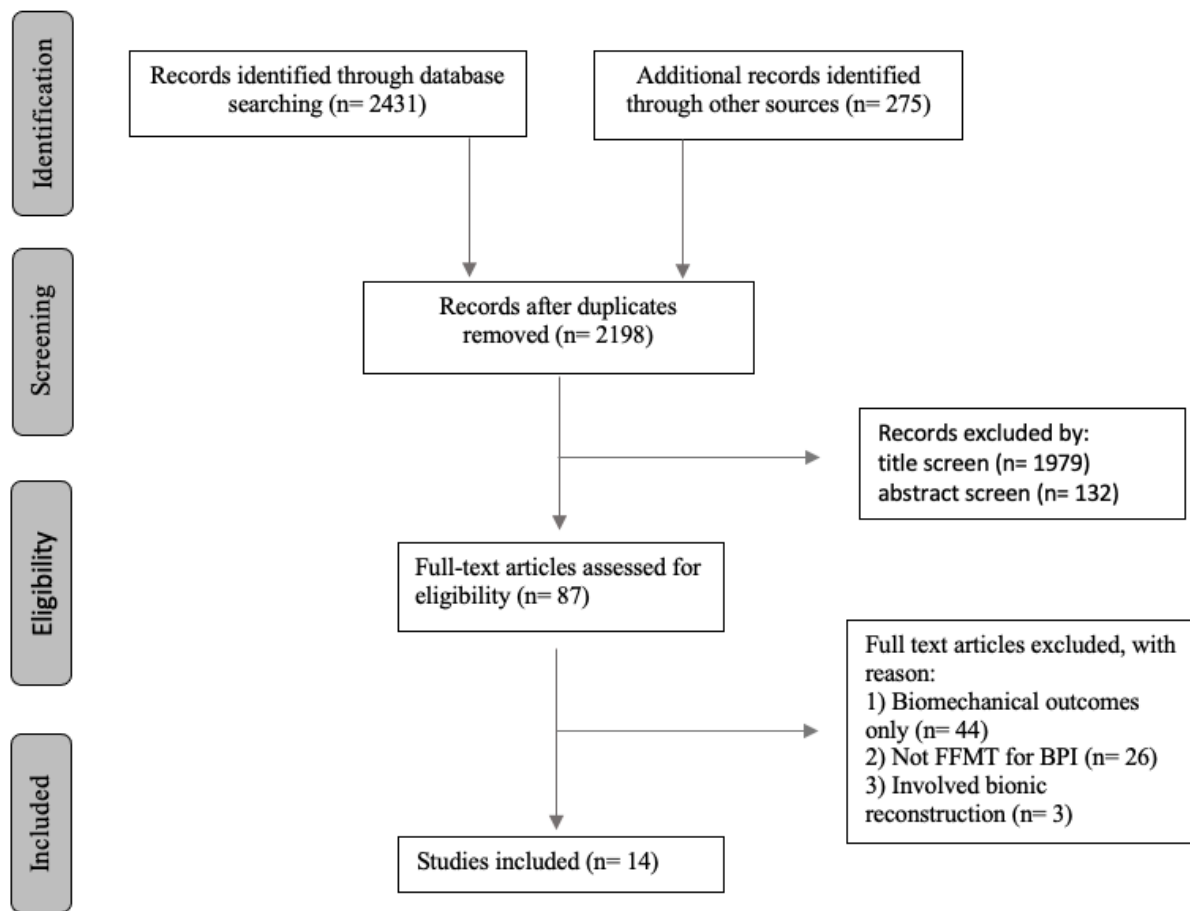
The current review's research question is: "What psychosocial outcome measures have been used following FFMT surgery for BPI?" In the current study the term psychosocial is defined as "...human psychological, emotional, and social function and experience that occurs within daily occupations ..." (Krupa, 2016, p. 4 p.4).

4.6.2 Identifying relevant studies

In April 2021, both the peer-reviewed and grey literatures were examined using the following databases: Allied and complementary Medicine Database (AMED), Cumulative Index to Nursing and Allied Health Literature (CINAHL), Excerpta Medica database (Embase), Ovid Medline, PsychInfo, and Scopus. Searching was also undertaken in the *Hand Clinics* journal, Google Scholar, ProQuest Dissertation & Theses Global, and Ethos and DART-Europe e-theses portal (see Figure 5). Database search terms used two search strategies that included brachial plexus and FFMT, as well as, brachial plexus and psychosocial. A copy of the search terms applied can be found in Appendix C (p. 271).

Figure 5:

Search results PRISMA



4.6.3 Study selection / data extraction

A multi-stage screening process was conducted (Figure 1). All articles' references were initially exported to Endnote referencing software and duplicates were removed. References were then exported from EndNote to an Excel database for review by two reviewers (SB & BH). Articles were retained if they met the following criteria: 1) published in English after 1990 (this year was chosen because the first surgical articles relating to FFMT for the management of BPI were published in 1991(Akasaka et al., 1991; Doi et al., 1991)) 2) human study including FFMT reconstructive surgery for management of BPI with or without amputation, and 3), quantitative in design with outcomes reported using a reproducible measure. Articles

were excluded if: 1) outcomes only reported physical impairment (i.e. movement, strength and/or pain), 2) study focused on brachial plexus birth injury, and 3) multiple diagnostic groups were included in data set and FFMT BPI specific data could not be extracted. Once articles were included/excluded based on title and abstract reviews, full-text versions of the articles were examined. Differences regarding the inclusion/exclusion of specific articles were discussed by the two reviewers in order to reach agreement. Data extracted included: sample size, location of study, participant demographics, study design, diagnosis, and outcome measures applied.

4.7 Manuscript 1 Results

Fourteen articles that met the inclusion criteria were identified. (Table 4). Of the 87 full-text articles assessed, 51% were excluded because they measured range of movement or strength only and used no psychosocial outcomes measures.

Geographically the studies come from a small number of countries with four (29%) from one setting in Japan (Addosooki et al., 2012; Dodakundi et al., 2013; Kitajima et al., 2006; Satbhai et al., 2016). In respect to authorship and sampling, most of the included articles were authored by medical doctors/surgeons and involved convenience sampling.

Ten were case series reviews (Addosooki et al., 2012; Coulet et al., 2011; Dodakundi et al., 2013; Estrella & Montales, 2016; Franzblau & Chung, 2015; Franzblau et al., 2014; Gillis et al., 2019; Kitajima et al., 2006; Maldonado et al., 2017a; Maldonado et al., 2017b; Potter & Ferris, 2017; Yang et al., 2016), one cohort design (Satbhai et al., 2016), and one case study (Elzinga et al., 2014). Two studies used a mixed methods design (Franzblau & Chung, 2015; Franzblau et al., 2014), six reported pre- and post-intervention data (Dodakundi et al., 2013; Gillis et al., 2019; Maldonado et al., 2017a; Maldonado et al., 2017b; Potter & Ferris, 2017;

Satbhai et al., 2016), with the remaining six employing a cross-sectional design (Addosooki et al., 2012; Coulet et al., 2011; Estrella & Montales, 2016; Kitajima et al., 2006; Potter & Ferris, 2017; Yang et al., 2016). Franzblau (2015; 2014) published two different studies using the same participant group. Three of the articles were published using participants from one setting (Addosooki et al., 2012; Dodakundi et al., 2013; Kitajima et al., 2006), while Dodakundi et al.(2013) and Satbhai et al.(2016) reported results from one setting with an overlapping time period. The second of these studies (Satbhai et al., 2016) appears to be an extension of the first. Two other studies, Maldonado (Maldonado et al., 2017a; Maldonado et al., 2017b), also reported from one setting with likely overlap of participants between the two studies. Using the National and Health Medical Research Council's criteria (National Health and Medical Research Council (NHMRC), 2007), all articles were categorized as Level IV research (National Health and Medical Research Council [NHMRC], 2007).

The majority of included articles performed well on Joanna Briggs Institute Critical Appraisal of case series (The Joanna Briggs Institute, 2016) in 1) clearly stating inclusion criteria, 2) clear reporting of participant demographics, 3) clear reporting of clinical information of participants, 4) outcomes were clearly reported, and 5) appropriate statistical analysis was performed (Appendix F, p. 285). Inconsistency in the information provided (e.g. classification of injury level/ diagnosis) makes replication of the studies impossible and generalisability problematic.

Table 4:*Overview of 14 articles included in scoping review*

Articles	Research location	Authors' professions*	Study design/ Level of evidence (NHMRC)	Sample	Injury diagnosis	Surgical intervention	Aim
Addosooki et al. (2012)	Japan	Surgeons x4	Cross-sectional, case series/ IV	n= 18	injury level not reported	Wrist arthrodesis with FFMT	Determine effect of wrist arthrodesis on digital motion and function for patients who previously underwent a double free muscle transfer
Coulet et al. (2011)	Unclear	Surgeons x 5	Retrospective case series/ IV	n= 12	C5-7= 5 C5- T1= 7	Single FFMT to restore elbow flexion	1. Evaluate results and function of FFMT surgery for delayed management of traumatic, BPI

2. Compare above results to published primary re-innervation results

Dodakundi et al. (2013)	Japan	Surgeons/ doctors x7	Longitudinal , case series/ IV	n= 36	injury level not reported	Double FFMT	Report double FFMT outcomes, including disability and quality of life scores, and evaluate changes between pre- and post-operative scores.
Elzinga et al. (2014)	Canada	Surgeons, BSc x 1	Case study/ IV	n= 2	Root avulsion resulting in flail arm	Double FFMT	Report two case study experiences of double FFMT in Canada.
Estrealla and Montales (2016)	Philippines	Surgeons x 2	Retrospective, case series/ IV	n= 42	C5-6 Or C5-7= 3 C5-T1= 39	Single FFMT= 36 Double FFMT= 6	Report outcomes and complications following FFMT

Franzblau and Chung (2015)	USA	Surgeon x 1, BSc x 1	Mixed methods/ IV	n= 12	C5-T1- 12	4= Single FFMT; 2= Double FFMT; 1= NT; 1= amputation; 4= none	To understand psychosocial outcomes, coping and adjustment after complete avulsion traumatic BPI
Franzblau et al. (2014)		Surgeon x 1, BSc x 1, MPH x 1	Mixed methods/ IV				Examine patient reported outcomes and better understand the patient perspective.
					21=		
					complete		
					16= C5, 6		
Gillis et al. (Gillis et al., 2019)	USA	Surgeons x 5 Registered nurse x 1	Retrospecti ve, case series/ IV	n= 58	11= C5, 6, 7 3= C5, 6, 7, 8 2= poster cord +	Nerve grafting, transfers, or FFMT	To examine if there is a difference in outcomes in patients over 50 years old when surgically reconstructing elbow flexion associated with traumatic BPI.

					suprscapula r nerve 1= C6,7,8,T1 1= C5, 6, 7, 8, T1		
Kitajima et al. (2006)	Japan	Surgeons x 4	Cross- sectional, case series/ IV	n= 30	complete lesion= 26; upper type lesions= 6; lower type lesions= 4	26- Double FFMT; 3- Oberlin's procedure; 1- Intercostal nerve transfer	Evaluate patient satisfaction after surgery and to correlate satisfaction scores with upper extremity range of motion.
Maldonado et al. (Maldonado	USA	Surgeon x 4 Registered nurse x 1	Retrospecti ve case series/ IV	n= 56	C5-T1 root avulsion	32 (FFMT only) 33 (FFMT and nerve transfer)	Determine if the combination of a gracilis FFMT and a nerve transfer provides stronger elbow flexion compared with the gracilis FFMT alone.

et al.,
2017a)

Maldonado et al. (Maldonado et al., 2017b)	USA	Surgeons x 5 Registered nurse x 1	Retrospecti ve case series/ IV	n= 39	C5-T1 root avulsion	29 (FFMT with biceps tendon attachment) 10 (FFMT with FDP/ FPL tendon attachment)	To determine which insertion point resulted in better elbow flexion
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Potter & Ferris (Potter & Ferris, 2017)	Australia	Surgeons x 2	Retrospecti ve case series/ IV	n= 24	Complete- BPI	8= nerve transfer and salvage/ secondary FFMT 13= FFMT (primary reconstruction)	To report outcomes of surgery to restore elbow flexion
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Satbhai et al. (2016)	Japan	Surgeons x 4	Cohort study/ IV	n= 81	C5 injury		
					with or without involvement of the Spinal accessory nerve= 81	Double FFMT= 47; Single FFMT= 16; N= 18	Evaluate range of movement, strength, quality of life and disability pre- and post-operatively for three surgical interventions used for management of BPI for at least 24 months. Compare outcomes between the three intervention groups.
Yang et al. (2016)	China	Unclear- members of orthopaedic departments x 10	Cross-sectional, case series/ IV	n= 42	Traumatic, total BPI= 42	FFMT	Describe and compare multiple outcomes for pan-BPI patients following FFMT reconstruction.

Note:

BPI= brachial plexus in jury; BSc= Bachelor of Science; DFMT= double free muscle transfer; F= female; FFMT= free functioning muscle transfer; MPH= Masters Public Health, NHMRC= National Health and Medical Research Council; PhD = Doctor of Philosophy; SFMT= single free muscle transfer

4.7.1 Outcome measures identified

Eleven articles reported using the Disability of the Shoulder, Arm, and Hand (DASH; Hudak et al., 1996), five used the Medical Outcome Study 36 Item Short-Form Health Survey (SF-36; Ware & Sherbourne, 1992), two reported the Modified-Swap for the same population (mSWAP; Franzblau & Chung, 2015) (Table 5). In addition to the SF-36 total score, three of the studies included in this review also reported sub-scale scores (e.g. social functioning, role emotional, etc) including the SF-36 mental health sub-scale score (Dodakundi et al., 2013; Franzblau & Chung, 2015; Kitajima et al., 2006). The following measures were reported once: Upper Extremity Functional Index (UEFI; Stratford et al., 2001), Canadian Occupational Performance Measure (COPM; Law et al., 2005), Self-rating Anxiety Scale (SAS; Zung, 1971), Self-rating Depression Scale (SDS; Zung, 1965), Michigan Hand Outcomes Questionnaire (MHQ; Chung et al., 1998), Brief-Coping with Problems Experienced (Brief-COPE; Lawrence et al., 1998). In addition three developed study-specific questions (Coulet et al., 2011; Dodakundi et al., 2013; Satbhai et al., 2016), with responses scored using either a visual analogue (Coulet et al., 2011) or Likert scale (Dodakundi et al., 2013; Satbhai et al., 2016). The study specific question included the following: two assessed pain (Dodakundi et al., 2013; Satbhai et al., 2016), one cosmetic appearance (Coulet et al., 2011), two activity (e.g. cutting meat) (Dodakundi et al., 2013; Satbhai et al., 2016), two participation (e.g. work) (Dodakundi et al., 2013; Satbhai et al., 2016), and three environmental and personal factors (e.g. patient satisfaction with procedure) (Coulet et al., 2011; Dodakundi et al., 2013; Satbhai et al., 2016).

Table 5:*Outcomes measures reported in included articles.*

	DASH (Hudak et al., 1996)	SF-36 (Ware & Sherbourne, 1992)	Modified-SWAP (Franzblau & Chung, 2015)	UEFI (Stratford et al., 2001)	COPM (Law et al., 2005)	SAS (Zung, 1965)	SDS (Zung, 1971)	MHQ (Chung et al., 1998)	Brief-COPE (Lawrence et al., 1998)	Study specific questions
Addosooki et al. (2012)	x									
Coulet et al. (2011)	x	x								x
Dodakundi et al. * (2013)	x	x								x
Elzinga et al. (2014)	x				x					
Estrealla and Montales (2016)	x									
Franzblau and Chung (2015)**		x	x						x	
Franzblau et al. (2014)**		x	x					x		

Gillis et al. (2019)	x									
Kitajima et al. (2006)		x								
Maldonado et al. (2017a)***	x									
Maldonado et al. (2017b)***	x									
Potter & Ferris (2017)	x			x						
Satbhai et al. (2016)*	x					x	x			x
Yang et al. (2016)	x									
Number of articles	DASH 11	SF-36 5	Modified- SWAP 2	UEFI 1	COPM 1	SAS 1	SDS 1	MHQ 1	Brief-COPE 1	study specific questions 3
Percentage of articles	79%	36%	14%	7%	7%	7%	7%	7%	7%	study specific questions

									21%
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Note. Brief COPE= Brief Coping with Problems Experienced; COPM= Canadian Occupational Performance Measure; DASH= Disability of the Arm, Shoulder and Hand; MHQ= Michigan Hand Outcomes Questionnaire; Modified SWAP= Modified Satisfaction with Appearance Scale; SAS= Self Rating Anxiety Scale; SDS= Self-rating Depression Scale; SF-36= Medical Outcomes Study: 36-Item Short Form Health Survey; UEFI= Upper extremity functional index

*= The findings reported in Satbhai (2016) build on and extend the results from Dodakundi et al (2013)

** = The findings reported relate to one participant group that has been used across both articles.

*** = The findings reported relate to one participant group that has been used across both articles.

4.8 Manuscript 1 Discussion

This scoping review identified 14 studies from six countries, with 64% conducted from either the USA or Japan. The location of the studies was likely limited due to the fact that surgical experience with FFMT reconstruction is not geographically widespread, and that the number of patients who have had an FFMT is relatively small. This study is the first to specifically explore which psychosocial outcome measures have been used with BPI patients post-FFMT reconstruction surgery. While severe BPI is a devastating injury, this review has found that few studies have reported psychosocial outcomes. Except for the DASH, there was little if any consistency across the studies with a total of nine measures identified across 14 projects. The measures identified in this small set of studies aligned well with the concept of a biopsychosocial perspective that recognises that health and well-being involve a dynamic interplay between the person, their personal factors, and their environment (World Health Organization, 2001). Concepts assessed included functioning in daily activity, psychological factors, quality of life/ health status, and satisfaction. The outcome measures identified are discussed using these categories below.

4.8.1 Functioning in daily activity

Measuring function or use of the upper limb is reported differently across the literature. In BPI literature the term 'function' is often used with no definition to refer to range of motion, strength or sensory outcomes (Barrie et al., 2004; Vekris et al., 2008). However, good motor or sensory outcomes do not necessarily equate to use of the limb in daily life (Kretschmer et al., 2009a). The term functional as it is used in this paper, is defined as the ability to complete tasks and activities of everyday life

(World Health Organization- Regional Office for the Western Pacific., 2001). Three outcome measures identified specifically address this aspect of arm use the DASH, MHQ, UEFI, and the COPM.

The DASH (Hudak et al., 1996) was the most frequently used outcome measure identified in this review (79%), and is the most frequently used psychosocial outcome measure following BPI more broadly (Dy et al., 2015; Hill et al., 2015). Developed to assess disability-related symptomatology and functional status in cases of upper extremity musculoskeletal condition the first 16 items are specific to activity (Hill et al., 2018). (Hudak et al., 1996). The included articles used the DASH to report on several different outcome domains: hand function (Addosooki et al., 2012), disability (Elzinga et al., 2014), functional outcomes (Estrella, 2011; Satbhai et al., 2016), and/or, quality of life (Satbhai et al., 2016; Yang et al., 2016). A systematic review of the DASH's clinimetric properties found that the measure has excellent internal consistency ($\alpha = 0.92 - 0.98$), but noted that there is a strong likelihood of item redundancy with items measuring the same concept (Kolber et al., 2014).

The use of the DASH following BPI has attracted some criticism as its response options do not relate to the affected limb; therefore, improvement cannot be attributed to change in the affected arm. It is unclear if use of the affected limb has actually improved or the person has employed compensatory techniques (Eggers & Mennen, 2001; Hill et al., 2015; Scott et al., 2013). Moreover the effect size of the DASH in a group of people with various degrees of BPI severity was only 0.15 and based on known groups validity and the DASH could not discriminate between people who self-reported hand use (Hill et al., 2018).

One included study (2014) used the MHQ. The MHQ has 37 items that relate to the left and right hands and assesses overall hand function, activities of daily living, pain,

work performance, aesthetics, and satisfaction with hand function (Chung et al., 1998), but is included here as the first three sections assess overall hand function, activities of daily living, and work - which align most closely with functional use in daily life. In using the MHQ, Franzblau et al. (2014) concluded that the BPI population is relatively unique in comparison to other upper limb injury populations and they would benefit from a measurement tool that is developed to assess outcomes relevant to BPI. Whilst the MHQ is a valid and reliable measure of wrist and hand function (Arwert et al., 2016), it does not directly measure proximal function. As most BPI patients have sustained injuries involving shoulder and elbow function the MHQ may be more appropriate for use with patients with lower plexus injuries, for example C8-T1.

The UEFI, used in one included study (Potter & Ferris, 2017), was designed for use with individuals with musculoskeletal disorders and predominately measures their ability to complete daily activities (e.g. lifting grocery bag, washing hair, driving, opening jar) (Stratford et al., 2001). The original measure included 20 items (UEFI-20); however, Potter and Ferris (2017) used a Rasch-refined 15-items version (UEFI-15) (Chesworth et al., 2014). Items are scored using a 5 point Likert scale indicating ability to complete tasks from “extreme difficulty/ unable to do” to “no difficulty” (Stratford et al., 2001). Previous research by Hill et al. (Hill et al., 2018) investigated the UEFI for individuals following BPI. While the effect size was larger than the DASH (Cohen’s $d = 0.36$) the UEFI was unable to discriminate between people who self-report hand use, indicating items may not be targeted enough for use with BPI particularly those with very limited hand use.

The COPM is a client-centred assessment tool for patients to self-identify issues in their daily life and their level of satisfaction with their identified ability to perform the

activity (Law et al., 2005). It is completed via a semi-structured interview during which the patient nominates performance concerns related to any life role (i.e. if and how they are able to undertake chosen self-care, leisure, and/or productive activities) and their corresponding level of satisfaction with their abilities (Law et al., 2018). Following a systematic review, the COPM was found to demonstrate an excellent internal consistency for its two subscales (performance $\alpha = 0.93$ and satisfaction $\alpha = 0.89$) (Carswell et al., 2004). However, as the COPM is a client-centred measure that assesses individual patient's perceptions in respect to their own life goals, comparisons among patients and between cohorts is problematic.

4.8.2 Psychological factors

Research indicates that psychosocial factors can and do impact rehabilitation success following upper limb injury (Hannah, 2011). Psychosocial factors such as depression, anxiety and catastrophizing following nerve injury have been associated with the level of disability experienced by patients (Novak et al., 2011), it is reasonable to conclude that such psychosocial factors also impact BPI patients. While the measurement of (Wilson et al., 2016) and referral (Franzblau & Chung, 2015) for depression and/or anxiety is recommended following traumatic, BPI, Yang et al. (2016) was the only study that measured either. Depression was measured using the SDS (Zung, 1965) and anxiety with the SDA (Zung, 1971). Both measures consist of twenty items that relate to the assessment of either depressive or anxiety-related symptomatology and have been extensively used in studies on traumatic injury and long-term illness (Fasano et al., 2010; Frühwald et al., 2001; Place et al., 2018; Pohjasvaara et al., 1998). The psychometric properties of both scales have been established by Tanaka-Matsumi and Kameoka (1986) concluding that both had good internal consistency (SDS, $\alpha = 0.81$; SDA, $\alpha = 0.82$).

The rehabilitation literature demonstrates an association among body image, depression, and anxiety (van Diemen et al., 2017), as well as an association with physical and global self-esteem (Keppel & Crowe, 2000). Body image is conceptualised as a person's thoughts and feeling about their body (Keppel & Crowe, 2000; van Diemen et al., 2017). Longstanding BPI and avulsion injury is associated with autonomic changes that can result in discoloration of the limb combined with muscular atrophy changes (Carlstedt, 2008); and, as such, body image issues and feelings of self-consciousness related to the appearance of the injured arm are a common finding in the BPI literature (Wellington, 2010). Body image has been considered in the broader BPI literature (Wellington, 2010), as well as in this review through the use of the modified Satisfaction with Appearance Scale (mSWAP) (Franzblau et al., 2014) and study-specific questions (Coulet et al., 2011; Satbhai et al., 2016).

Franzblau and Chung (2015) reported on self-efficacy and body image using the mSWAP, a modified version of the Satisfaction with Appearance Scale developed by Lawrence et al. (1998) to assess body image following severe burns. The modifications to the original measure eliminated body parts not related to BPI (e.g. scalp, face, legs, etc.) and replaced them with more applicable items (e.g. shoulder and arm). The original measure demonstrated high internal consistency ($\alpha=0.87$) but low test-retest reliability ($\alpha=0.59$) (Lawrence et al., 1998). Satisfaction with Appearance Scale scores have been negatively correlated with mental health, as measured by the SF-36, as well as with its social functioning and vitality subscales (Lawrence et al., 1998). To date, no psychometric data has been published regarding the mSWAP. Coutlet et al. (2011) – measured satisfaction with attractiveness using a visual analogue scale. Satbhai et al. (2016) asked, “Do you

worry about the appearance of the reconstructed hand?” with responses measured using a Likert scale. Adjustment to changed appearance of the upper limb is of particular focus given most individuals who sustain BPI are young men who are more concerned with appearance (Hanna, 1996). While reporting cosmesis/ body image outcomes seems conceptually appropriate, deeper understanding of how the patients’ perceptions of their appearance impact them in daily life is still required. To explore coping, Franzblau and Chung (Franzblau & Chung, 2015) applied the Brief-COPE (Lawrence et al., 1998), a self-reported coping measure. The measure assesses the frequency of coping strategies used by adults in response to trauma and other challenging events. The psychometric properties have been established using a sample of natural disaster survivors and it has been used with a range of other populations (e.g. men living with HIV, women living with breast cancer)(Jewett et al., 2010). The internal reliability of Brief COPE’s subscales has been reported as being between $\alpha = 0.50- 0.90$ (Anderson et al., 2008; Cooper et al., 2008; Monzani et al., 2015; Yusoff et al., 2010). While the relationship between coping and outcomes has been explored in broader rehabilitation literature (Greenglass et al., 2005; Sinyor et al., 1986); Franzblau and Chung (2015) concluded that a better understanding of adjustment over time is necessary when working with BPI patients.

Measuring psychological outcomes post trauma and during rehabilitation reflects a more holistic approach to patient care and assists health care workers to provide appropriate and thus more effective interventions and care (MacDermid et al., 2017). Franzblau and Chung’s (2015) work recommended that the BPI literature could utilise existing models of coping and adjustment to further consider mental health factors and outcomes. In summary, patients’ psychological states and coping mechanisms are very salient when dealing with the challenges posed by BPI but

rarely assessed. The upper limb rehabilitation literature generally focuses on negative psychological factors (e.g. depression), further consideration of positive psychological factors associated with rehabilitation (e.g. enhancing independence) is warranted (MacDermid et al., 2017).

4.8.3 *Quality of life*

The SF-36 was used in five of the included studies (2011; 2013; Franzblau & Chung, 2015; 2014; 2006). The SF-36 assesses health status using eight health domains: physical functioning, role limitations due to physical problems, social functioning, bodily pain, general mental health, role limitations due to emotional problems, vitality, and general health perceptions (Ware & Sherbourne, 1992). The eight domains have collectively been recognised as representative of an individual's quality-of-life by the World Health Organization (World Health Organization, 1998). When summed, the eight domains produced two scores – one regarding physical health and the second regarding mental health. While some items in the SF-36 may be less reflective or relevant to the upper limb following BPI (e.g. climbing stairs, walking, and bending) it still provides a measure of a patient's quality of life. One benefit of using the SF-36 is it has normative population data (Butterworth & Crosier, 2004). Another is it has subscale scores for physical and mental health – both impacted following BPI. Despite the potential benefits of using this measure, Kitajima et al. (2006) found the relationship between the ability to move the arm at the shoulder elbow or fingers was not correlated with quality-of-life as measured by the SF-36 and they do not recommend its use for people with BPI.

4.8.4 *Satisfaction*

Satisfaction is a complex construct that has received considerable recent interest in the literature in relation to care quality, ownership in decision-making, and the

economic impact of care (Chow et al., 2009; Kretschmer et al., 2009b; Shirley & Sanders, 2013). Patients' perspectives and opinions are key when understanding their needs and their level of satisfaction post-surgery (Ahmed-Labib et al., 2007; Bengston et al., 2008; Choi et al., 1997; Kitajima et al., 2006). In the current review, three articles assessed patient satisfaction with their surgical procedure (Coulet et al., 2011; Dodakundi et al., 2013; Satbhai et al., 2016).

Franzblau et al. (Franzblau et al., 2014) discussed that satisfaction was not always linked to upper extremity activity but rather prior expectation. Most of the salient points in their study related to satisfaction for this population including the need for increased pre-operative education including tangible examples (e.g. detailing activity examples that they will and will not be able to complete, meeting with an individual who has had the procedure). The Franzblau et al. (Franzblau et al., 2014) study also discussed the difficult balance between being realistic without dashing the patients hope for future improvement (Franzblau et al., 2014). The latter of these two is more individually driven and therefore more difficult for health professionals to get the balance right between patients.

Collectively, the measures identified suggest that researchers are keen to understand outcomes of both BPI more broadly, and from patients' perspectives. The measures applied examine health broadly (e.g. DASH & SF-36) and also specifically (e.g. depression, body image, coping, etc.). However, the inclusion of study-specific questions seems to demonstrate that researchers wish to explore outcomes that are important to this population but were unable to locate outcome measures they believed assessed these outcomes. That said, participation and environment were either omitted or superficially considered in the papers included in this review. The ICF defines participation as "involvement in a life situation" and

environment as “the physical, social and attitudinal environment in which patients live and conduct their lives” (World Health Organization, 2002, p. 10 p.10). As such, inclusion and reporting of such outcomes together with a better understanding of patients’ experiences during rehabilitation would provide a deeper understanding of factors associated with enabling or challenging patient recovery and assist health professionals working with this group following surgery.

4.9 Manuscript 1 Implications for practice & future research

Future research should utilise measures that have been validated for use with BPI. Two new BPI-specific measures have been published recently (Hill et al., 2016; Mancuso et al., 2018). Neither has been used to evaluate outcomes following FFMT, however, as BPI specific measures they are worthy of mention here. Hill et. al. (Hill et al., 2016) developed the Brachial Assessment Tool (BrAT) a valid, reliable and responsive patient-reported measure, to assess day-to-day activity limitations (Hill et al., 2016; Hill et al., 2017; Hill et al., 2018). Mancuso et al. (2018) developed the Impact of Brachial Plexus Injury Questionnaire which addresses both physical and psychological outcomes associated with BPI. They represent condition-specific, psychometrically robust standardised measures to record outcomes following BPI, and their use will allow in depth comparison of studies and generate further discussion about management and health care specific to BPI.

A biopsychosocial frame of reference emphasises the interaction between the person, their personal factors, and their environment as it influences health and well-being (World Health Organization, 2001). This scoping review identifies gaps in outcomes measures related to psychological outcomes and social participation outcomes. Further research is currently underway to establish a core outcome set for traumatic BPI (Miller et al., 2019). Using outcome measures that examine these

constructs in a consistent manner would not only provide insight into patients' lives and needs, but also avail comparison among studies and provide the opportunity for the meta-analysis of findings. Future research following severe BPI needs to continue to consider physical impairment measures (e.g. strength and range of motion), but extend this in a more holistic manner to include other psychosocial outcomes (e.g. social participation and quality of life).

4.10 Manuscript 1 Limitations

This review was limited to literature in English and yielded only a small number of articles. As discussed in the results, the articles identified had a substantial overlap in respect to authorship, setting, and/ or time periods (Dodakundi et al., 2013; Satbhai et al., 2016) (Maldonado et al., 2017a; Maldonado et al., 2017b) (Franzblau & Chung, 2015; Franzblau et al., 2014). While this review's search strategy and article review processes were undertaken in a manner that was both fulsome in scope and ensured due diligence, it might be possible that additional articles were not discovered.

4.11 Manuscript 1 Conclusion

Following highly skilled, surgical repair, patients who have undergone FFMT following BPI require rehabilitation that optimises their health, wellbeing, and return to day-to-day lives and rehabilitation providers need improved ways of measuring these outcomes. Despite the lack of consistency of outcome measures used, this scoping review has found studies exploring a range of outcomes following these profound and life-altering injuries. It is unlikely that any single measure will be able to measure or even consider all of the germane factors. However, this review provides the opportunity to reflect on current approaches in measuring outcomes for this

population and encourages rehabilitation providers to draw on what is known about these patients to ensure that they measure relevant and holistic outcomes.

4.12 Chapter Summary

In the background chapter it was identified that most of the BPI literature and research uses a biomedical frame of reference. This chapter has identified that the literature looking at outcomes measures used following FFMT for BPI has a higher rate of psychosocial outcomes measures used than the broader BPI literature. Most of the included studies were conducted by surgeons with minimal input from rehabilitation professionals regarding post-op management, the patient experience, or relevant clinical settings. The findings of this scoping review have informed the subsequent investigations and outcomes measures used in this thesis. The following chapter will investigate the results of two activity-related outcomes measures following FFMT for management of BPI.

Chapter 5 - Measuring Activity Following FFMT for Pan-BPI: A Case Series

5.1 Chapter Introduction

Chapter 4 contains the scoping review that was completed to identify measures currently being used and reported following FFMT surgery for management of BPI. This chapter is informed by findings of Investigation 1 (Chapter 4). This chapter contains the manuscript associated with Investigation 2, which aimed to report activity-related outcomes following FFMT for pan-BPI.

5.2 Manuscript 2 Information

Brito, S., Hill, B., McCulloch, M., Ferris, S., & Thomacos, N. (manuscript submitted). Measuring activity following free functioning muscle transfer for pan-brachial plexus injury: A case series. *Disability and Rehabilitation*.

Date submitted: 19 April 2021

5.3 Abstract

5.3.1 Introduction

Pan-brachial plexus injuries (pan-BPIs) result in severe upper limb impairment with permanent dysfunction of the affected upper limb. A range of reconstructive surgeries can be performed including free functioning muscle transfer. However, little is understood about how the restored arm movement is used in day-to-day life. The aim of this study was to report the outcomes of two activity measures to better understand this.

5.3.2 Methods

Case series of individuals with a traumatic, pan-brachial plexus injury. Two measures were utilised to examine ability to complete activities in daily life. Findings were considered through comparison to other similar studies using One-sample *t*-tests and through comparison of the two measures to one another.

5.3.3 Results

This study consisted of eight males with a mean age of 43.5 (11.67) years. Participants scored a mean 44.17 (SD = 16.29) on the Disability of the Arm, Shoulder and Hand and 14.25 (6.2) on the Brachial Assessment Tool. When attributing response to the affected limb using the BrAT 75% of responses were 'cannot' perform the activity while using the DASH gave opposing views – 59% of responses were 'no' or 'mild' difficulty.

5.3.4 Conclusion

While people with pan plexus injury have significant global deficits the selection of appropriate outcome measures is central to understanding if changes related to increased use of the affected limb or the use of compensation strategies. Health professionals need to understand the underlying concept of the measures they use to enable them to select the most appropriate tool and to recognise its meaning to patient recovery.

5.4 Investigation 2 Manuscript 2

The manuscript below, linked to Investigation 2.

5.5 Manuscript 2 Introduction

Brachial plexus injuries (BPIs) in adults are most commonly caused by motor cycle accident and result in severe injury (Brophy & Wolfe, 2005). The brachial plexus is the anatomical name given to the nerves that originate from spinal roots C5-C8 and T1 and provides both motor and sensory innervation to the shoulder, arm, forearm, and hand (Brophy & Wolfe, 2005; Vekris et al., 2008). Presentation of injury and outcomes following BPIs vary significantly depending upon the mechanism of injury and the level and pattern of lesion (Brophy & Wolfe, 2005). Pan-plexus injuries, sometimes called flail limb, complete-, total-, or global-BPI, involve injury to all root and/ or trunk levels and result in impaired motor and sensory function of the whole limb. These injuries (pan-BPIs) are devastating and result in life-long disability and negative socio-economic consequences (Kretschmer et al., 2009; Vekris et al., 2008). Management of pan-BPIs is challenging due to few donor nerve options and the need for multiple reconstructive surgeries often occurring over many years (Terzis & Kostopoulos, 2009). Doi et al. (2000) described a double gracilis transfer which uses the first free-functioning muscle transfer (FFMT) to restore elbow flexion and finger extension and the second to restore finger flexion whilst adding power to elbow flexion. A similar two-stage FFMT approach was used in the majority of patients from this study, although some only had a single FFMT.

A recent systematic review of all brachial plexus surgery found that studies typically did not include patient-reported outcomes, but rather strength, range of movement and sensory outcomes (Dy et al., 2015). The pan-BPI literature has extended this with some of the previous studies reporting psychosocial and activity outcomes (Addosooki et al., 2012; Potter & Ferris, 2017; Yang et al., 2016). The concept of activities as a construct, is often poorly conceptualised and therefore difficult to

measure (Whiteneck & Dijkers, 2009). For the purpose of this study the term activity is defined as 'the execution of a task or action by an individual' (World Health Organization, 2002, p. 10). Activity measurement following BPI is important to better understand the use of the injured arm as well as an indicator of an individual's ability to complete daily activities. The Disability of the Arm, Shoulder and Hand (DASH) (Hudak et al., 1996) is the most widely used patient report outcome measure following BPI (Dy et al., 2015). While designed to measure disability by measuring symptoms and physical function (Hudak et al., 1996) it also contains items that assess activity (Metcalf et al., 2007). The Brachial Assessment Tool (BrAT) is a patient-reported outcome measure designed specifically to measure day-to-day activity limitations for all levels of BPI including those with very limited to no hand function (Hill et al., 2016). Items are attributed directly to the affected limb unlike the DASH that assesses items regardless of which limb is used (Mancuso et al., 2016). As a consequence the DASH measures compensatory strategies using the unaffected arm, rather than increased functional use of the injured arm (Mancuso et al., 2016). It is hoped that the current study will begin to provide a profile of expected activity outcomes for people with a pan-plexus injury and can be used to assist with goal setting following reconstructive surgeries. The current study aims to (i) report activity outcomes for individuals following FFMT reconstructive surgery for management of a pan-BPI using two different patient-report outcome measures, (ii) to better understand how patients use the affected arm following reconstructive surgery.

5.6 Manuscript 2 Methods

This exploratory study was conducted at a private, hand therapy clinic in Melbourne, Australia that specialises in managing people with BPI. The Joanna Briggs Institute Critical Appraisal tool for Case Series provided guidance during the reporting of this study (Moola et al., 2017) (Table 6). Inclusion criteria were: a diagnosis of traumatic, pan-BPI confirmed by magnetic resonance imaging; nerve conduction studies or clinical findings; had undergone their first FFMT surgery between 2007 and 2015; were 18 years or older, with no prior dysfunction of the upper limb; and were at least 1-year post first FFMT surgery. Participants were excluded if they had sustained a partial BPI or did not provide informed consent. Recruitment occurred between February and November 2017 following approval from Monash University Human Research Ethics Committee approval (Project Number: 392).

Table 6

Joanna Briggs Institute Appraisal Checklist for Case Series (16)

	Yes	No	Unclear	Not applicable
1. Was there clear criteria for the inclusion in the case series?	✓			
2. Was the condition measured in a standard, reliable way for all participants included in the case series?	✓			
3. Were valid methods used for identification of the condition for all participants included in the case series?	✓			
4. Did the case series have consecutive inclusion of participants?	✓			
5. Did the case series have complete inclusion of participants? Yes, all that consented.	✓			

6. Was there clear reporting of the demographics of the participants in the study? Table 7 & 8	✓			
7. Was there clear reporting of clinical information of the participants?	✓			
8. Were the outcomes or follow up results of cases clearly reported?	✓			
9. Was there clear reporting of the presenting site(s)/ clinic(s) demographic information?	✓			
10. Was statistical analysis appropriate?	✓			

5.6.1 Data collection

Participants that returned signed consent forms were sent a hyperlink to a Google Form survey. There was no missing data. Participants completed the Disability of Arm, Shoulder, and Hand (DASH) and the Brachial Assessment Tool (BrAT) (Hill et al., 2016). Unidimensional measures assess one construct, whereas multidimensional measures assess more than one construct. The DASH, a multidimensional measure, consists of 30 questions (measuring daily activity, pain, and sleep) that are scored using a five-point Likert scale, with higher scores indicating higher levels of physical dysfunction (Hudak et al., 1996; Lehman et al., 2011). The first 16 items are specific to daily activity (Hill et al., 2018). The BrAT uses 31 questions that measure one construct – day-to-day activity limitation, thus the items themselves are not unidimensional, but rather the BrAT is. The BrAT was developed to assess day-to-day activity limitations of the affected limb in people with BPI and consists of 31 items with responses rated using a 5-point Likert scale (Hill et al., 2016). Its total score is the sum of its three subscales: activities of daily living

(Dressing and personal care), daily activities that require arm and hand use (Arm and hand), and daily activities that require mostly shoulder and elbow use (No hand).

5.6.2 Data analysis

Findings are presented as means and standard deviations, then compared to the results of other BPI studies. Descriptive data was used to compare total scores, subscale scores, and single items across the two activity measures. Analyses were carried out using SPSS 25 (IBM Corp., Released 2017). Comparative analysis were performed using One-sample t-tests.

5.7 Manuscript 2 Results

A total of 23 individuals met the inclusion criteria and were sent information packs regarding this study via post. Eight patients provided written informed consent to take part, four declined, and 11 did not respond. Participants were all male with a mean age of 43.5 years (SD 11.67; range 27-64) and a mean age of 35.47 years (SD 10.23; range 20-51) at time of injury (Table 7). Mean time post-injury was 7.94 (2.43) years. All participants underwent secondary procedures (i.e. joint fusion, tendon transfer, and one below elbow amputation) that are detailed in Table 8. All participants received compensation from the Transport Accident Commission. The Transport Accident Commission provides a 'no-fault' insurance scheme for people involved in motor vehicle accidents that occur in the state of Victoria or involve a Victorian registered vehicle (Transport Accident Commission, 2018). This insurance assists people involved in motor vehicle accidents access a comprehensive range of health and well-being services (e.g. primary and tertiary health, allied health, travel support, rehabilitation, community re-integration services, etc.).

Table 7*Diagnosis and medical data*

Participant:	Gender	Diagnoses	Time post injury (years)	Time from injury to FFMT surgery	Time from 1st to 2nd FFMT	Time since 1st FFMT surgery to time of study (years)	Time since 2nd FFMT surgery to time of study (years)	Dominant hand injury
1	Male	Complete avulsion all 5 levels (C5,6,7,8 & T1) of plexus as identified by surgical exploration.	6.75	2-5 years	N/A	5.33	N/A	Yes
2	Male	MRI - C5 rupture, C6,7,8,T1 avulsions.	11.33	5+ years	N/A	6.00	N/A	No
3	Male	MRI - C5, 7, 8 and T1 avulsions (C6 nerve root intact) Surgical exploration confirmed complete avulsions all 5 levels (C5,6,7,8 &T1) and scarred plexus reason for MRI difficulty.	10.29	2-5 years	12-24 months	8.42	8.83	No

4	Male	<p>MRI - C5 root rupture, C6 inconclusive, C7/C8 & T1 nerve root avulsions.</p> <p>NCS & EMG - C7,8 & T1 avulsions, as well as C5 and C6 being affected proximally.</p> <p>Surgical exploration confirmed C5 rupture with viable stump & intact Long Thoracic nerve from C5 stump & Phrenic nerve in good condition, C6 no viable stump C7,C8 & T1 avulsed.</p>	5.99	12-24 months	12-24 months	3.25	0.42	No
5	Male	<p>MRI C5,C6 ruptures with C7,C8,T1 avulsions;</p> <p>NCS - Rhomboids intact & Trapezius intact.</p>	5.42	0-6 months	0-6 months	5.00	4.67	Yes
6	Male	<p>Surgical exploration demonstrated C6 - T1 avulsions, extremely poor C5 outflow. DSN intact but not stimuable. No viable fibres available from C5. No outflow C6 and below.</p>	7.08	0-6 months	N/A	6.83	N/A	Yes
7	Male	<p>Surgical exploration showed no available cervical root Right brachial plexus. Only outflow C5 DSN but not stimuable. C6, C7 root rupture, C8, T1 avulsions.</p>	8	2-5 years	12-24 months	4.92	0.67	Yes

8	Male	<p>NCS - consistent with significant Cervical root avulsion injury (specific levels not reported).</p> <p>MRI- C5 rupture, C6-T1 avulsions.</p> <p>Surgical exploration showed C5, C6 and C7 ruptured with no viable fibres. C8 and T1 avulsed.</p>	7	6-12 months	12-24 months	6.5	6.25	Yes
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Table 8*Demographic and surgical information*

Age (years) at time of study*	27-64 (mean 43.50; SD 11.67)
Age (years) at time of injury*	20-51 (mean 35.47; SD 10.23)
Injury mechanism*	Motorbike x 7 Pushbike x1
Concomitant injuries*	Pneumothorax x 3 participants Acquired brain injury x 3 participants Spinal fracture x 2 participants Facial fracture x 1 participants Rib fracture x 2 participants Clavicle fracture x 1 participants Scapular fracture x 1 participants Hand fracture x 2 participants Leg fracture x 2 participants Knee reconstruction x 2 participants Partial foot amputation x 1 participants
Nerve Transfer Surgery*	FFMT (EF/FF) with ICN transfer x 7 participants FFMT (EF/FE) with Accessory n. transfer x 5 participants FFMT (EF/FE) with previous Cross neck transfer x 1 participant Cross neck VUNG C7 transfer to MN or SSN or Axillary n. x 3 participants ICN transfer to MCN x 2 participants ICN transfer to Triceps x 1 participant Accessory n. transfer to SSN x 2 participants Phrenic n transfer with graft to Triceps x 1 participant
Direct Nerve Surgery*	C5 nerve root graft direct repair x 1 participant C5 nerve root graft to Axillary n x 1 participant
Additional surgeries related to brachial plexus injury*	Wrist fusion x 7 participants Shoulder fusion x 4 participants MCPJ finger joint fusion x 1 participant PIPJ finger joint fusion x 2 participants Thumb IPJ fusion x 5 participants Thumb tendon transfer x 4 participants Below elbow amputation (post FFMT) x 1 participant FFMT flap revision x 8 participants
Primary funding source*	Transport Accident Commission x 8
Highest level of education completed*	High school x 2 TAFE/ trade school x 4 Certificate x 1 Diploma x 1

Job prior to injury*	Technician/ trade worker x 4 Sales worker x 1 Machine operator/ driver x 1 Volunteer x 1 Other x 1
Job at time of survey*	Managerial x 1 Sales worker x 1 Labourer x 1 Unemployed x 2 Unemployed (Compensable payment) x 2 Other x 1
Length of time from injury to return to work*	12-18 months x 2 >24 months x 2 Have not returned to work x 4

Note:

*Aggregate information provided for participant anonymity.

DSN= dorsal scapular nerve; EE= elbow extension; EF= elbow flexion; EMG= electromyography; FE= finger extension; FF= finger flexion; FFMT= free functioning muscle transfer; ICN= intercostal nerve; IPJ= interpalangeal joint; MCN= musculocutaneous nerve; MCPJ= metacarpophalangeal joint; MN= median nerve; MRI= magnetic resonance imaging; N/A= not applicable; NCS= nerve conduction study; PIPJ= proximal phalangeal joint; SSN= supra scapular nerve; VUNG= vascularised ulnar nerve graft

The mean DASH score for the current study was significantly higher, and thus indicative of greater levels of disability than evident in the normative population data reported by Hunsaker et al.(2002) The current study's mean score was not statistically different to other populations that had FFMT reconstructive surgery for management of BPI (Table 9) (Addosooki et al., 2012; Coulet et al., 2011; Estrella & Montales, 2016; Yang et al., 2016).

Table 9*DASH scores for current and comparison studies*

	<i>N</i>	<i>Mean (SD)</i>	<i>p-value</i>	<i>t</i> (7)	Cohen's d
Current study	8	44.17 (16.29)			
<i><u>Normative data:</u></i>					
Hunsaker ²⁸	1,706	10.1 (14.68)	0.001*	5.914	2.1
<i><u>BPI populations following FFMT reconstructive surgery:</u></i>					
Addosooki (2012) ¹	18	43	0.845		
Coulet (2011) ¹	7	32 (SD not reported; range 22- 40)	0.073		
Estrella (2016) ¹	38	43.09 (14.9)	0.857		
Yang (2016) ¹	42	51.14 (SD not reported range: 17.5- 90.8)	0.265		

Note: N= number of participants in the study; SD = standard deviation

This study's cohort scored a mean total BrAT score of 14.25 (6.23) with the majority of the score in subscale 3 (No hand items). The subscale mean scores were as follows: Subscale 1: 0.75 (1.39)/ 24, subscale 2: 2.88 (2.85)/ 51, subscale 3: 10.63 (4.44)/ 18. In respect to comparing this study to another, it was not possible to undertake either parametric or non-parametric analyses for two of the three subscales that make up the BrAT as most of the current study's participants reported zero or extremely low scores. Accordingly, to avail some appraisal of the differences between the current study's findings and those from Hill et al.,(Hill et al., 2018) the

mean and median BrAT scores from the current study and the mean scores from Hill et al.(Hill et al., 2018) have been reported here – summarised in Table 10.

Table 10

BrAT scores for current study and comparison study

	1- Dress	<i>Sub-scales</i> 2- ArmHand	3- Nohand	Total
Current study – Mean (SD)	0.75 (1.39)	2.88 (2.85)	10.63 (4.44)	14.25 (6.23)
Hill (2018) - Mean	16.68	22.89	11.36	51.93

For a deeper understanding of activity-specific outcomes two comparisons were reported. First the BrAT items were compared to the DASH activity items (first 16 items) (Table 11). Then similar items from both scales were grouped, summed, and compared to one another (Table 12). Eighty-three percent (83%) of all response options assessed by the BrAT, were reported as ‘cannot do now’ or ‘very hard to do now’ when attributed to the affected limb. However only 20% of the DASH activity items were reported as being ‘unable to’ or ‘severe difficulty’ to perform when using any method to complete the activity. Table 12 presents a direct comparison of the responses to similar activities as measured by the BrAT and the DASH. For these items 91.6% were reported as “cannot’ or ‘very hard to do’ when using the BrAT versus 52.5% of responses on the DASH indicating that the same or similar activities can be done with ‘no’ or ‘mild difficulty’.

Table 11

Comparison of number of responses for activity items in the BrAT and DASH

BrAT	Cannot do now	Very hard to do now	A little hard to do now	Easy to do now
Sub scale 1 number responses	60	2	2	
Subscale 2 number responses	118	13	5	
Subscale 3 number responses	8	4	27	9
Total number responses (%)	186 (75%)	19 (8%)	34 (14%)	9 (4%)

DASH activity items (1-16)	Unable	Severe difficulty	Moderate difficulty	Mild difficulty	No difficulty
Total number responses (%)	5 (4%)	20 (16%)	28 (22%)	46 (36%)	29 (23%)

Table 12

Direct comparison of responses for similar BrAT and the DASH activity items

BrAT Subscale 1: Item 1 -use both arms to put on a t-shirt	Cannot do now	Very hard to do now	A little hard to do now	Easy to do now
	5	2	1	0
DASH: Item 15- put on a pullover sweater	Unable	Severe difficulty	Moderate difficulty	Mild difficulty
	0	2	2	3
BrAT Subscale 1: Item 6 – tuck your shirt in using your affected hand	Cannot do now	Very hard to do now	A little hard to do now	Easy to do now
	8	0	0	0

DASH: Item 14- wash your back	Unable 1	Severe difficulty 3	Moderate difficulty 0	Mild difficulty 3	No difficulty 1
BrAT Subscale 2: Item 15 -use a knife and fork at the same time	Cannot do now 8	Very hard to do now 0		A little hard to do now 0	Easy to do now 0
DASH: Item 16- use a knife to cut food	Unable 0	Severe difficulty 2	Moderate difficulty 4	Mild difficulty 2	No difficulty 0
BrAT Subscale 2: Item 16 -carry an object only using your affected arm so your arm/ hand is free to do another task	Cannot do now 3	Very hard to do now 3		A little hard to do now 2	Easy to do now
DASH: Item 10- carry a shopping bag or briefcase	Unable 0	Severe difficulty 0	Moderate difficulty 2	Mild difficulty 3	No difficulty 3
DASH: Item 11- carry a heavy object (over 10lbs)	Unable 0	Severe difficulty 0	Moderate difficulty 3	Mild difficulty 3	No difficulty 2
BrAT items: total number of responses (%)	24 (75)	5 (16.6)	NA	3 (9.4)	0 (0)
DASH items: total number of responses (%)	1 (2.5)	7 (17.5)	11 (27.5)	14 (35)	7 (17.5)

5.8 Manuscript 2 Discussion

Measuring outcomes is an essential component of rehabilitation. The initial pan-BPI results in an inanimate flail limb and the on-going physical dysfunction can be profound and long lasting (Potter & Ferris, 2017). This study found that surgery and rehabilitation following pan-BPI can reanimate the injured upper limb for use in daily activity. However, if the scores for the two outcome measures, or individual items are compared, the outcomes are not as clear given that findings are often contradictory. The discussion will first consider the outcomes of the two measures in this study as compared to other BPI populations, then compare the BrAT and DASH findings to better understand outcomes for this population and the outcome measures at a more granular level.

The first aim of the study was to report participants' perceived ability to complete daily activities following FFMT surgery for BPI. This study's DASH outcomes were consistent with other similar post-operative, pan-BPI populations (Addosooki et al., 2012; Coulet et al., 2011; Estrella & Montales, 2016; Yang et al., 2016). While the DASH is one of the most common patient-reported outcome measures used following BPI (Dy et al., 2015), it has not been validated for use with this population. A scoping review of the DASH by Baltzer et al (2014) detailed DASH scores for a range of upper extremity diagnoses, concluding that DASH scores do not correspond to the severity of the condition.

Accordingly, the current study instead compared directly to other similar populations.

As indicated earlier, the BrAT is a condition-specific measure developed to assess activity limitations of the affected limb in people with BPI (Hill et al., 2016). The authors identified only one paper that published data using the BrAT. While the BrAT score in this study were lower than those reported by Hill et al. (2018), this would be expected given the different cohorts. Specifically, Hill et al.'s (2018) study included 29 participants following surgery with BPI diagnoses including C5-6, C5-7, C5-8, C8/T1, and complete avulsion

injury. The current study only included people with a pan-BPI so any comparison needs to consider the heterogeneity of injury diagnosis across the two studies. In this study, participants scored themselves very low for activities requiring use of the shoulder, elbow and hand (subscales 1: e.g. put on t-shirt, buckle belt, put on/ do up trousers, etc. and subscale 2: e.g. push shopping trolley, zip clothing, tie shoe laces, use knife and fork, etc). However, subscale 3 (which assesses activities that require little or no hand) better represented the ability of individuals who sustained a pan-BPI. This is not surprising as following pan-BPI the returned movement is generally a gross motor pattern. The Hill et al. study (2018) also found that, unlike the DASH, the BrAT was able to distinguish between people who reported they could use their hand versus those who were unable to use their hand to complete activities - results that were repeated here (2018).

The second aim of this study was to better understand how individuals who have had FFMT reconstructive surgery following pan-BPI use the affected arm. Through review of outcome measure items, it was found that a person following FFMT for pan-BPI might expect to use their reconstructed limb as a *helper arm* through increased control of the arm, carrying objects, and to stabilize objects during bilateral tasks (BrAT subscale 3). While both the DASH and the BrAT assessed activity in daily life, participant reports of perceived ability to complete tasks as assessed by the two measures are almost reversed, with responses weighted on opposite ends of the ability spectrum (Table 3). We hypothesised that this is related to the BrAT asking specifically if the affected limb is completing the activity and the DASH measuring if the individual is able to complete the activity regardless of the limb. In short, one is assessing the use of the affected arm in daily activities (BrAT) and the other is assessing overall ability to complete the activities of daily life by any means (DASH). Caution around the interpretation of DASH scores have been raised (Baltzer et al., 2014), as has the concept that the DASH does measure compensation when used with BPI populations (Mancuso et al., 2016).

While individuals with pan-BPI experience global upper limb dysfunction and the potential for proximal recovery has been demonstrated, on-going poor hand function is likely (Aszmann et al., 2015; Elzinga et al., 2014). While some studies question the use of the DASH with BPI populations (Hill et al., 2018; Mancuso et al., 2016), this study indicates it could play a role in the assessment of the pan-BPI population where compensation is required for individuals to complete many necessary activities of daily life. The findings highlight an important nuance between measuring actual use of the affected limb versus the development of compensatory techniques (e.g. using the unaffected upper limb or holding an object between the legs). While the DASH is an appropriate measure for this population, caution needs to be exercised when attributing DASH outcomes to recovery of the affected limb. While the DASH provided valuable information regarding the overall experience and impact of injury, the BrAT demonstrated potential for measuring the specific outcomes of surgical procedures and subsequent upper limb rehabilitation programs on the affected limb. This is one of the few studies that has looked at this discreet subset of brachial plexus injury and the only that has used a BPI specific activity measure to date.

This study had a number of limitations including a small sample size of all males - despite direct access to this population via a specialist BPI rehabilitation service. However, this sample is consistent with similar studies of this distinctive diagnosis (Addosooki et al., 2012; Dodakundi et al., 2013; Estrella & Montales, 2016; Yang et al., 2016). Additionally, there was a majority of non-responders despite follow up during recruitment. A final limitation of this study was not having a pan-BPI population that did not receive FFMT surgery for comparison.

Recommendations for further research needs to consider which post-operative outcome measures should be used following FFMT for management of pan-BPIs, with a study underway to establish a core outcome set for traumatic BPI (Miller et al., 2019). Future

investigation of distinct BPI diagnoses and outcomes should be explored for better understanding of this heterogeneous condition. Data that is attributed to the use of the affected limb could be used to develop a specific set of activities that may be achievable by people with pan-BPI and to assist with expectations and goal setting. Longitudinal studies that start pre-operatively and collect data at regular intervals using these two activity measures is needed to better understand change across time are also recommended.

5.9 Manuscript 2 Conclusion

While movement and use of the affected upper limb following FFMT for pan-BPI is manifestly different to available and appropriate population norms, the current study indicates that individuals that sustain a pan-BPI report using their affected upper limb for daily activity. Daily activity as reported by these two measures have the potential to be complementary assessments. As such, using both the DASH and BrAT has the potential to yield a more complete understanding of daily activity in people with pan-BPI. While the BrAT measures the affected limb and its use in daily activity, the DASH provides a measure of an individual's ability to complete daily activities of living (e.g. through compensation). It is recommended that clinicians are clear about what is being measured when completing assessments with this population in order to ensure an accurate interpretation of these findings. That said, the use of a range of measures provides a more holistic understanding of outcomes following pan-BPI.

5.10 Chapter Summary

This chapter has reported outcomes related to two activity measures used following BPI. The results of this chapter's investigation indicate that interpretation of activity related scores from the DASH should be carefully considered when drawing conclusions and attributing improvement. This was highlighted by the manifestly different responses patients recorded for similar items to the BrAT. This finding is both clinically relevant and

represents an original contribution to the BPI literature. The next chapter considers the long-term impact of pan-BPI on participation.

Chapter 6 - Participation Following Brachial Plexus Injury: An Australian Case Series

6.1 Chapter Introduction

Chapter 6 contains the manuscript using data gathered as part of Investigation 2. As reported in Chapter 2, rehabilitation therapists commonly aim to increase range of motion and strength post FFMT, but they do so to improve occupational goals (e.g., increase strength of elbow flexion to enable individual to carry lunch bag over forearm when in engaging in work) (Gillen, 2013). This chapter uses a patient-reported outcome measure to report long-term, participation outcomes for individuals who have sustained a pan-BPI.

6.2 Manuscript 3 Information

Brito, S., Brown, T., & Thomacos, N. (manuscript under review). Participation following brachial plexus injury: An Australian case series. *Hong Kong Journal of Occupational Therapy*.

Date submitted: 30 November 2020

6.3 Investigation 3 Manuscript

The manuscript below, linked to Investigation 3, has been formatted for publication in *Hong Kong Journal of Occupational Therapy*.

6.4 Abstract

6.4.1 Design

Exploratory, case series design.

6.4.2 Methods

Participants included were adults diagnosed with a traumatic, BPI that subsequently underwent reconstructive surgery. Convenience sampling was used for recruitment from a

private hand therapy clinic. Descriptive data reported included demographic, injury, surgical, pain scores, and participation measures. One-sample t-tests were conducted for comparative analysis with other studies of individuals with severe/ chronic diagnoses to help understand outcomes for this group compared to other better-known diagnoses.

6.4.3 Results

Fourteen males consented to participate in this study and were a mean of 6.6 years (SD 2.96) post-injury. Their mean Utrecht Scale for Evaluation of Rehabilitation (USER)-Participation scores were: frequency 34.33 (SD 11.30); restriction 77.80 (SD 15.59); and satisfaction 62.95 (SD 18.26). Whilst, brachial plexus injury is an upper limb injury, the USER-Participation scores were not significantly different statistically compared to participation reported by individuals following spinal cord injury and stroke.

6.4.4 Conclusions

This study reported long-term outcomes for this small, hard to reach diagnostic group. It provides details about participants' frequency, restrictions, and satisfaction with their participation in a range of life situations following this traumatic injury that frequently results in physical impairment.



Participation following brachial plexus injury: An Australian case series

Journal:	<i>Hong Kong Journal of Occupational Therapy</i>
Manuscript ID	HJO-20-0089.R1
Manuscript Type:	Original Research Article
Keywords:	brachial plexus, occupational therapy, participation, patient reported outcome measures, rehabilitation
Abstract:	<p>Introduction Brachial plexus injuries (BPI) frequently result in life-altering injuries. While it seems likely that these consequences of injury would impact participation, outcomes are not well understood.</p> <p>Methods This exploratory, case series design aimed to report the participation in productive, leisure and social roles for individuals following BPI. Participants included post-operative, adults diagnosed with a traumatic, BPI. Descriptive data reported included demographic, injury, surgical, and participation measures. One-sample t-tests were conducted for comparative analysis with other studies following severe/ chronic diagnoses.</p> <p>Results Fourteen males consented to participate. Their mean Utrecht Scale for Evaluation of Rehabilitation-Participation scores were: frequency 34.33 (SD 11.30); restriction 77.80 (SD15.59); and satisfaction 62.95 (SD18.26).</p> <p>Conclusion This long-term follow up study found on-going and profound impact on participation in a range of life situations for this small, hard to reach diagnostic group. Participation in productive roles, home duties, and physical exercise were particularly impacted and need to be prioritised during rehabilitation.</p>

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1 Participation following brachial plexus injury: An Australian case series

2

3 Abstract

4 Introduction

5 Brachial plexus injuries (BPI) frequently result in life-altering injuries. While it seems likely
6 that these consequences of injury would impact participation, outcomes are not well
7 understood.

8 Methods

9 This exploratory, case series design aimed to report the participation in productive, leisure
10 and social roles for individuals following BPI. Participants included post-operative, adults
11 diagnosed with a traumatic, BPI. Descriptive data reported included demographic, injury,
12 surgical, and participation measures. One-sample *t*-tests were conducted for comparative
13 analysis with other studies following severe/ chronic diagnoses.

14 Results

15 Fourteen males consented to participate. Their mean Utrecht Scale for Evaluation of
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18 Conclusion

19 This long-term follow up study found on-going and profound impact on participation in a
20 range of life situations for this small, hard to reach diagnostic group. Participation in
21 productive roles, home duties, and physical exercise were particularly impacted and need to
22 be prioritised during rehabilitation.

23
24 **Key words:** brachial plexus, occupational therapy, patient reported outcome measures, rehabilitation

25 Introduction

26 Traumatic brachial plexus injury (BPI) is a serious injury that can negatively impact physical
27 ability and psychological health (Quick & Brown, 2020). In adults it is most commonly the
28 result of a motorbike accident (Kaiser, Waldauf, Ullas, & Krajcova, 2018). A BPI is damage
29 to the nerves originating from the spinal column between C5-C6 and T1, and depending on
30 the level and completeness of the lesion, there can be variable patterns of resultant deficits
31 and degree of recovery (Kaiser et al., 2018). Impaired use of the arm and hand due to BPI
32 results in difficulty completing daily tasks which contributes to disruption of participation in
33 pre-injury occupations. Despite agreement that BPI frequently leads to ongoing disability, a
34 scoping review of outcomes reported following brachial plexus surgery found that the most
35 commonly reported outcomes were related to motor recovery (Dy et al., 2015).

36 Meaningful participation following BPI can be challenging due to physical and psychosocial
37 impairments and its disruption often leads to major disability (Kang & Wolfe, 2011). While
38 psychosocial outcomes (i.e. pain, psychological health, daily activities, and appearance of
39 effected limb) are increasingly considered in the BPI literature (Landers et al., 2018; Rasulić
40 et al., 2017), participation remains an area that is not well understood. Given that BPI impacts
41 both physical and psychosocial aspects of an individual, it is reasonable to conclude that it
42 would have a profound impact on participation.

43 Participation is embedded in the practice of both hand therapy and occupational therapy
44 (Fenton, Gagnon, & Pitts, 2003; Radomski & Trombly Latham, 2008; Schoneveld, Wittink,
45 & Takken, 2009); although, measurement of participation in hand therapy practice remains
46 under-utilised (Schoneveld et al., 2009; Weinstock-Zlotnick & Bear-Lehman, 2012). Despite
47 the acknowledgement that participation can be significantly impaired following nerve injury
48 and recommendation to consider meaningful engagement in daily life (Bailey, Kaskutas, Fox,

49 Baum, & Mackinnon, 2009), the authors have found a dearth of empirical studies measuring
50 or reporting participation following BPI. To date participation in the BPI literature is
51 predominately limited to reporting if participants returned to work (Bengtson et al., 2008;
52 Quick & Brown, 2020).

53 The current study aimed to therefore address this lack of literature and is an exploratory study
54 that investigates participation following BPI by specifically reporting participation outcomes.
55 Participation, as a construct, is often poorly conceptualised and therefore difficult to measure
56 (Whiteneck & Dijkers, 2009). For the purpose of this study, participation is defined as an
57 individual's 'involvement in a life situations' (World Health Organization, 2002, p. 10). The
58 aim for this study was to report subjective and objective participation outcomes following
59 BPI. The questions were designed to inform clinicians working with this population of long-
60 term outcomes and to serve as a starting point for further investigations. Accordingly, the
61 research questions for this investigation were as follows: 1) What are the long-term
62 participation outcomes (i.e. work, leisure and social roles) following BPI?; and, 2) How do
63 participation outcomes following BPI compare with other life-changing conditions that result
64 in significant physical impairment (i.e. stroke and spinal cord injury)?

65 **Methods**

66 This exploratory study used a patient reported participation measure to investigate
67 engagement in roles and life situations following BPI. Participants were recruited from a
68 private, multi-centre, hand therapy service that specialised in the management of participants
69 who presented with traumatic BPI. Inclusion criteria for this study were: a diagnosis of
70 traumatic, BPI (as per medical referral from surgeon), ≥ 18 years old, no prior dysfunction of
71 the upper limb, and at least 1-year post-injury. This retrospective, consecutive case series
72 design identified a total of 72 participants met these criteria that had undergone surgery

73 between the years of 2007 and 2015. Information packs regarding this study were sent via
74 post to the 72 individuals identified. Participants who did not reply were followed up with up
75 to two phone calls with messages left if there was voicemail. Recruitment occurred in
76 November 2017 following approval from [REDACTED] Human Research Ethics
77 Committee approval (Project Number: 392). Participants were sent the hyperlink to the
78 Google Form following receipt of their signed consent forms. Data was collected online using
79 Google Forms. There was no missing data, as response settings in the questionnaire were set
80 to 'required response'.

81 The current study used the USER-Participation measure (van der Zee, Priesterback, van der
82 Dussen, & Post, 2010), which was designed using the International Classification of
83 Functioning, Health and Disability (World Health Organization, 2001) for use in community-
84 based rehabilitation. Subjective and objective concepts of participation are used to create this
85 32-item measure. The USER-Participation is comprised of three sub-scales: frequency
86 (objective measure), restriction (subjective measure), and satisfaction (subjective measure)
87 (van der Zee et al., 2010). Sub-scale scores for the USER-Participation are summed and
88 converted to a 0 – 100 scale score where higher scores indicate better levels of participation
89 (i.e. higher frequency, fewer restrictions, higher satisfaction) (van der Zee, Visser-Meily,
90 Lindman, Kappelle, & Post, 2013). The USER-Participation has satisfactory reliability (van
91 der Zee et al., 2010) and validity (Post et al., 2012). The USER-Participation's construct
92 validity was reported as satisfactory for each subscale (Frequency $\alpha = 0.70$, Restrictions $\alpha =$
93 0.91 , satisfaction $\alpha = 0.88$) (Post et al., 2012).

94 *Data analysis*

95 All quantitative data was screened for missing data and their suitability for analysis using *t*-
96 tests was established as per recommendations by Pallant (2016). The USER-Participation

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4 97 scores are presented as means with accompanying standard deviations and ranges (Table 2 &
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6 98 3). The current study's means were compared to the summary statistics of other studies (de
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8 99 Ruijter, de Groot, Adriaansen, Smit, & Post, 2018; Mader et al., 2016; van der Zee et al.,
9
10 100 2013) (Table 2). All analyses were carried out using SPSS 25 (IBM Corp., Released 2017).

11 12 13 14 101 **Findings**

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16
17 102 Fourteen males with a mean age of 49.14 months (SD 13.43; range 27-68) agreed to
18
19 103 participate, six declined, and 52 did not reply. Eight of the 14 injured their dominant arm.
20
21 104 Participants reported mechanism of injury as motorbike accident (7), pushbike accident (5)
22
23 105 and other (2) (Table 1). The participants were a mean of 78.96 months post-injury (SD 35.56;
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25 106 range 29-144 months). The mean scores of each scale on the USER-Participation measure
26
27 107 were: frequency 34.33 (SD11.30); 77.80 restriction (SD15.59); satisfaction 62.95 (SD18.26).
28
29 108 Frequency of participation items found that 50% had returned to paid work. Overall
30
31 109 participants reported that 64.3% were very satisfied-satisfied, 20.5% neutral, and 15.2%
32
33 110 dissatisfied- very dissatisfied with their participation in everyday life. Participants in this
34
35 111 study rated their highest level of satisfaction (as either satisfied or very satisfied) in relation
36
37 112 to their relationships with family (92.3%), going out (85.7%), and day trips/ outdoor activities
38
39 113 (71.4%); while being dissatisfied or very dissatisfied with their participation in sports/
40
41 114 physical exercise (35.7%), work/ education (33.3%), and household duties (33.3%).
42
43 115 Participants reported perceived restrictions in their roles and social relationships as follows:
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45 116 without difficulty 57.9%, with assistance 13.1%, with difficulty 23.4% unable 5.5%. No
46
47 117 statistical differences were demonstrated between this study's population and the other two
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49 118 studies (de Ruijter et al., 2018; Mader et al., 2016; van der Zee et al., 2013) (see Table 1).
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120 Table 1:

121 *Demographic data*

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123 Table 2:

124 *One-sample t-test for User-Participation scores for the current study and other life-altering*
125 *conditions*

126 Discussion

127 The findings of this study are the first, to the knowledge of the authors, that used a patient
128 reported outcome measure to describes participation-specific outcomes following BPI.
129 Previous BPI literature reported functional outcomes using measures of quality of life or
130 involvement in activities (Ahmed-Labib, Golan, & Jacques, 2007; Aras et al., 2013; Cole et
131 al., 2020; Potter & Ferris, 2017). The USER-Participation measures three aspects of
132 participation and applies a consistent set of questions that allow for comparison with this
133 study's findings to future BPI studies. Given the lack of normative data or other BPI studies
134 using the USER-Participation measure, other studies reporting outcomes following life-
135 changing events that also result in significant physical impairment were selected for
136 comparison. These studies were also selected because they, like the current study, reported
137 long-term outcomes following injury. Time since injury was deemed significant as it would
138 be a relevant variable when considering an individual's adaptation following injury. Re-
139 engagement in participation following BPI as reported using the USER-Participation measure
140 found no statistical differences in any of the three domains of the USER-Participation for this
141 cohort and the other cohorts following stroke (van der Zee et al., 2013) and spinal cord injury
142 (de Ruijter et al., 2018; Mader et al., 2016). Whilst the literature acknowledges that BPI often

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4 143 results in lifelong disability (Ayhan, Soldado, Fontecha, Bertelli, & Leblebicioglu, 2019), this
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6 144 finding adds weight to such an understanding of impairment by comparing post-BPI
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8 145 participation with participation in other more commonly known diagnoses. This study used
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10 146 cohorts that experienced stroke and spinal cord injury as the comparison populations as they
11
12 147 also experience on-going physical impairment, not because the authors felt the cohorts
13
14 148 experience similar barriers to participation.
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18 149 Stroke and spinal cord injury frequently involve disrupted lower limb function and therefore
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20 150 mobility, the similarity and differences in participation following BPI would require different
21
22 151 considerations. Gallagher, O'Donovan, Doyle, and Desmond (2011) explored participation
23
24 152 restriction following amputation (with and without prosthesis) of both upper and lower limbs.
25
26 153 This study that may assist in understanding the current results (BPI- upper limb impairment)
27
28 154 as they relate to the comparison studies (stroke and spinal cord injury- likely upper and lower
29
30 155 limb impairment). The Gallagher et al. (2011) study found that while both upper and lower
31
32 156 limb amputation groups reported some shared barriers to participation, if the two groups were
33
34 157 analysed separately the frequency of each barrier experienced was different. For individuals
35
36 158 with an upper limb prosthesis the top barriers were employment, family life, and leisure/
37
38 159 cultural activities (Gallagher et al., 2011), which are similar to the current study. Importantly
39
40 160 it needs to be noted that while this study's cohort experienced similar levels of participation
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42 161 in each subscale as individuals following stroke or spinal cord injury, it does not indicate
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44 162 similarity in each item (e.g. spinal cord injury may have scored lower in mobility restriction
45
46 163 items than the current study's participants). While existing literature indicates some
47
48 164 challenges for this population include: reduced physical ability of affected upper limb (Yang,
49
50 165 Chang, & Chung, 2012), psychosocial factors (Franzblau & Chung, 2015), and pain
51
52 166 (Ciaramitaro et al., 2017), better understanding of the specific barriers and challenges to
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54 167 participation for individuals following BPI is still needed.
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4 168 Occupational therapists aim to enable clients to participate in activities and occupations that
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6 169 are personally relevant to them (Proding, Darzins, Magasi, & Baptiste, 2015). While re-
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8 170 engaging clients in meaningful participation, occupational therapists recognize the
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10 171 importance of the subjective experience.

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14 172 Previous BPI studies have considered the concept of satisfaction, but only as it relates to
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16 173 satisfaction with surgery (Ahmed-Labib et al., 2007), social relationships (Gray, 2016),
17
18 174 appearance (Giuffre, Kakar, Bishop, Spinner, & Shin, 2010), and pain (Giuffre et al., 2010).
19
20 175 The USER-Participation measures the client's subjective experience of participation through
21
22 176 its Satisfaction sub-scale. Participants in this study who reported the highest levels of
23
24 177 satisfaction in participation were able to be active outside of their homes and engaged in
25
26 178 family relationships. Satisfaction was poorest in relation to their participation in productive
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28 179 roles, home duties, and physical exercise with more than one-third of all participants reported
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30 180 being dissatisfied or very dissatisfied. It has been proposed that an individual's experience of
31
32 181 participation in occupations has the ability to provide a global view of how they experience
33
34 182 life as a whole (Persson, Eklund, & Isacson, 1999). While this study reports high levels of
35
36 183 satisfaction in some areas of psychosocial participation, it is still unclear if this has an
37
38 184 influence on their overall experience of well-being. The relationship of satisfaction with
39
40 185 participation in everyday life, frequency of participation in various roles, and perceived quality
41
42 186 of life should be explored in future studies.

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48
49 187 The current study, whilst small, is proportionate with other studies reporting outcomes
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51 188 following BPI (Coulet, Boch, Boretto, Lazerges, & Chammas, 2011; Wellington, 2010). The
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53 189 small number of participants limit both the power of the data analysis performed and the
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55 190 ability to generalise these findings. Low participation may be impacted by the long-term
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57 191 follow up. As there were no other BPI studies to compare the current participant group to,
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4 192 participation could only be compared to other populations with diagnoses that profoundly
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6 193 impact physical ability (i.e. following stroke and spinal cord injury). Future studies reporting
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8 194 participation outcomes following BPI are therefore needed to replicate and extend the current
9
10 195 findings. Finally, there has also been little consideration of changes across the life span as it
11
12 196 relates to BPI, longitudinal research will assist in better understanding of long-term outcomes
13
14 197 for this population.

18 198 **Conclusion**

21 199 This study indicated that areas that should be monitored when working with individuals with
22
23 200 BPI include engagement in employment/ education, physical exercise, and an ability to
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25 201 undertake household duties. The findings of this study also indicate that participation is
26
27 202 impacted upon for many years after BPI, and that the impact is consistent with other
28
29 203 significant, life-changing conditions. The current research, and its long-term follow-up, will
30
31 204 hopefully enhance the available knowledge of how BPI impacts individuals' lives across the
32
33 205 lifespan and also inform health professionals and compensable bodies when planning care for
34
35 206 individuals following BPI.

41 207

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For Peer Review

Table 1
Demographic data

Participant ID:	1001	1002	1003	1004	1005	1006	1007	1008	1013	1017	1021	1022	1028	1047
Gender	male	male	male	male	male	male	male	male	male	male	male	male	male	male
Age	32	49	64	36	47	27	44	49	54	58	65	62	33	68
Time since injury (years)	6.75	11.33	10.29	5.99	5.42	7.08	8.00	7.00	2.42	9.58	2.58	6.45	4.00	3.58
Cause of injury	bicycle	motorbike	motorbike	motorbike	motorbike	motorbike	motorbike	motorbike	bicycle	bicycle	Fall from truck	bicycle	water-skiing	bicycle
Dominant hand sided injury	X				X	X	X	X				X	X	X
BPI surgeries:														
Direct nerve repair				X								X		X
Nerve transfer	X	X	X	X	X	X	X	X	X	X	X	X	X	X
Wrist fusion	X	X	X	X	X		X	X						X
Finger joint fusion			X	X			X							
Shoulder fusion	X			X	X			X						
FFMT surgery	X	X	X	X	X	X	X	X						
2 nd FFMT other surgeries			X	X	X	X	X	X						
Highest education completed	diploma	TAFE/ Trade school	High school	TAFE/ Trade school	High school	Certificate	TAFE/ Trade school	TAFE/ Trade school	Undergraduate degree	Post-graduate qualification	Undergraduate degree	Post-graduate qualification	TAFE/ Trade school	Undergraduate degree

Occupation:														
Job prior to injury	technician/ trade worker	sales worker	machinery operator/ driver	technician/ trade worker	technician/ trade worker	technician/ trade worker	volunteer	other	Professional	Professional	Machinery operator/ driver	Managerial	Technician / trade worker	Machinery operator/ driver
Job at time of questionnaire	managerial	sales worker	unemployed	compensable payment	unemployed	compensable payment	labourer	other	Managerial	Professional	Unemployed	Unemployed	Technician / trade worker	Unemployed
Did you return to your pre-injury job?	I chose to study or retrain in another job	Yes, I returned to my pre-injury job/ study	No. I became, and remain, unemployed following my injury.	No. I became, and remain, unemployed following my injury.	No. I became, and remain, unemployed following my injury.	No. I became, and remain, unemployed following my injury.	No. I became, and remain, unemployed following my injury.	Yes, I returned to my pre-injury job/ study	Yes, I returned to my pre-injury job/ study	Yes, I returned to my pre-injury job/ study	No. I became, and remain, unemployed following my injury.	No. I became, and remain, unemployed following my injury.	Yes, I returned to my pre-injury job/ study	No. I became, and remain, unemployed following my injury.
Time from injury to return to work	12-18 months	12-18 months	I have never returned to work following my surgery; despite having a desire to do so.	I am unable to work because of my injuries	I have never returned to work following my surgery; despite having a desire to do so.	I did a computer course, but still not working	> 24 months	> 24 months	Less than 6 months	Less than 6 months	I have never returned to work following my surgery; despite having a desire to do so.	I have never returned to work following my surgery; despite having a desire to do so.	Less than 6 months	I am retired.

Note: FFMT= free functioning muscle transfer

Table 2:

One-sample t-test for User-Participation scores for the current study and other life-altering conditions

USER- Participation (sub-scales)	Current study's Mean (SD)	van der Zee study's (2013) Mean (range)	<i>p</i> -value	Mader's study (2016) Mean (SD)	<i>p</i> -value	de Ruijter's study (2018) Mean (SD)	<i>p</i> -value
N =	14	111		1549		98	
Diagnosis	Brachial plexus injury	Stroke		Spinal cord injury		Spinal cord injury	
Time since injury	6.6 years (2.96)	3.4 months (2.4- 4.6)		16.9 years (12.7)		15.1 years (2.7)	
Frequency	34.33 (11.30; 15-54)	26.1 (10.7)	0.078	34.2 (12.2)	0.975	35.4 (9.5)	0.797
Restriction	77.80 (15.59; 48- 97)	78.7 (21.6)	0.875	70.0 (21.7)	0.200	77.9 (19.4)	0.986
Satisfaction	62.95 (18.260; 39- 98)	71.7 (17.8)	0.217	69.3 (18.0)	0.358	71.3 (15.4)	0.237

Note: SD = standard deviation

6.5 Chapter Summary

The manuscript in this chapter is the first study that used a participation-specific outcome measure for patients with BPI. Chapters five and six have used patient reported outcome measures to explore the concepts of activity and participation following pan-BPI. While quantitative studies provide valuable data that allows for comparison between populations, it does not capture the subjective experience of BPI. The next two chapters are the qualitative studies that will explore the experience, meaning, and importance of activity and participation to patients following pan-BPI. Then next chapter contains the manuscript from the patient interviews.

Chapter 7 - Pan-BPI: The Lived Experience

7.1 Chapter Introduction

Chapter 7 contains the manuscript written in relation to data gathered as part of Investigation 4. Investigation 4 aimed to gather better understanding of the subjective experience of individuals following pan-BPI.

7.2 Manuscript 4 Information

Brito, S., White, J., Thomacos, N., & Hill, B. (2019). The lived experience following free functioning muscle transfer for management of pan-brachial plexus injury: reflections from a long-term follow-up study. *Disability and Rehabilitation*, 1-9. doi:10.1080/09638288.2019.1668970

7.3 Abstract

7.3.1 Background

Traumatic, pan-brachial plexus injuries result in major functional disability. Surgical advancements, such as free functioning muscle transfers, are restoring physical capacity that was not achieved 3-4 decades ago. Despite reconstructive procedures, brachial plexus injury patients report chronic pain, changes in work circumstances, concerns about their appearance, increased reliance on others, and difficulty completing daily activities. This suggests that recovery needs to be considered to better deliver post-injury health services.

7.3.2 Objectives

1) Investigate the lived-experience of patients following free functioning muscle transfers for management of traumatic, pan-brachial plexus injuries.

2) Better understand issues during recovery and implications for rehabilitation with this population.

7.3.3 Methods

A phenomenological, qualitative design was employed that involved 5 participants who underwent surgery between 2007-2015. In-depth, semi-structured interviews were conducted, and data were analysed using interpretative phenomenological analysis.

7.3.4 Results

Three interrelated themes were generated from the data. The first theme 'Experience of health care systems' captures the participants' reflections of their post-injury experience and health care received. The second 'Psychosocial considerations' consists of emotional responses, relationship disturbance, and coming to terms with the permanence of their changed arm. The last theme, 'Creating a new self-identity', relates to the participants experience of adjustment to their new circumstances.

7.3.5 Conclusions

The findings of this study demonstrate that comprehensive medical coverage and access to expert brachial plexus injury health providers support patients following injury. However, recovery also requires the need for the patient to adjust and establish a new self-concept. Health care providers can assist patients by establishing positive therapeutic relationships, as well as, reducing the number of care providers by providing a continuity of care from the same health professionals.

7.4 Investigation 4 Manuscript

The manuscript below has been inserted as it was published in *Disability and Rehabilitation*.

The lived experience following free functioning muscle transfer for management of pan-brachial plexus injury: reflections from a long-term follow-up study

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ABSTRACT

Background: Traumatic, pan-brachial plexus injuries result in major functional disability. Surgical advancements, such as free-functioning muscle transfers, are restoring physical capacity that was not achieved 3–4 decades ago. Despite reconstructive procedures, brachial plexus injury patients report chronic pain, changes in work circumstances, concerns about their appearance, increased reliance on others, and difficulty completing daily activities. This suggests that recovery needs to be considered to better deliver post-injury health services.

Objectives:

1. Investigate the lived-experience of patients following free-functioning muscle transfers for management of traumatic, pan-brachial plexus injuries.
2. Better understand issues during recovery and implications for rehabilitation with this population.

Methods: A phenomenological, qualitative design was employed that involved 5 participants who underwent surgery between 2007 and 2015. In-depth, semi-structured interviews were conducted and data were analyzed using interpretative phenomenological analysis.

Results: Three interrelated themes were generated from the data. The first theme 'Experience of health care systems' captures the participants' reflections of their post-injury experience and health care received. The second 'Psychosocial considerations' consists of emotional responses, relationship disturbance, and coming to terms with the permanence of their changed arm. The last theme, 'Creating a new self-identity', relates to the participants experience of adjustment to their new circumstances.

Conclusions: The findings of this study demonstrate that comprehensive medical coverage and access to expert brachial plexus injury health providers support patients following injury. However, recovery also requires the need for the patient to adjust and establish a new self-concept. Health care providers can assist patients by establishing positive therapeutic relationships, as well as, reducing the number of care providers by providing a continuity of care from the same health professionals.

► IMPLICATIONS FOR REHABILITATION

- Individuals with pan-brachial plexus injuries felt it was beneficial to work with health care providers with extensive brachial plexus injury knowledge.
- Stable, long-term relationships with health providers during rehabilitation were reported as beneficial to recovery.
- Greater consideration of the process of adjustment and creating a new self-identity following pan-brachial plexus injury needs to be considered during rehabilitation.

ARTICLE HISTORY

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KEYWORDS

Brachial plexus;
occupational therapy;
outcomes; rehabilitation;
self-efficacy

Introduction

It is well recognized that adjustment to injury, that results in significant physical disability, both generally and of the upper limb is a difficult process [1–4]. Adult brachial plexus injuries (BPIs) can result in a significant reduction in physical functioning [5], with most occurring in young men as a result of motorbike accidents [6]. There is a vast diversity in the presentation of BPI depending on the mechanism of injury as well as level and pattern of lesion [7]. Upper plexus injuries (C5, C6 ± C7) result in motor impairment of shoulder (abduction and external rotation) and elbow (flexion,

± extension) [8]. Lower plexus injuries result in motor impairment of the wrist and hand [8]. A pan-brachial plexus injury damages innervation from C5–T1 and results in impairment of shoulder, elbow and hand motor and sensory function [9]. Pan-brachial plexus injury has been associated with poor recovery outcomes [10] including greater disability and decreased quality of life [9].

Surgical options vary depending on many factors including: time since injury, degree of nerve injury and availability of viable donor nerves [11–14]. Gains in technology and innovation are enabling surgeons to complete reconstructive procedures

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including nerve grafts/transfers and free-functioning muscle transfers for reconstruction of the upper limb following brachial plexus injury [15]. However, given the extent of damage following a pan-BPI, there are often few donor nerves available. Some common donor nerves used for a free-functioning muscle transfer include the intercostal nerve or spinal accessory nerve [16,17]. Despite the skill and expertise required for complex surgical procedures, patients continue to experience significantly poorer physical and psychosocial health [18].

In order to gain a rich and deep understanding of the reasons, processes and types of strategies that patients use to deal with injury and recovery, qualitative study designs are necessary. Previous qualitative research has explored the experience of people with brachial plexus injury and identified serious challenges [19–22] including: infrequent return to work, poor body image, and social anxiety; which are often exacerbated by financial strain of wage loss and medical expenses [22–25]. Key themes identified have pertained to employment challenges, [21,23,26], adjusting to physical changes (e.g., pain or appearance) [21,22,26,27] and function [22,27], psychosocial impacts [21–23,26,28].

No studies were located that explored the health care journey of patients neither in Australia nor following free-functioning muscle transfer reconstructive surgery. Further, previous qualitative studies typically incorporate a range of brachial plexus diagnoses. It is recognized that brachial plexus injuries vary in the degree of motor and sensory impairment. This study aims to explore only those with pan-brachial plexus injuries. Findings can identify gaps in service provision and inform practice improvement. As a result, this study aimed to explore patients' experiences following free-functioning muscle transfer reconstructive surgery for the management of traumatic, pan-brachial plexus injury.

Method

This was a qualitative study involving individual, semi-structured interviews with patients following pan-brachial plexus injury using an Interpretative Phenomenological Analysis (IPA) methodology [29]. IPA allows for the exploration of lived experiences, that is how people make sense of their personal and social world, and aims at generating rich and detailed descriptions of how individuals are experiencing a phenomena under investigation rather than one prescribed by preexisting theoretical preconceptions [30]. Further, IPA recognizes that the exploration of meaning of personal experiences is an interpretative endeavor on behalf of both the participant and researcher [31]. While both the participant and the researcher are involved in the co-construction of meaning, the IPA researcher is tasked with producing an interpretative analysis which is tied closely to the participant's account [31]. In this study the first author is an occupational therapist an experienced hand therapist

with an interest in brachial plexus injury and rehabilitation. She has treated some of the patients in the past, but was at no stage their primary therapist.

Recruitment occurred between during October and November of 2017. This project received approval from the Monash University Human Research Ethics Committee (project number 2017–0392-15483).

Setting

The current study was conducted in Melbourne, Australia. All participants received rehabilitation services from a private hand therapy practice. In Australia, health care is delivered by both public and private insurance systems. All participants received compensation from the Transport Accident Commission (TAC) which provides a 'no-fault' insurance scheme for people involved in motor vehicle accidents that occur in the state of Victoria or involve a Victorian registered vehicle [32]. This scheme provides insurance for a comprehensive range of services (e.g., primary health, allied health, community services, travel support, rehabilitation, etc.). This is of particular note as often a limiting factor in other contexts may be access geographically or financially to health care, rehabilitation and other services following injury. Participants in this study had access to both health professionals with brachial plexus specialty knowledge and financial support.

Recruitment

As IPA is an idiographic approach [33], a purposive sample of potential participants that met the inclusion criteria (see Table 1) was identified from a private, clinical practice that specializing in the rehabilitation of brachial plexus injury. Information packs were posted to 23 patients that met the criteria. Seven provided written informed consent to take part in the study, four declined, and 12 did not reply. Of the seven who agreed to take part, only five were interviewed. The other two failed to be available for multiple scheduled appointments. Participants were not followed up after two missed interview times.

Data collection

Data was gathered using semi-structured interviews, in line with the IPA guidelines set out by Smith et al. [33]. Interviews were conducted by a single researcher (SB) in mutually convenient locations (e.g., medical consulting suite, café, participant's home). Two of the interviews were conducted over the phone due to the distance required to travel. The interview schedule was developed by the first author, a therapist with extensive clinical experience with patients following BPI, with the research questions in mind and alongside her professional expertise (Table 2). As part of the

Table 1. Participant inclusion and exclusion criteria.

Inclusion-	Exclusion-
<ul style="list-style-type: none"> • Pan* traumatic brachial plexus injury presentation prior to first surgery • ≥18 years old at time of research participation • normal upper extremity function before injury occurred • ≥1 year post-op free functioning muscle transfer • Have a functional level of English, both spoken and written (i.e., can undertake a medical assessment and read online survey without requiring an interpreter) • Consenting to take part in the study 	<ul style="list-style-type: none"> • nerve palsies that completely resolve spontaneously • congenital abnormalities of the UE • Complex Regional Pain Syndrome diagnosis • not having functional ability to read or speak English • Declining to take part in the study
<p>*Complete, will be defined here as:</p> <ol style="list-style-type: none"> 1. Clinical diagnosis of C5-T1 palsy, persisting until time of first surgery for brachial plexus injury 2. EMG of complete C5-T1 palsy on a single occasion 	

Table 2. Interview questions.

1. How long was it between your brachial plexus injury and your surgery?
2. What things changed as a result?
3. Can you remember how you felt about your arm when you looked at it?
4. Did your relationships change at any time after your injury?
5. Were there changes with work/ study after the injury?
6. What can't you do as well now because of your arm?
7. What accommodations have you had to make because of your arm?
8. Can you tell me what things changed or stayed the same because of your free-functioning muscle transfer(s)?
9. Who or what has helped you in dealing with your injury and recovery?
 - a. How did it/ they help?
10. Who or what didn't help you in dealing with your injury and recovery? How?
11. Knowing everything you know now, would you have the surgery again? Why/ why not?
12. What are your thoughts about the post-op therapy you received?
13. What do you feel is challenging to rehab and recovery following the brachial plexus injury and free-functioning muscle transfer(s)?
14. Tell me the main things you do in a normal week? How satisfied are you with this?
15. Has pain impacted you, if so how?
16. Following your brachial plexus injury if you could go back, what would you do differently?
17. What remains your biggest difficulty?
18. What are your thoughts about the future?
19. If you met today with someone who had just had the same injury as you, what would you tell them?
20. Is there anything that we haven't discussed that you would like to share?

development, existing literature was reviewed and the additions were made to encourage further description and elaboration from the participants. The semi-structured nature permitted flexibility for participants to elaborate upon or cover important topics that would not have otherwise surfaced [31]. Prompts were selectively used to probe topic areas that did not organically come up in the interview.

Data analysis

Semi-structured interviews, ranging from 1 h to 2 h, were recorded with the participant's permission and transcribed verbatim with identifying data removed. Data analysis, guided by recommendations for IPA [34], was conducted by two occupational therapists (SB and JW). The first step involved sustained engagement with the data through initial reading and re-reading of transcripts to identify sections that were meaningful. Each participant's transcript was read and interpreted individually, with each researcher paraphrasing the experience of each participant. The researchers then identified key words to describe categories or emerging themes for the interviews. Following team discussions, identified words were applied to the paraphrased data and emerging categories. Then, commonalities among the transcripts were merged into a single Word document. At this stage, both researchers re-read the transcripts in order to ensure that the categories appropriately fitted the original text. The final step was to develop subordinate themes – a particular aspect of participants' experiences – and superordinate themes or umbrella themes. Researchers met regularly to ensure analytic rigor. Any differences in researchers' perspectives were resolved by negotiation and, if necessary, regrouped, and recoded until consensus were reached. New codes were then fed back into the analysis to cross-check themes and superordinate themes in order to develop an overall interpretation of the data. Member checking was used to ensure the rigor of data analysis [35]. This involved posting all participants a one-page summary of the study themes for feedback. Two of the five responded providing confirmation of the findings and did not recommend any changes.

Results

Demographic and injury specific information is provided for participants in Table 3. Three superordinate themes relating to the experience of recovery and adjustment following brachial plexus injury included:

1. Experience of health care systems
2. Psychosocial considerations
3. Creating a new self-identity

The first superordinate theme captures the participants' experiences in the context of the health care system. This includes management of their injuries, rehabilitation, and comprehensive care received due to the TAC here in Victoria. The second superordinate theme reveals a reality about both their emotional responses to such a severe injury but goes beyond to discuss how this impacts a range of their social relationships (including parents, intimate partners, friends, and coworkers and the community). Participants also spoke about the difficulty coming to terms with the permanence of the injury. The last superordinate theme relates to the participants speaking of reaching a level of acceptance with their arm, their new reality, and ultimately, a recognition that 'things could have been worse', and that they were ready to change in order to reengage in an adapted, meaningful life.

These superordinate themes and their themes are conceptualized in Figure 1.

Experience of the health care systems- "I don't think I really understood what was going on."

Injury and early health care experience

The majority of participants experienced a brachial plexus injury following a significant accident with varying levels of consciousness due to trauma and head injuries. As a result participants initially reported their experience of having a brachial plexus injury as being unaware because they required a high level of assistance with everyday tasks and that their early memories related to the life-threatening nature of concomitant injuries. As a result other medical priorities (*collapsed lung and fractured collarbone*- Silas) were prioritized above the brachial plexus injury.

Participants reported having numerous surgeries following their accident (for both their brachial plexus injury and concomitant injuries) and as such, the timing between brachial plexus injury and free-functioning muscle transfer reconstructive surgery varied. With time participants comprehended the gravity of their brachial plexus injury and appreciated knowing that their health care providers were highly specialized in the management of brachial plexus injuries.

...you go and have whatever surgery or you go and do this... I never thought too much of it. I just kept doing it and you just trust that that's the best thing. Asher

Experience of rehabilitation

As an integral part of recovery participants expressed gratefulness that the health care system processes led to immediate referral to surgeons and hand therapists with expertise in brachial plexus injury and they didn't have to look for their own options.

You can't Google... and find someone who can fix you. Silas

In fact, one participant preferred to travel long distances from his rural home location to the city to access a therapist with brachial plexus injury specific knowledge instead of seeing a local

Table 3. Participants demographic information.

Pan- brachial plexus injury participants (n = 5)					
Pseudonym	Asher	Daniel	Mason	Ben	Silas
Sex	Male	Male	Male	Male	Male
Time since injury (months)	81	136	71.5	65	85
Dominant arm injured	Yes	No	No	Yes	No
Number of FFMTs	1	1	2	2	2
Time from injury to 1 st FFMT	2–5 years	5+ years	1–2 years	≤0.5 years	≤0.5 years
Time from 1 st to 2 nd FFMT	N/A	N/A	12–24 months	0–6 months	6–12 months
Age (years) at time of interview*	27–64 (mean 43.50; SD 11.67)				
Injury mechanism*	Motorbike × 4 Pushbike × 1				
Additional surgeries related to brachial plexus injury*	Nerve transfer(s) × 5 wrist fusion × 4, shoulder fusion × 2, finger joint fusion × 1 thumb surgery × 1				
Primary funding source*	Transport Accident Commission				
Highest level of education completed*	High school × 1, TAFE/ trade school × 2 Certificate × 1 Diploma × 1				
Job prior to injury*	technician/ trade worker × 4 sales worker × 1				
Job at time of survey*	Managerial × 1 Sales worker × 1 Unemployed × 1 Unemployed (Compensable payment) × 2				
Return to job prior to injury*	I chose to study or retrain in another job × 1, Yes, I returned to my pre- injury job/ study × 1, No, I became, and remain, unemployed following my injury × 3				
Length of time from injury to return to work*	12–18 months × 2, Have not returned to work × 3				

*Aggregate information provided for participant anonymity.

FFMT: free functioning muscle transfer; N/A: not applicable; TAC: Transport Accident Commission.

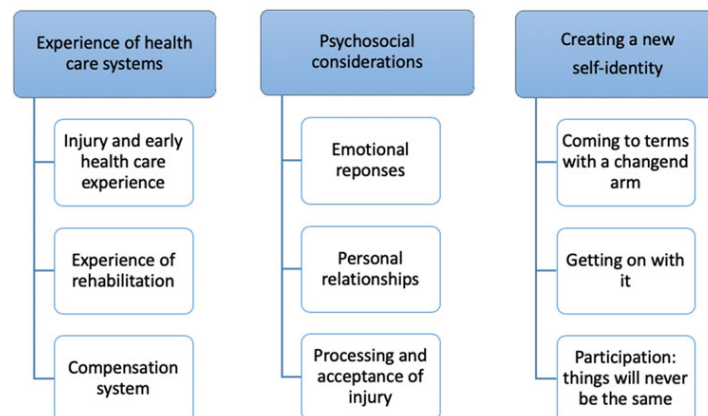


Figure 1. Superordinate themes and themes generated from data.

therapist with no brachial plexus injury experience which was, "Not that reassuring." (Mason)

Specifically, participants noted that forming a therapeutic relationship was a significant part of their recovery. Perceived benefits included the experience of continuity of care and regular contact with a health professional, usually a hand therapist, that was characterized by genuine connection and positive regard for

one another and being able to talk about life beyond brachial plexus injury, instead of feeling "really on your own." (Silas)

I've always seen a value in [therapy] and it's still to this day that I still come... You can come in and you talk about your weekend, you talk about your life. I know about your life. You know about my life. It's always just a- it's an easy thing to do and it doesn't (pause) you don't dread going to therapy. Asher

Furthermore, participants reportedly valued attending specialized clinics where they met and could share common experiences with other “people with the same injuries.” (Ben). Another cited benefit of regular participation in therapy was education about their injury, surgical procedures and the opportunity to review this information multiple times, and ask questions. Participants reportedly found knowledge empowering and allowed them to become experts in their own health and brachial plexus injury.

There was a lot of benefits to the therapy- understanding the injury. It was like, if I hadn't gone to all the therapy, I wouldn't have known about the brachial plexus and the injury... It makes it easy to explain to other people. Silas

Most participants required multiple reconstructive surgeries which involved months to years of rehabilitation while balancing other demands in life. Two participants, who returned to employment, cited difficulty balancing the demands of work and pursuing a careers with additional surgeries, rehabilitation and follow-up medical appointments.

It was tough [to balance work with surgery and rehabilitation]... just getting away from work [for medical appointments]... so you lose a good couple of hours. Daniel

Compensation system

All participants valued access to health services and rehabilitation as well as the varying levels of financial support provided through the TAC compensable scheme.

They [TAC] pay my medical bills for life... unbelievable TAC, ...the best. Without it I would be stuffed [in trouble]. Daniel

The participants also had reportedly accessed various adaptive equipment to assist with daily activities. Several participant had also undergone driving assessments and been prescribed adaptive equipment (e.g., for car, home, work).

So, I've got lots of equipment that helps out just makes it [cooking and cleaning] a lot easier. Mason

Many participants who are many years post-surgery still reported accessing services for assistance with community reintegration and reengagement in activities such as new leisure pursuits. This ability to access on-going support was utilized and valued.

If I rang [my occupational therapist] and I said I've got a problem, she'd help out. Mason

Most participants were able to access a loss of earnings benefit following injury. However, for the two participants who did not meet criteria for benefits (e.g., people who are found to have drugs or alcohol in their systems at the time of their accident) reported the struggle of managing financially after a significant injury.

So because alcohol was a part of [the accident], obviously TAC then won't pay the full loss of wages... and I had a mortgage and [a child]. So financially it was stressful and especially a year off work. Daniel

The experience of psychosocial changes- “it's just a rollercoaster of emotions throughout everything”

Emotional responses

Participants spoke about the array of emotions experienced post injury and during recovery. These varied widely and included concern for how the accident impacted on themselves and love ones.

There's some low periods in there... it's just a rollercoaster of emotions throughout everything. The arm, the life, the whole lot. Asher

The post injury trajectory was underpinned by an array of feelings such as guilt, depression, and fear. Some participant attributed feelings of self-blame for the accident that caused their brachial plexus injury and subsequent regret for the pain caused to family and friends.

There was a lot of guilt with it because it was my own fault. That was probably the toughest thing to be honest. Because I saw the pain and everything I inflicted on my family. So it wasn't good to see. You know like my Dad in tears and my Mum in tears and thinking you're going to die. Yeah not good. Daniel

Several participants reported periods of significant depression after their injury, characterized by withdrawal from previously valued activities and social networks, risk taking behaviors and suicidal ideation.

I fully dropped out. I wouldn't turn on my phone for weeks... [After discharge], you get kind of left on your own, with all your medications. I was careless about everything... You stop caring what people think. Like, I don't care if I have a crash and I die. You just don't care, because you're that bad. Silas

Despite the trauma and expression of emotional impact, participants reported short-term engagement or no engagement with mental health services. Most recalled referral and recommendation to attend, but chose not to pursue or continue. These services would have been accessible under the TAC insurance.

While participants were assisted by their general practitioners to progressively reduce their opioid pain medications, some doctors identified dependency earlier than others.

I had to go to the doctor every few months, to get prescription repeats, and he noticed straight away. He was like, this is not right. He had worked with addicts and he was really good [at identifying my addiction and assisting me]. Silas

Participants also expressed feeling frustrated by the lack of understanding and insight by the general community towards brachial plexus injury and the seriousness of their prognosis or their experience of ongoing pain.

Some people just don't get it. ...like when your hand's in a sling... it would just be too hard to explain... if I tell everyone I've torn the nerves, they'd be like, 'oh yea, I tore the nerves in my arm once'. I thought, yeah-right. Silas

[If] I say my arm is hurting... they go, 'how can it hurt when you can't feel anything in your arm?' Daniel

Other participant's recounted scenarios where friends would send information about how other people were recovering following different upper limb injuries and showed a lack of comprehension about pan-brachial plexus injury.

...people they send me videoclips like on YouTube and they're like, oh, look at this girl. She's got no arm and she can surf and yeah, she does all this stuff. And I'm like, I try to explain to them and they're like, you should be able to do that. You've still got your arm. It's hard to explain... Mason

The responses of others to trophic changes (i.e., shiny skin, changed appearance to nail bed and muscle wasting) following brachial plexus injury contributing to feelings of self-consciousness which continued over the long-term.

If I'm in the shopping centre funny enough I might put my hand on the trolley to look normal. I'm a bit vain that way I've got to say. Like I asked [the surgeon] last time I saw him I said, 'Can you put any implants into my arm to make it look more normal?' Daniel

Self-consciousness toward the appearance of their arm impacted participants' social interactions. This was compounded

for David who indicated that his work involved meeting new people on a daily basis.

Probably the hardest thing I deal with every day is that feeling or that thought, ... I'm meeting someone new and they're noticing something about me that I then feel like I need to explain. I don't know... I know I wouldn't feel that way if I didn't have this injury. That thought of meeting someone new wouldn't bother me...

Participants were also embarrassed by the reaction of others when they attempted to explain their injury and subsequent surgeries. Challenges were commonly reported with regards to explaining the experience of involuntary action of a recipient muscle following a nerve transfer, such as when hiccupping or sneezing.

...if I sneeze [after the muscle transfer]...my arm will move. They [people] just look at you, like, "What?" Asher

Personal relationships

All participants reported that their inter-personal relationships were strained following brachial plexus injury. Initially all participants discussed the need to rely on others for assistance following discharge from hospital causing additional stress to loved ones (i.e., partners, parents and other family members). Several participants needed to move back in with parents and felt it was a backward step in life.

I lived at home ... six to eight months ... [after discharge], which was trying... you know, you're [an adult]. You don't want to be living at your parents, do you? ... A normal life- living on your own or living with friends and then socialising. You're going to do more... than if [living with] your parents... Asher

Participants with intimate partners at the time of the accident reported that these relationships ended. Some were unable to say if it was a result of the accident, while others reported it was secondary to experiences related to the injury.

I think the accident actually enlightened me as to the situation I was in... Made me realise that this isn't the place I sort of want to be, or the person I want to be with I should say. Daniel

Some participants reported that developing new relationships after their injury was made easier when the other person knew about their injury and physical status from the beginning. One participant shared that his changed physical ability impacted his sex life but this was aided by being with someone who only knew him following his injury.

My arm has actually affected my sex life a lot as in - but yeah, [de-identified] the girl that I was with for a couple of years, she was really good because I didn't know her before my accident so I met her afterwards and she accepted it 100%. Mason

Participant also noted that friendships underwent significant changes following brachial plexus injury whereby they felt they didn't fit in with their peers especially when they are no longer being able to engage in previously enjoyed shared leisure activities.

You pick up on all the little things. You don't get invited to go play golf any more, or when they'd all be around someone's house playing Xbox. I think they didn't want to feel bad that I was there but couldn't participate, so they wouldn't invite me. Silas

This created feelings of emotional disconnection.

When I'm with everyone, I don't sort of feel like I'm sort of one of the boys. I'm just someone that's there now, just tagging along... Mason

Processing the injury and acceptance of changed circumstances and life trajectory

Coming to terms with the prognosis of having a permanent injury was challenging. Participants expressed that initially they assumed

life would get "back to normal" (Silas). As a result all participants reflected that time was needed to process the gravity and consequences of their brachial plexus injury.

I just remember you go through a period of time where...you're in denial. It's like a broken arm. You think it's going to get better... I do remember a turning point of acknowledging or becoming aware that it's not going to get better...I think you've sort of accepted it by 12 months... Asher

For some participants the process of accepting their injury was helped by reframing their circumstances and realizing: "things could have been worse" (Daniel). This created feelings of gratefulness for being alive when participants realized they could have experienced additional physical impairments or died as a result of their injuries.

I always look at it as in, I know I've got an arm not working, but [that] is a million times better than [it could have been]. Mason

Ultimately, participants were able to reconcile the reality of changed physical ability and appearance of the injured arm and that now need things need to be done differently. While it took time participants gradually accepted that these changes were part of their reality.

I'm at the point now where I just go you know what? It is what it is. Daniel

Creating a new self-identity- "I guess now I do other things."

Coming to terms with a changed arm

All participants perceived their surgery as being beneficial despite the experience of on-going functional limitations and concerns about the future. Participants recognized that their impaired arm was a helper arm and would not return to pre-injury ability. However participants noted that even small gains in ability were better than a flail limb and all participants felt that some arm use was better than no use.

Now I can position it... [But] I hardly use it at all. Daniel

With my arm, I accept that it's - I've got a bum arm, but it's pretty much is a helping hand. Even if the only thing I can do is open and close doors, that's awesome. That helps a lot Mason

Only one participant expressed a lack of satisfaction with the ongoing limited use of his arm.

Yeah. But 15 operations later, I've only got like 10 per cent use out of it. Ben

Getting on with things

For most participants the concept of 'getting on with things' required a change in how they perceived life as they embraced their future with changed physical capacities. Significant shifts were noted when participants were able to make transitions in their thinking and value the future ahead.

I can't go through life feeling sorry for myself and letting this stop me doing everything you know, to rule the rest of my life. Daniel

Having an arm with limited function required adapting how tasks are completed and modifying the environment (e.g., equipment for daily tasks, modifications to allow return to driving, single arm swimming technique). Participants demonstrated ingenuity and pride in using their own problem-solving skills to overcome challenges doing things they wanted to do or sourcing equipment. For example one participant modified the

activity of hunting through sourcing and use of adaptive equipment.

... I use what's called a bi-pod and it mounts to the sort of front end of the rifle so I can rest the front down and I can just position it... David

Participation- things will never be the same

Whilst participants felt that virtually everything changed following their injury, two areas were consistently mentioned including ongoing pain and their participation in daily life. A key step toward reengagement in daily life involved acceptance that what they did and how they did it would need to be altered and self-expectations changed. This shift was part of a larger realization related to a change in self-concept and reconceptualisation of self-identity. Varying levels of pain remained a significant factor for many. Some felt on-going pain impacted their day-to-day life, however most were able to shift their pain to the background even though it was always present.

[Pain] is the hardest thing to deal with... [It's] bad, yeah. It's not so much that it stops me [doing what I want to do], but it interferes. Daniel

...even six years later I'm still a bit cautious around big groups. If someone bumps it, you know, that's horrible. Mason

All participants reportedly valued being able to return to participation in meaningful activities. However, all participants acknowledged that there were some things they would not be able to do again and would need help with.

Like if I'm stuck doing something I'll ask [my partner] to give me a hand and she helps. She knows what to do to help me out. Daniel

It doesn't hold me back... the only thing is it takes a bit longer ... there's some things you need two hands to do and a lot of my mates are car fanatics and they come and help me... I don't want to be the kind of guy that always needs something. Mason

Participants development of new self-identity was closely linked to accepting have a life-long change in physical capacity. All participants expressed a keen desire to reengage in valued life roles. However this required accepting the need to either adapt activities or engage in new ones. All participants reported struggling with the initial loss of roles in leisure activities and the impact it had on friendships. However, with time some adopted new interests.

... if my mates go and play a game of golf, I don't go... you don't do those sorts of things or don't go and play cricket... I guess now I do other things. Asher

[Before my injury,] I played sport on the weekends, but now on the weekends, rather than play sport, I watch sport." Mason

All participants were working at the time of their injury and faced many challenges returning to the role of worker. Most participants were unable to return to their pre-injury job. Some participants failed to return to work and expressed feelings of disappointment and grief with their ongoing self-identity.

They couldn't get me [work] in the office of where I used to work, because there was just no room... I used to love all my workmates and I used to love working... I love work and I miss that workmanship. Having workmates and doing stuff... being unemployed is the worst thing about it... I feel a lot of social pressure [related to not being back at work] ... Silas

Discussion

This is the first study conducted of this nature in Australia and the results are useful for clinical practice, service planning, and

future research. Despite access to comprehensive insurance that assisted with income protection, medical services fees, and access to brachial plexus specialists, this study reveals that patients following pan-brachial plexus and free-functioning muscle transfer encounter a range of challenges consistent with previous studies [21–23,26,28].

This study highlighted a range of complex factors related to the long term adjustment to brachial plexus injury. A central finding was that participants had limited use of their arm even after the experience of multiple surgeries and rehabilitation. Furthermore, participants' experienced psychological morbidity frequently characterized by expressions of depression and guilt. This is consistent with previous research demonstrating the impact of brachial plexus injury on psychological health [19,24,36,37]; indicating that psychological support is very often needed post injury and surgeries. However, most participants in this study did not access psychological support despite access to one via their compensable insurance scheme. One reason for this may be that young men are less likely to seek and engage in mental health services [38]. However this study found that participants reported their therapeutic relationships with the rehabilitation team served as consistent, positive connections that meaningfully assisted with adjustment following injury. Whilst not a substitute for professional psychological care, it is known that positive and supportive relationships minimize distress during recovery [2,39].

Individuals who experience a traumatic injury are faced with not only a change in their physical abilities, but also significant interruption of their self-identity. This is consistent with other studies that have found that after injury individuals experience discontinuity of self and loss of personal identity [1,26]. At the same time, relationships are substantially and qualitatively changed from what they were previously. Relationship changes impacted participants' ability to engage in previously valued life roles (e.g., as a father- unable to play with daughter, as a friend- unable to play cricket with friends, as a partner- interruption with intimacy, etc.). As in other brachial plexus injury studies, a key challenge for participants was maintaining or finding alternate work duties or change of career [23,40]. Finding employment is critical, as a person's occupation/job influences their self-identity and contributes to financial, psychological, and social well-being [41]. The processes of merging their previous self-identity and their new reality in order to create a new self-identity can be facilitated by appropriate supports post-surgery and as people adjust to their new realities [1]. Rehabilitation providers need to be cognizant of the need for individuals to create new self-identities. They can and should encourage exploration of both compensatory strategies to continue day-to day roles and involvement in activities that they enjoy and value [42], while also encouraging them to take up new ones. This need for hand therapists to engage in research that considers patients' ability to engage in their day-to-day activities has been specifically highlighted [43], with some studies proposing that ability to perform these daily tasks are more important than objective measures of hand function [44,45] and have been shown to enhance client motivation and success [46–48].

Study strengths/limitations

A major strength of this study is the generation of rich data about understanding recovery from pan-brachial plexus injury. We acknowledge the limited number of participants, and our homogeneous sample; thus, we are unable to adequately gauge the degree of thematic saturation (an important component of

qualitative research). Additionally, this study involved a single interview many years after the injury, thus recalling events may vary slightly from contemporaneous thoughts and feelings. Additionally, participants' knowledge that the interviewer was a therapist that previously worked at the private clinic where they received their community rehabilitation may have contributed to a response bias, particularly when discussing therapy related information. We recommend that further research should use more representative sampling methods and undertake serial interviewing in order to better understand the longitudinal experience of recovery.

Conclusion

This qualitative study was sensitive in identifying a range of educational, physical and psychological factors that play a role in recovery and rehabilitation. The findings demonstrate that despite access to comprehensive medical and rehabilitation services participants still struggled with physical deficits, relationship changes, dependence on pain medication, developing a new identity, and returning to valued roles (i.e., employment). Service deliverers must consider personal and social needs including follow up of common issues such as pain management (including addiction to analgesics), depression, establishing a new self-concept, and adjustment to disability. There is need to research and explore interventions that address psychological functioning, loss of self-identity and challenges related to reengagement in life roles.

Continuity of health care providers was shown to be an important component of effective therapy in the current study. Therefore, such continuity is warranted more generally for people post brachial plexus injury, as is the development of relevant community support programs. Consideration of methods to better support patients that do not live near health professionals with specialist knowledge of brachial plexus injury treatment is also required. Allied health professionals are well positioned to provide services that assist with the process of adjustment, pain management, psychological impacts of injury, and reengagement in meaningful roles. It is hoped that some of the insights gained from this study will assist other health professionals, planners, and funders when working with individuals following brachial plexus injury.

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No potential conflict of interest was reported by the authors.

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7.5 Chapter Summary

This chapter's manuscript confirmed that the experience of patients with pan-BPI is similar in some respects to other BPI experiences, but also distinct particularly in the aspect of the psychosocial considerations including the process of adjustment and creation of a new self-identity that aligns with their new physical capacity. The results of this investigation also highlighted the value and perceived benefit by patients on stable, long-term relationships with their rehabilitation therapists.

Chapter 8 - Effective Long-term Management of Brachial Plexus Injury Following Surgery: What is Needed from Hand Therapists' Perspectives

8.1 Chapter Introduction

Chapter 8 contains the published manuscript that was prepared to report on Investigation 5. While the previous chapter considered the impact of pan-BPI from the perspective of the patient, this qualitative investigation considered the injury and rehabilitation from a therapist's perspective. The rationale for the investigation was that seeking feedback directly from therapists involved in the care of specific diagnoses provides real-world insights and identifies factors that hinder or facilitate care (Ranford et al., 2019; Titzler et al., 2018).

8.2 Manuscript 5 Information

Brito, S., White, J., Hill, B., & Thomacos, N. (manuscript under review). Effective long-term management of brachial plexus injury following surgery: what is needed from hand therapists' perspectives. *Journal of Hand Therapy*.

Date submitted: 27 October 2020

8.3 Investigation 5 Manuscript

The manuscript below has been formatted as required for publication in *Journal of Hand Therapy*.

Journal of Hand Therapy

Effective long-term management of brachial plexus injury following surgery: what is needed from hand therapists' perspectives

--Manuscript Draft--

Manuscript Number:	HANDTHE-D-20-00220
Article Type:	Full Length Article
Keywords:	Brachial plexus injuries; Occupational therapy; Rehabilitation; adult
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Abstract:	<p>Introduction</p> <p>Traumatic, brachial plexus injuries (BPI) result represent a significant cost to the individual and society. Recovery involves multiple surgeries, takes years, and often results in permanent physical dysfunction. While the last couple of decades have seen advancements in surgical management, the BPI rehabilitation literature has not kept pace with these developments.</p> <p>Purpose</p> <p>To explore hand therapists' experiences in delivering rehabilitation services to individuals with BPI in Australia.</p> <p>Study design</p> <p>A qualitative design was employed with two focus groups.</p> <p>Methods</p> <p>Data were analyzed using an inductive thematic approach.</p> <p>Results</p> <p>Three key themes were generated from the data. The first theme 'Falling through the gaps' captures participants' thoughts on post-injury health care and rehabilitation services. The second 'Developing a therapeutic alliance that endures over time' relates to the relationship building challenges and opportunities following trauma that will withstand the long-term recovery of individuals following BPI. The last theme, 'Just because you've seen one BPI, doesn't mean you've seen them all', considers the variation seen with these clients in relation to therapy needs and outcomes.</p> <p>Conclusions</p> <p>The findings of this study bring attention to the need to better equip hand therapists' skills and knowledge in responding to pain and psychological management post BPI, and to develop interdisciplinary models of care that are better able to treat and rehabilitate individuals with BPI.</p>

Highlights

Highlights

1. Given the long-term recovery following BPI, consideration should be given to relevance of slow stream rehab and interdisciplinary care.
2. Consider upskilling or an interdisciplinary care model to assist hand therapists and the provision of pain management and psychological support.
3. Increased dissemination of resources to support hand therapists working with individuals following BPI and enhanced communication opportunities to develop networks both nationally and internationally.

Effective long-term management of brachial plexus injury following surgery: what is needed from hand therapists' perspectives

Abstract

Introduction

Traumatic, brachial plexus injuries (BPI) result represent a significant cost to the individual and society. Recovery involves multiple surgeries, takes years, and often results in permanent physical dysfunction. While the last couple of decades have seen advancements in surgical management, the BPI rehabilitation literature has not kept pace with these developments.

Purpose

To explore hand therapists' experiences in delivering rehabilitation services to individuals with BPI in [REDACTED].

Study design

A qualitative design was employed with two focus groups.

Methods

Data were analyzed using an inductive thematic approach.

Results

Three key themes were generated from the data. The first theme 'Falling through the gaps' captures participants' thoughts on post-injury health care and rehabilitation services. The second 'Developing a therapeutic alliance that endures over time' relates to the relationship building challenges and opportunities following trauma that will withstand the long-term recovery of individuals following BPI. The last theme, 'Just because you've seen one BPI, doesn't mean you've seen them all', considers the variation seen with these clients in relation to therapy needs and outcomes.

Conclusions

The findings of this study bring attention to the need to better equip hand therapists' skills and knowledge in responding to pain and psychological management post BPI, and to develop interdisciplinary models of care that are better able to treat and rehabilitate individuals with BPI.

Keywords:

Brachial plexus injuries, occupational therapy, rehabilitation, adult

Effective long-term management of brachial plexus injury following surgery: what is needed from hand therapists' perspectives

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Declaration of Interest:

The authors report no conflicts of interest.

1 **Effective long-term management of brachial plexus injury following surgery: what is needed**
2 **from hand therapists' perspectives**

3 **Introduction**

4 Adult, brachial plexus injuries (BPIs) are associated with physical and psychological impacts and
5 result in life altering consequences.¹ Closed traction injuries commonly involve young men involved
6 in motor vehicle accidents.² Recovery following BPI often takes years and represents a substantial
7 cost to both the individual and society at large.³⁻⁶ Recent research indicates there are significant direct
8 and indirect costs (e.g. wages lost, disability payments) associated with BPI.^{5,6} Over the last few
9 decades surgical options for BPI have both increased and improved.⁷ While reconstructive surgery
10 following BPI is individualized, there are some commonly used procedures that include nerve
11 transfers, tendon transfers, joint arthrodeses, and free functioning muscle transfers.⁷ While there have
12 been many surgical advancements, in relation to nerve transfers and free functioning muscle transfers,
13 the corresponding rehabilitation/ therapy literature has not kept up with these changes.

14
15 Hand therapists, in [REDACTED], are registered occupational therapists or physiotherapists who have
16 gained additional training and clinical experience in the area of upper limb conditions.⁸ While some
17 may treat BPI, hand therapists predominately treat upper limb, musculoskeletal conditions, including
18 arthritis, tendon injury/ repair, carpal tunnel syndrome, distal radius fractures, and joint pathologies.⁹
19 Rehabilitation following BPI and reconstructive surgery requires specialized knowledge and should
20 be carried out by therapists with appropriate experience.¹⁰⁻¹² To the authors' knowledge, there is no
21 previous literature exploring the therapists' experiences of post-operative rehabilitation following
22 BPI. As such, the aim of this study was to explore this issue further by examining hand therapists'
23 experiences in delivering rehabilitation services to individuals with BPI in [REDACTED].

24
25 **Methods**

26 This qualitative study involved two focus groups conducted with hand therapists involved in the
27 treatment of people following BPI reconstructive surgery. Approval for this project was obtained from
28 the [REDACTED] Human Research Ethics committee (Project ID: 12210).

29 *Recruitment*

30 Recruitment was open to hand therapists practicing or specializing in the rehabilitation of BPI across
31 [REDACTED]. A convenience, snowballing sampling approach was used to recruit participants. Potential
32 participants were identified from professional hand therapy networks of therapists practicing or
33 specializing in the rehabilitation of brachial plexus injury across [REDACTED]. The email distribution list
34 included 8 individuals who were asked to forward the email invitation to other colleagues who had
35 previously treated patients with BPI. The inclusion criteria were that the participant was an
36 occupational therapist or a physiotherapist who had treated more than one patient with BPI. While all
37 participating clinicians may not have had formal hand therapy training, their experiences were
38 considered valuable to help inform better practice. Detailed information was given about the study,
39 time, and location of each focus group. All participants provided written informed consent.

40

41 *Data Generation*

42 Two focus groups, 60 minutes in length, were conducted using videoconferencing (Zoom®) due to
43 the diverse participant locations. A moderator and experienced qualitative researcher ([REDACTED]) conducted
44 the focus group while another researcher ([REDACTED]) took detailed notes that informed data analysis. The
45 moderator was not a hand therapist; with this intended to reduce bias and encourage participants to
46 share their opinions openly. A schedule of questions (see table 1) guided discussion however, the
47 semi-structured nature of the focus groups availing flexibility for participants to elaborate upon or
48 introduce important topics or issues that would not have otherwise surfaced.¹³

49

50 *Data analysis*

51 Focus group data were audio-recorded with participant consent and transcribed verbatim, with
52 identifying data removed. Data was analyzed using an inductive thematic analysis approach
53 involving: (i) familiarization and identifying codes of meaning by reading the transcripts line-by-line,
54 (ii) grouping codes into categories to assist with data retrieval, and (iii) examining relationships
55 between codes based on connections and similarities to form themes.¹⁴ Data were analyzed within and

56 between the focus groups by two independent researchers (), both occupational therapists.
57 Any differences between researcher perspectives were resolved by negotiation in multiple meetings.
58 Themes achieved saturation, where by no new themes emerged between the two focus groups. To
59 increase the credibility of the data, strategies such as peer debriefing, reflexive analysis and member
60 checking were used.¹⁵ Also, a summary of findings was sent to all participants for member checking
61 to ensure rigor of the findings, with five participants responding with no suggested changes ¹⁶. The
62 Consolidated Criteria for Reporting Qualitative research (COREQ) checklist provided guidance
63 during the reporting of this study(Supplementary 1).¹⁷

64 Results

65 Participant demographics are shown in Table 2. Eleven agreed to take part in two focus groups (n=5,
66 n=5), one declined, and two did not respond. One participant missed the focus group due to a
67 scheduling error. The participants included nine occupational therapists and one physiotherapist. The
68 participants reported working as therapists for a mean of 16.1 years (SD 5.5) and having treated
69 patients following BPI for the last 7.25 years (Mean; SD 4.7). When asked to self-rate their level of
70 confidence in treating individuals with BPI they reported a mean of 7.5 (SD1.4) on a scale where 0
71 represented not at all and 10 was very confident.

72 Three key themes emerged from the analysis:

- 73 1. Falling through the gaps
- 74 2. Developing a therapeutic alliance that endures over time
- 75 3. Just because you've seen one BPI, doesn't mean you've seen them all

76

77 *Falling through the gaps*

78 All participants expressed value in providing early, targeted therapy and patient education. While
79 BPIs represent a small percentage of most participants' caseload, they reported BPI patients were
80 more severely impacted by their injury and its long-term physical and psychological consequences

81 than other patients in their caseload. Since the experience of BPI frequently followed a life
82 threatening, traumatic accident, BPI diagnosis and referral for upper limb rehabilitation was often
83 reportedly delayed due to serious concomitant injuries.

84 *Even though they're in a center that may have experience with brachial plexus, they're not*
85 *always getting perhaps appropriate treatment. Because the head injury, or the bigger picture,*
86 *femur fractures, or whatever else, seems to take priority over the BPI in the early days.*

87 Group (G) 1, participant (P) 3

88 Participants posited the benefit of routine scans of trauma patients involved in high velocity
89 motorcycle or motor vehicle accidents, especially as many of these patients were already receiving
90 diagnostic testing.

91 *The majority of the patients...all have CTs and MRIs of their spine. It doesn't actually then go*
92 *that much further to get a brachial plexus [diagnostic test] as part of that. G1, P5*

93 Early referral was reportedly facilitated by therapists working in the acute trauma wards who had
94 experience with BPI. Other participants highlighted the benefit of close collaboration with
95 experienced allied health clinicians in sub-acute towards the early identification of BPI.

96 *... from any kind of allied health therapy perspective, the upper limb wasn't really getting any*
97 *attention... So, because [de-identified therapist] was part-time in brachial plexus [outpatient*
98 *clinic] and part time trauma therapist on the ward, she was able to identify them when they*
99 *came in day 1. ... The perception on the wards, I think, was, "I'll wait and see, there's nothing*
100 *anyone can do." So, there was no allied health referral...it seemed like allied health wasn't*
101 *seen as required for early BPI... G1, P2*

102 All participants reinforced the need for early intervention towards oedema management, protection
103 and positioning, range of motion, and managing pain. Commencing early education about BPI injury

104 and its prognosis was considered important as it often took time for patients to appreciate and
105 understand their diagnosis.

106 *It's actually two years down the track when they realize that everything is going to be hard*
107 *for a long time and maybe it's not going to get better- that adjustment period.*
108 G2, P3

109 Participants reported care was often fragmented following discharge, leading to gaps in service
110 provision. Staffing levels often meant that therapy occurred less frequently than desired. In response,
111 therapists working in public hospitals often referred patients with private or compensable insurance
112 cover to private hand therapy clinics as they felt that private clinics would have capacity to see the
113 patients more frequently.

114 *We have a very, very small team and we're managing all of upper limb injuries. So, it's very*
115 *limited... Even our non-compensable, if they're not immediately post-operative, they might*
116 *only get 45 minutes once a month. So, they just don't get very much, it's not adequate, but it's*
117 *what we can do.* G1, P4

118 Participants indicated the need for referral to a multidisciplinary team in order to address complex
119 needs beyond upper limb rehabilitation. This included access to resources that supported
120 independence and re-integration to their community such as pain management and psychological
121 support. Participants reported concern that many BPI patients did not receive the breadth of assistance
122 they needed, such as equipment prescription to promote independence.

123 *Often, I would say [equipment prescription] even happens very late...they might have been*
124 *needing assistance for showering. I think because in the hospital setting perhaps there was*
125 *other priorities [so it is not addressed]...Sometimes [hospitals] are not allowed to provide*
126 *equipment in [de-identified state] if it's less than \$100 and obviously the small items that*
127 *would help you eat, drink, cut up food, and such fall in that category.* G2, P2

128 All participants perceived significant gaps in respect to access to pain management support and
129 psychological services to assist with trauma and adjustment. The experience of pain was significant in
130 all patients but was reported to be poorly managed with delayed referral or limited access to expert
131 pain management.

132 *Pain is a massive ... We actually don't have an onsite pain unit. We have almost zero*
133 *psychology. It's all medicine based... Getting back to work when you're on so many*
134 *medications making you drowsy and trying to operate machinery if that's what your job*
135 *involves, it's just not possible... Patients frequently get lost to follow up ... our access to pain*
136 *services is very, very low. G1, P4*

137 Only one participant worked in an out-patient service that delivered a multi-disciplinary approach,
138 highlighting the benefit working in close collaboration and proximity to other clinicians (hand
139 therapy, pain clinic, and psychological services).

140 *We have an outpatient clinical psychologist who works very closely with all of our trauma*
141 *upper limb patients. I think there is benefit ... because it is in the same area and it's the same*
142 *hospital and the same network, they seem to be a bit more open to it, rather than going and*
143 *seeing somebody in a different setting. G1, P5*

144 ***Developing a therapeutic alliance that endures over time***

145 All participants reported that developing trust and an early therapeutic relationship with patients was
146 integral to facilitating better outcomes. This notion was underpinned by ongoing continuity of care
147 especially since rehabilitation was typically a long-term process requiring multiple surgeries. For
148 example, a free-functioning muscle transfer occurs “about three to four years [post injury]” G1, P2

149 *They get a lot of consistency and a lot of relationship building and also I make it a point to*
150 *collaborate with other health professionals and if that means they come in [needing a*

151 *surgeon] or I speak with them and we just work together so these [patients] feel supported.*

152 G2, P2

153 While participants were conscious not to generalize, many reflected that the BPI cohort often involved
154 young men who demonstrated similar attributes including: risk-taking behaviors, a desire for a quick
155 fix, and a propensity to be easily frustrated. There was also an acknowledgement that gender
156 influenced the therapeutic alliance. Participants expressed the challenges of predominately female
157 therapists working with young men who had experienced a life changing injury and were struggling to
158 accept an altered identity, such as transitioning from feeling invincible to being dependent.
159 Participants discussed that they felt at times the young men did not respond well to taking direction
160 from female therapists and it took extra time and effort, on their behalf, to develop the trust needed to
161 span the years of rehabilitation ahead.

162 *I think it's often the patients that do tend to have these major trauma incidents ... it's not just*
163 *the patients who have brachial plexus injuries, it's risk-taking behavior males who think*
164 *they're invincible and then suddenly their life is over, and they have to sometimes listen to a*
165 *young female telling them that they need to do these exercises to get better. It's tough... they*
166 *were previously an independent, active, usually young males and yeah and they have - and*
167 *it's not just the brachial plexus injury that's going on... So, [the BPI] is often seems to be*
168 *sort of like the last thing that gets dealt with. So, they've been through this huge emotional*
169 *trauma ...and the rehab process is going to be years and years. The biggest challenge I find*
170 *from that is getting them on board to be in there for the long haul. G2, P5*

171 The establishment of trust was also complicated by the experience of multiple surgeries such that
172 patients were anticipative of significant improvement, as surgery required time to recovery and
173 rehabilitate before gains were perceived. This ongoing cycle of surgery and delayed hope was seen as
174 being difficult for many patients.

175 *I think their headspace takes longer because patients are having another operation and then*
 176 *they pin their hopes on the next movement they're going to get.*
 177 G1, P2

178 Maintaining a therapeutic alliance, that is sustained over many years, reportedly requires the need for
 179 client-centered and goal focused relationships. Psychological adjustment to changes in physical
 180 appearance and altered function following BPI was noted to be a difficult process which took time
 181 that required targeted therapy. Participants emphasized that therapy goals should be focused on what
 182 was, *'Important to the patients. [And that] ...therapy is based on function.* 'G2, P5

183 For many patients, commitment to therapy was perceived to wane over time as demonstrated by late
 184 arrival to appointments, failing to attend appointments, or not adhering to home exercise programs
 185 and even taking a break and, *'Turn[ing] up three or four years after their injury and have lived with it*
 186 *for a number of years,'* G1, P2

187 *Oh so even if it's just purely their personality where they're not doing exercises or they might*
 188 *have rocked up 20 minutes late to an appointment so you might have - if it's a 40-minute time*
 189 *slot you've wasted half your time just waiting for them. Or you can't get through as much or*
 190 *it puts the rest of your day behind, those sorts of things.*
 191 G2, P1

192 ***Just because you've seen one BPI, doesn't mean you've seen them all.***

193 Participants found treating BPI challenging and considerable time was required to understand the
 194 variation in BPI (presentations, surgical interventions, therapy needs, and outcomes), being more
 195 marked than many other upper limb conditions they treated. Likewise, outcomes were noted to vary.

196 *I think one of the challenges is the differing diagnoses. you're talking a very different*
 197 *journey for a C5/6 to a complete flail arm.* G1, P1

198 While considered a rewarding caseload, participants expressed feeling overwhelmed and emotionally
199 drained from treating patients with BPI. Even experienced therapists reflected on feelings of
200 trepidation when initially working with BPI as the ‘*great unknown*’ (G1, P1) and given the
201 psychosocial needs of their patients.

202 *... I find that [sessions] end up being half the time a bit of a counselling session with them...*
203 *Initially I think it is quite overwhelming.* G2, P1

204 In response to the needs of this caseload, participants felt it was important to look beyond the goal of
205 simply promoting arm function but rather consider, “*What is a good outcome from a patient*
206 *perspective and from my perspective*’. G1, P5

207 *What I would look at, is the patient reengaged in occupations? Are they independent with*
208 *being able to do some things for themselves and being able to engage in whatever they think*
209 *is important to them?* G1, P5

210 Participants felt they often worked beyond the boundaries of services provided to their non-BPI
211 patients, especially in response to addressing their psychological needs. That said, the occupational
212 therapists in the groups felt their profession equipped them for, “*filling the void ...and [addressing*
213 *what] they actually need.*” G1, P5

214 *I think the occupational therapy perspective does give us a broader set of skills to look at the*
215 *whole person... if you start delving and asking about mood and how they're coping, quality of*
216 *life, pain factors, it's such a huge component, the disability that they experience. I think,*
217 *having a background in OT allows you to explore that psychosocial aspect... and some*
218 *[patients] are quite resistant to see psychologists.* G1, P2

219 As seen in the quote above participants often assumed the role of counsellor in order to ensure
220 patients received support towards the extent of their physical and psychosocial needs. Consequently,

221 participants felt that patients would benefit from better case coordination to manage their complex
222 needs through referral to and engagement with appropriate health services.

223 *...it's so much easier if they've got a case manager of some sort[otherwise] I tend to turn into*
224 *their case manager, really. G2, P5*

225 Given that access to and engagement with pain and psychological services was limited for many BPI
226 patients, many participants expressed the desire for upskilling and training opportunities in these
227 areas, especially given there were long wait times for professional support.

228 *you have to develop skills in being able to counsel these patients from an emotional*
229 *perspective even though it's not something that we're necessarily trained in or do a lot of*
230 *focus around upskilling in this area. G2, P3*

231 To assist with the challenges of treating BPI, participants readily sought support from other BPI
232 therapists at conferences and other professional gatherings in order to get, 'help or discuss a case.'
233 (G2, P3). The idea of having specific BPI interest groups was mentioned as a way of facilitating
234 debriefing and sharing of knowledge.

235 *I feel very isolated ... even having some support, some sort of system that we can support...to*
236 *be able to talk about brachial plexus and see what other people are doing, for me, I think that*
237 *would be completely awesome and very, very helpful. G1, P4*

238 Discussion

239 Therapists providing rehabilitation to patients following BPI had consistent experiences. Results
240 highlight considerations for BPI therapists due to the complex and long-term nature of rehabilitation,
241 especially the need for review of the model of care; and upskilling in pain and psychological
242 management; and improved access to and use of multi-disciplinary teams when treating individuals
243 with BPI. The authors located only one other study reporting data from therapists that treated

244 individuals diagnosis of neuralgic amyotrophy or BPI.¹⁸ The Janssen et al. study's¹⁸ population was
245 different in that individuals with neuralgic amyotrophy generally do not result from a traumatic injury,
246 do not require surgical reconstruction, and often improve spontaneously within months to a few
247 years.¹⁹

248

249 Results are consistent with previous research demonstrating the impact of pain and adjustment
250 following BPI, especially from the patient's perspective.²⁰⁻²² Participants discussed the need to look
251 beyond biomedical factors and focus more on biopsychosocial factors.²³ Indeed, the care following
252 traumatic BPI could benefit from being considered alongside other conditions requiring long-term
253 recovery such as spinal cord and brain injury.²⁴ A slow stream rehabilitation model of care better
254 supports individuals experiencing prolonged recovery^{25,26}, and is underpinned by patient-centered,
255 goal focused care provided within a multidisciplinary approach within an integrated model of
256 functioning, disability and health.^{27,28} Slow recovery, long-term rehabilitation models have the
257 potential to assist health professionals, including hand therapists, to plan and deliver the holistic care
258 that is required following BPI.²⁹

259

260 Hand therapists that provide rehabilitation for individuals with BPI, expressed that they felt unskilled
261 when providing psychological and pain management support. Therapists who find themselves filling
262 the gaps for patients that either do not have access to or are not engaging with additional health
263 services may benefit from either taking part in additional educational and upskilling activities.

264 Another option is to move from the current multidisciplinary care approach toward an
265 interdisciplinary approach. An interdisciplinary approach is one that a team of health care providers
266 work together and support one another by sharing their expertise, knowledge and skills.³⁰

267 Interdisciplinary care has the benefit of treatment plans with input from all team members (including
268 patients) for working toward the best outcome.³¹ There are frameworks available that could be used to
269 inform such service delivery³², but how to best implement this service model for this client group has
270 not been documented. Therapists that participated in this study felt that pain management and

271 psychological supports were essential for good outcomes, and, if managed, allowed therapists to
272 direct more of their attention on the rehabilitation of the upper limb.

273

274 A lack of professional development opportunities available that are specific to the management of BPI
275 was identified. Our participants used their own professional networks to locate and contact others for
276 advice or support. The need for professional development and peer support is amplified for the
277 management of BPI partly due to the homogeneous nature of the diagnosis and the multiple
278 reconstructive surgeries. BPI as a diagnosis has a variety of presentations depending on the level and
279 completeness of lesion.² To add to this variation, there are also a range of reconstructive surgeries that
280 are used to address the range of physical impairments secondary to the BPI.³³ The need for more
281 formal networks to promote skills development should be explored in future research.

282

283 *Limitations*

284 While this study was able to provide rich data regarding the treatment and experience of treating
285 individuals following BPI, there is the potential that participants may have been missed given the
286 purposive recruitment method. This study reflects health care and systems related to [REDACTED];
287 therefore, there is also limited generalizability of these findings - especially the concepts of
288 compensable insurance and service delivery as this would be contextually driven. The authors
289 recommend further investigation of health systems and their approach to managing BPI,
290 rehabilitation, and hand therapists' experiences in a range of settings to better understand facilitators
291 and challenges of long-term management of BPI.

292

293 **Conclusion**

294 Patient care following BPI is challenging to manage due to the variety of presentation and surgical
295 reconstructive procedures, poor access to experienced hand therapists for mentoring, and the need to
296 support patients with interdisciplinary teams in the community. Outcomes post-BPI can be improved
297 through early diagnosis and reframing of patient care within a long-term, slow recovery model that

298 utilizes an interdisciplinary team approach. These recommendations will improve patient outcomes
299 and protect hand therapists from feeling overwhelmed.
300
301

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Table 1*Focus group interview guide*

Question	Prompt
To start, can you please introduce yourself and describe your role managing BPI.	Have you treated both partial BPIs and flail limbs?
Managing BPI is often the result of a trauma and can be complicated by the experience of other injuries. What is your experience managing BPI?	What works? What makes it difficult? Are you confident? Why? Why not?
Based on your clinical experience what are your goals for these patients?	Pre-surgery Post-surgery Retraining for use in day to day activity Other
Based on your clinical experience what works best with managing BPI?	How do you decide? Who do you involve in the decision?
What does a good outcome look like to you in patients with BPI?	Range of motion/ muscle strength Ability for injured arm to assist or complete activities Engagement in and return to roles of daily life (home maintainer, employment/ volunteer, partner/ spouse, parent, etc.) Other
When working with the patient group what have you found to be challenges and opportunities?	a. Level of educ or work industry for RTW? b. Pain management? Drug dependency c. Depression/ anxiety? d. Financial concerns? e. Social supports/ stresses
Our research with patients who were many years post BPI identified that most: <ul style="list-style-type: none"> - Had limited use of their arm - Had difficult with pain with 2 becoming addicted - Had struggled with developing a new self-identity Reported changes in relationships with those close to them - Had struggled significantly with returning to work 	What are your reactions? Expand

Participants also found the long-term relationship with their hand therapist as integral to recovery especially the experience of positive regard after a traumatic event	What are your thoughts? Do you think more support is needed?
Is there anything that you could suggest to make your job easier in treating BPI	What? Expand
Final comments	

Table 2*Participant demographics*

<i>Participant ID</i>	<i>Are you an occupational therapist (OT) or a physiotherapist (PT)?</i>	<i>How long have you been an occupational therapist/ a physiotherapist?</i>	<i>How long have you been treating patients with brachial plexus injury (BPI)?</i>	<i>Please estimate how many patients you have treated that had a BPI.</i>	<i>Please rate your level of confidence in assessing and treating a patient with a BPI from 1-10.</i>
Focus group 1					
1	OT	16 years	1 years	12	7
2	OT	23years	10 years	50+	10
3	OT	17 years	10 years	50-60	7.5
4	OT	23 years	5-6 years	10-15	5
5	OT	18 years	9 years	10	8
Focus group 2					
1	OT	8 years	6 years	20+	8
2	OT	21 years	17 years	200-300	9
3	PT	8 years	7 years	20	7
4	OT	13 years	4 years	35	7
5	OT	14 years	~2 years	50	7

Supplementary 1

Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

Domain 1: Research team and reflexivity	
<i>Personal Characteristics</i>	
1. Interviewer/facilitator- Which author/s conducted the interview or focus group?	See Data generation, page 2
2. Credentials- What were the researcher's credentials? E.g. PhD, MD	Title page
3. Occupation- What was their occupation at the time of the study?	See Data generation, page 3
4. Gender- Was the researcher male or female?	N/A
5. Experience and training- What experience or training did the researcher have?	See Data generation, page 2&3
<i>Relationship with participants</i>	
6. Relationship established- Was a relationship established prior to study commencement?	Participants were briefed on the study and provided written informed consent. They understood the that this was research project.
7. Participant knowledge of the interviewer- What did the participants know about the researcher? e.g. personal goals, reasons for doing the research?	At the time of the Focus group participants were briefed on the moderator (JW). The original 8 therapists contacted by direct email knew the other researcher (SB).
8. Interviewer characteristics- What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	Introduction, page 1
Domain 2: study design	
<i>Theoretical framework</i>	
9. Methodological orientation and theory- What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	Methods, page 2-3
<i>Participant selection</i>	
10. Sampling- How were participants selected? e.g. purposive, convenience, consecutive, snowball	Methods, page 2
11. Method of approach- How were participants approached? e.g. face-to-face, telephone, mail, email	Methods, page 2
12. Sample size- How many participants were in the study?	Results, page 3
13. Non-participation- How many people refused to participate or dropped out? Reasons?	Results, page 3
<i>Setting</i>	
14. Setting of data collection- Where was the data collected? e.g. home, clinic, workplace	Methods, page 2
15. Presence of non-participants- Was anyone else present besides the participants and researchers?	Methods, page 2
16. Description of sample- What are the important characteristics of the sample? e.g. demographic data, date	Results, page 3
Data collection	
17. Interview guide- Were questions, prompts, guides provided by the authors? Was it pilot tested?	Data generation, page 2
18. Repeat interviews- Were repeat interviews carried out? If yes, how many?	No. Data generation, page 2
19. Audio/visual recording- Did the research use audio or visual recording to collect the data?	Data generation, page 2
20. Field notes- Were field notes made during and/or after the interview or focus group?	Data generation, page 2

21. Duration- What was the duration of the interviews or focus group?	Data generation, page 2
22. Data saturation- Was data saturation discussed?	Data analysis- page 3
23. Transcripts returned- Were transcripts returned to participants for comment and/or correction?	Study resources did not allow for return of transcripts for checking
Domain 3: analysis and findings	
<i>Data analysis</i>	
24. Number of data coders- How many data coders coded the data?	Data analysis- page 3
25. Description of the coding tree- Did authors provide a description of the coding tree?	N/A
26. Derivation of themes- Were themes identified in advance or derived from the data?	Data generation- page 2
27. Software- What software, if applicable, was used to manage the data?	N/A
28. Participant checking- Did participants provide feedback on the findings?	Data analysis, page 3
<i>Reporting</i>	
29. Quotations presented- Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. participant number	Results
30. Data and findings consistent- Was there consistency between the data presented and the findings?	Relationship to existing knowledge discussed
31. Clarity of major themes- Were major themes clearly presented in the findings?	Results
32. Clarity of minor themes- Is there a description of diverse cases or discussion of minor themes?	N/A

8.4 Chapter Summary

The investigation that comprises this chapter's manuscript aimed to consider the therapist's perspective of rehabilitation following BPI. Therapists agreed that patients who sustain a pan-BPI have more challenges during rehabilitation and that the therapeutic relationship is keystone to planning and achieving client-focussed goals. Therapists also identified that managing patients with BPI requires skills and knowledge that most experienced hand therapists do not have. These include specific understanding of the injury, surgical reconstructions, and knowledge of how to respond best to the management of their pain and psychological sequelae.

Chapter 9 - Integrated discussion

9.1 Chapter Introduction

The selection of the pan-BPI subpopulation, the population focussed on in this thesis, was based on the author's clinical observation of this diagnosis and knowledge of its profound impact and poorer outcomes as indicated in the literature (Elzinga et al., 2014). The aim was to better understand outcomes post-surgery and rehabilitation, and to do so in a holistic way. This thesis used qualitative and quantitative measures to comprehensively report outcomes as it is acknowledged that a range of factors influence an individual's health and well-being (Townsend & Polatajko, 2007). Outcomes for this pan-BPI population were explored through a detailed review of the existing literature, patient reported outcome measures, patients' experiences, and the perspective of health professionals. This chapter will provide a critical explanation and an integrated discussion of the five investigations undertaken. This will be done by first reviewing the results of each investigation and then discussing the key findings. As well, this will be followed by a fuller examination of the findings collectively, their significance, and how they relate to the broader literature. This exploration is done through an occupational lens by applying the Canadian Model of Occupational Performance and Engagement (CMOP-E; Townsend & Polatajko, 2007) and considering what the findings mean for individuals and health care providers.

9.2 Reviewing the research questions and findings

The previous chapters (4-8), each corresponded to an investigation that related to research questions that contributed to answering the overall thesis research question, "*What are the experiences and psychosocial outcomes following free*

functioning muscle transfer reconstructive surgery for management of pan-brachial plexus injury in Australia?” The introduction of this thesis provided an overview of the research aims and questions for each investigation (Table 2, pp. 11-12). Table 13, below, outlines the research questions from each investigation with key findings from each. In the introductory chapter (Chapter 1) the five investigations were categorised into one of five key categories: theory and evidence; activity; participation; patients’ perspectives; and therapists’ perspectives. Theory and evidence provided the opportunity to explore the existing data and identify gaps. The investigations that explored activity and participation outcomes aimed to inform gaps in the literature, while taking a holistic view of health outcomes. And the final two categories that investigated the patients’ and therapists’ perspectives that aimed to better understand subjective experiences that are intangible in outcome questionnaires.

Table 13*Research Questions and Corresponding Key Findings*

		Questions	Key findings
Theory & evidence	Investigation 1	What psychosocial outcomes are currently reported for individuals following FFMT surgery for management of traumatic BPI?	<ul style="list-style-type: none"> • The most commonly use patient reported outcome measure following FFMT reconstructive surgery for BPI was the Disability of the Arm, Shoulder and Hand (DASH; 81%) and the 36-Item Short Form Survey (SF-36; 31%). • Other outcomes measures used only in one study included: <ul style="list-style-type: none"> ○ Modified-Satisfaction with Appearance Scale ○ Upper Extremity Functional Index ○ Canadian Occupational Performance Measure ○ Self-rating Anxiety Scale ○ Self-rating Depression Scale ○ Brief Coping with Problems Experienced
Activities	Investigation 2	<p>1) What are long-term outcomes for individuals with pan-brachial plexus injuries following FFMT reconstructive surgery in Australia?</p> <p>2) How do these outcomes relate to other similar populations?</p>	<ul style="list-style-type: none"> • Patients demonstrated significant global deficits in use of the arm and quality of life. • This population's scores were significantly worse than normative population data and similar to other populations post-serious injury. • Health professionals must select outcome measures with the knowledge of what is being measured when used with this population and its meaning to their recovery. • Patients report appreciably different perceptions of ability to complete similar activities between two measures (DASH & BrAT). It is proposed this difference is based on the question being asked around ability of the arm with BPI completing the activity versus completing the activity (in any way).

Participation	Investigation 3	<p>1) How do individuals report objective and subjective experiences of participation in life situations following surgery for management of a BPI?</p> <p>2) What frequency, restriction, and satisfaction outcomes are reported for participation?</p>	<ul style="list-style-type: none"> • Participants reported they were either very satisfied or satisfied (64.3%) with their participation in everyday life. • Participants in this study rated their highest level of satisfaction (as either satisfied or very satisfied) in relation to their relationships with family (92.3%), going out (85.7%), and day trips/ outdoor activities (71.4%) • They were most dissatisfied or very dissatisfied with their participation in sports/ physical exercise (35.7%), work/ education (33.3%), and household duties (33.3%). • The majority of participants perceived they could engage in their daily roles and relationships either without restriction or with some assistance (71%). • This mixed diagnosis BPI population reported similar outcomes to other significant injuries (e.g., stroke and spinal cord injury) in frequency, satisfaction, and restriction to participation.
Patients' lived experience	Investigation 4	What are patients' experiences following pan-BPI and FFMT surgery?	<ul style="list-style-type: none"> • Individuals with pan-brachial plexus injuries felt it was beneficial to work with health care providers with extensive brachial plexus injury knowledge. • Stable, long-term relationships with health providers during rehabilitation were reported as beneficial to recovery. • Greater consideration of the process of adjustment and creating a new self-identity following pan-BPI needs to be considered during rehabilitation.
Health professionals' perceptions	Investigation 5	1) What factors do rehabilitation therapists perceive to support/ challenge recovery following BPI?	<ul style="list-style-type: none"> • The heterogeneity of the presentation, surgical interventions, and complexity of the patients' recovery (e.g., pain and psychological adjustment and support) can make this a challenging population to treat. • Perceived positive support during rehabilitation were consistent health care providers that offer therapeutic relationship over the period of recovery, multi-disciplinary approach with collaboration between health care providers

9.3 Theory and Evidence

The first investigation (Chapter 4) was designed to identify which psychosocial outcome measures have been used with an FFMT population, identify domains being assessed, and to inform the measures used in this thesis. The scoping review identified a lack of consistent outcomes measures have been applied across studies, with the majority only being used once in individual studies. None of the measures identified had been psychometrically examined for use with BPI. The first investigation also identified that most psychological measures used were deficit-focussed and did not consider a strength-based approach (this will be examined further in section 9.5.1). As discussed in the methodology (Chapter 3 - section 3.3.3.), following identification of the outcomes measures that have been applied, the World Health Organization's International Classification of Functioning, Disability and Health Model (ICF; World Health Organization, 2001) was used to conceptualise outcome domains and ensure that this thesis would consider patient outcomes holistically for individuals following pan-BPI.

9.3.1 Activity and Participation

Investigation 2 aimed to consider patient outcomes as they relate to the activity domain of the ICF (World Health Organization, 2001). In this investigation, the Brachial Assessment Tool (BrAT; Hill et al., 2016) was used as an outcome measure as it was identified in the scoping review that none of the studies had used measures that were validated for use with BPI. This inclusion allowed for direct comparison with the most popular activity measure following BPI, the Disability of the Arm, Shoulder, and Hand (DASH; Hudak et al., 1996). The second manuscript was prepared using these data and explored the differences between patient reported ability to engage in daily activities as assessed by these two measures. This manuscript identified the nuances between the two activity measures when used with the pan-BPI population. Specifically, this investigation

found that while both measures reported activity level outcomes, the BrAT (Hill et al., 2016) seemed better suited to report activity level engagement of the affected limb because it specified the items related to the injured limb. The corresponding manuscript encouraged health professionals to both carefully select measures used and consider how to report outcomes related to this distinct diagnosis.

The questions generated for Investigation 3 were developed to gain a deeper insight regarding participation following pan-BPI. Participation outcomes were not identified in the scoping review (Chapter 4) despite *participation* being as recognised as an intrinsic aspect of an individual's health and well-being (World Health Organization, 2001). Investigation 3 examined this identified gap in the literature for the pan-BPI population by reporting participation scores on the USER-Participation. The participation findings for this pan-BPI cohort were similar to other severe conditions (e.g., stroke and spinal cord injury), with their greatest level of satisfaction reported being their participation in family relationships, going out and taking trips. The greatest of dissatisfaction reported was with their ability to exercise, work and perform household duties. However, despite some dissatisfaction with these key areas of participation being reported, more than two-thirds were satisfied with their participation in daily life without feeling any restriction or needing assistance to engage in daily roles and relationships.

9.3.2 Patients' Lived Experiences

Investigation 4 aimed to better understand the experience of this life changing injury and years of surgery and rehabilitation from the perspective of patients. Three key themes were generated from this investigation. The first theme that was generated from the data related to the value patients placed in receiving care from experienced BPI health care

workers. Participants noted that experienced health professionals were able to provide accurate information that aided with setting realistic expectations and provided positive social support across their long-term recovery.

There were barriers identified for some patients in accessing this type of support, including insurance and geographical location. Individuals that had insurance (private or compensatory) had more autonomy and choice both in selecting their provider, and also in the frequency and duration of therapy they accessed. Patients who do not reside near specialist facilities, predominately located in metropolitan areas, faced additional access challenges. Finally, patients discussed the process of adjustment after injury and the subsequent creation or re-creation of self-identity and how this was an important consideration in their ability to re-engage in meaningful, daily lives.

9.3.3 *Health Professionals' Experiences*

While specialised rehabilitation following BPI is recommended (Kahn & Moore, 2016), it can often be daunting and overwhelming for therapists. The main findings of Investigation 5 were:

- Patients can easily be lost to early rehabilitation due to delayed diagnosis.
- Identification of the challenges and opportunities that come with long-term relationship developed during recovery.
- There are challenges of treating such a heterogeneous diagnosis.

The second finding, challenges and opportunities of long-term relationships between patients and rehabilitation providers, mirrors patients' experiences articulated in Investigation 4 where they acknowledged the role of continuity of care with health care providers. However, while therapists acknowledge the need for continuity of care, they also discussed the challenges of this therapeutic relationship. Therapists reported feeling

ill-prepared to manage and support the psychological needs of these patients. While the trauma and distress following injury and multiple surgeries often warrants referral to professional psychological services, therapists did not seem to recognise the benefit that they themselves provided to patients through long-term, positive, social support as part of the delivery of hand therapy services.

Outcomes following FFMT for the management of pan-BPI result in continued reduction in ability to use the affected arm in daily activities and reduced participation in everyday life. The main findings from each investigation have been reviewed. As mentioned in this thesis's introduction, this thesis aimed to use a biopsychosocial view of health to explore the recovery and outcomes following pan-BPI. The ICF framework (World Health Organization, 2001) was applied in the planning and development of this thesis and writing of manuscripts, as it provides a multidisciplinary language for health care professionals and enables a more holistic consideration of outcomes from this population. However, the following section of the discussion uses an occupational therapy model to explore the findings, as this thesis is being completed in a Department of Occupational Therapy and occupational therapists are commonly involved with this patient group and assist with upper limb rehabilitation, community re-integration, and equipment prescription (Frampton, 1988).

9.4 Integrating the Findings

Biopsychosocial models of health, such as the ICF (World Health Organization, 2001) and the Canadian Model of Occupational Performance and Engagement (CMOP-E; Canadian Association of Occupational Therapists, 1997; Townsend & Polatajko, 2007), represent a range of health-related concepts that are often impacted following severe injury or chronic health condition, including participation (Sloan et al., 2004). The ICF

(World Health Organization, 2001) was chosen for use in the manuscripts included in this thesis as it provides a framework and classification that is globally recognised across health disciplines for use at both individual and population levels. And therefore, publications based on the investigation in this would be appropriate to a multidisciplinary audience. The ICF has been used in the injury literature to guide acute and rehabilitation care (Laxe et al., 2015; Stucki et al., 2005). Domains in the ICF framework (World Health Organization, 2001) and constructs of the CMOP-E (Canadian Association of Occupational Therapists, 1997; Townsend & Polatajko, 2007) have considerable overlap (Table 1, p. 3).

Both the CMOP-E (Townsend & Polatajko, 2007) and the ICF (World Health Organization, 2001) include domains that consider person-related, activity, participation, environmental, and personal factors. The domain of person, in the CMOP-E, considers an individual's mental, physical and affective functioning. Execution of a daily task, such as carrying a bag, is captured by the ICF (World Health Organization, 2001) as an activity, but is more deeply explored in the CMOP-E (Townsend & Polatajko, 2007) in the hierarchy of components that are required to execute said task. Involvement in life roles is captured by the ICF (World Health Organization, 2001) as participation, and by the CMOP-E (Townsend & Polatajko, 2007) as participation in occupations – with the addition of performance and engagement in roles from both objective and subjective perspectives. Environment and personal factors are conceptualised similarly in both the ICF and the CMOP-E, with both taking into account the physical, as well as cultural and societal contexts (including social relationships) of people's lives.

While activity and participation in daily life has become part of the medical vernacular following its inclusion in the ICF (World Health Organization, 2001), the concept of participating in valued activities and occupations has always been the central tenant of

occupational therapy (Townsend & Polatajko, 2007). Following pan-BPI, patients experience a significant and permanent loss of ability in the affected upper limb (Kretschmer et al., 2009). Patients also experience changes in their life roles and identity, expressed as changed role involvement within the family, loss as primary wage earner, and decreased participation as examined in Investigation 4 (Chapter 7) and one BPI study (McDonald & Pettigrew, 2014).

Neither the BPI systematic review (Dy et al., 2015), nor the pan-BPI scoping review (prepared as an outcome of Investigation 1) identified any studies that used an outcome measure that reported participation. This gap partly informed this thesis. Participation in daily life and valued roles featured as a priority in both the patient and therapist qualitative studies (Chapter 7 & 8), and is commonly assessed and reported on following other life altering injuries (i.e., spinal cord injury, acquired brain injury) (Müller et al., 2017; Sloan et al., 2009).

While the CMOP-E (Townsend & Polatajko, 2007) and the ICF (World Health Organization, 2001) models have some common concepts, the CMOP-E (Townsend & Polatajko, 2007) offers a more nuanced perspective to consider the concept of engagement in daily life (Polatajko et al., 2013). Concerns have been raised that the ICF framework (World Health Organization, 2001) does not clearly delineate between the concepts of activities and participation (Bakas et al., 2012). To understand the findings of this thesis and their impact more fully on individuals' engagement in daily life (activity and participation), this section of the discussion will consider the results of these investigations through an occupational framework by applying the CMOP-E.

9.5 Understanding BPI Occupationally

Despite that the majority of hand therapists are occupational therapists (Dixon, personal communication April 19, 2021), the hand therapy literature has minimal occupationally-focussed research (Colaianne et al., 2015; Robinson et al., 2016). Participation in everyday activities and occupations are central to occupational therapy theory, including the CMOP-E (Canadian Association of Occupational Therapists, 1997; Townsend & Polatajko, 2007). Using the CMOP-E to appreciate the range of psychosocial factors following FFMT surgery for pan-BPI, enables a deeper appreciation of this thesis' results and provides useful and relevant evidence for health professionals working with this population. Given the life altering impact of pan-BPI, patients need to be able to respond to changes in life roles and ultimately both their self and occupational identities. The CMOP-E (Townsend & Polatajko, 2007) has been used previously to better understand and plan health care and service delivery following serious injury using an occupational perspective following serious injury (Lund et al., 2012). The CMOP-E operationalises the dynamic and complex interactions of a person, their environment and their occupations to facilitate understanding, analysis, and intervention planning to enable individuals and their families to successfully engage in meaningful and desired occupations (Townsend & Polatajko, 2007).

9.5.1 Person-Related Findings

In the CMOP-E model, the person consists of three components: physical, cognitive, and affective, with spirituality anchored in its core (Townsend & Polatajko, 2007). The findings in this thesis reported on both physical and cognitive/ affective data. The physical data (Chapter 5) reported on included range of movement and muscle strength. While studies included in this thesis were cross-sectional and did not report on pre-operative functioning, the inclusion criteria for this investigation specified that

participants must have received a clinical diagnosis of C5-T1 palsy, persisting until time of first surgery. Therefore, the range of movement and muscle strength reported in Investigation 2 (Chapter 5) demonstrates that these patients did regain some movement in a previously flail limb.

While the reconstructive surgeries generally provided stability at the shoulder, elbow flexion (+/- extension), and minimal hand function (hook grasp at best), patients experienced reduced range of movement, strength, and sensation consistent with previously reported outcomes following this injury (Bertelli, 2019; Bertelli et al., 2011). Shin (2006, p. 1226) reminds us of Sterling Bunnell's assertion "to someone who has nothing, a little is a lot" was never more true than for patients who have sustained severe brachial plexus injuries. While this information provides information about the physical components of the Person domain, the issue of what this represents in relation to performance is discussed under the model's domain of *occupational engagement and performance* below (Section 9.5.4.).

Nevertheless, these are only physical factors, and as the patient qualitative study (Chapter 7) demonstrated, there are many affective factors that influence this population including periods of low mood (e.g., feeling depressed, grief, and loss). While psychological outcomes are increasingly being reported in the BPI literature (Landers et al., 2018; Wilson et al., 2016), the impact of low mood is not well understood in relation to its impact on participation in daily life. In Investigation 4 (Chapter 7), participants discussed the very emotional and difficult adjustment period following the injury and the prolonged grieving process for what they imagined life would be. These findings are mirrored in those from Investigation 5 (Chapter 8) from the therapists' perspectives (i.e., therapists discussed the challenges of supporting patients through such significant psychological

distress and adjustment). The finding in Investigation 5, that this population generally did not engage with mental health services is consistent with young men more broadly who have been found less likely to seek support for their mental health (Lynch et al., 2018). Reluctance with respect to health seeking behaviour is further considered in relation to gender under environmental factors as this is seen to be attributed to cultural and societal factors (*Section 9.5.2.*).

Some insight regarding the cognitive and affective impact of BPI were explored during the qualitative interviews (Chapters 7 & 8). The psychological impact of BPI together with physical limitations following BPI impacted participants' self-identity, motivation, and meaning-making, something that has been previously noted in the literature (Carlsen, 1988). Participants reported post-injury feelings of self-blame, guilt, depression, dependence on pain medication, withdrawal, and anxiety, with such findings being consistent with other BPI literature (Landers et al., 2018; Yannascoli et al., 2018).

A deficit approach to reporting outcomes following BPI is common, however this thesis identified many patients who, with time, developed a different, more positive view of themselves and their lives that is consistent with a strength-based perspective of illness and adaptation. Strength-based theory comes from the discipline of social work and emphasises self-determination and the strengths of people when facing adversity (Harvey, 2014). This strength-based perspective was reported by patients as part of their meaning-making and adjustment following injury (Investigation 4 – Chapter 7). Participants' deeper reflections, as reported in Investigation 4 (Chapter 7) captured, transition over time and this shift in meaning-making. Meaning-making is a term that originally comes from psychology and refers to how people make sense of their lives (including life events, relationship and their sense of self) (Carlsen, 1988).

Participants' discussion of transition over time and meaning-making aligned closely to the spirituality component of the CMOP-E (Townsend & Polatajko, 2007). Spirituality in the CMOP-E model is central to the *person* component and is conceptualised as the essence of the person rather than referring to religion (Townsend & Polatajko, 2007). In this thesis spirituality was expressed by participants (patients and therapists) in both qualitative studies as evidenced by their discussion of meaning making and a finding of perspective that assisted with their adjustment process. In some instances, the narrative of some patients with BPI described their experience and reflected on the loss, growth, and resilience they discovered during their recovery.

These concepts are consistent with the idea of post-traumatic growth (Tedeschi & Calhoun, 1996). Post-traumatic growth represents the change experienced by an individual as the result of them living through and emerging from a highly challenging life situation (e.g., near death experience, physically disabling injury) (Tedeschi & Calhoun, 2004). While this concept has not been explored with respect to the BPI population elsewhere, it provides a useful framework for health practitioners and patients to better understand the process of adjustment and adaptation that occurs post-BPI. The potential for positive reframing of events, that is present post injury, has been discussed following other traumatic injury though (Min et al., 2014). This making sense of the injury and reframing of their circumstances in a way that is meaningful to the patient has not been explored previously following BPI. Whilst time must be allowed for patients to process and grieve changes in their life post-injury, the benefit of encouraging patients to positively reframe their circumstances should be considered as part of a strength-based approach following injury.

9.5.2 *Environment-related Findings*

The CMOP-E (Townsend & Polatajko, 2007) conceptualises environment as including cultural, institution, physical, and social factors that impact on occupational opportunities (Polatajko et al., 2013). Social factors and relationships are considered to be part of the environmental component of the CMOP-E (Townsend & Polatajko, 2007). Investigation 4 (Chapter 7) provided new insights into the importance of psychosocial considerations including impacts on: social relationships (Brito et al., 2019). Patients discussed predominately the change in relationships, with some becoming stronger while others were discarded – these changes were often discussed in the context of a new prioritisation of personal values following severe injury.

The studies of this thesis also considered the impact of positive social support and their value during recovery. The quantitative data from Investigation 3 (Chapter 6), which explored participation outcomes, found that participants with BPI were most satisfied with their relationships with family and that almost two-thirds perceived they could engage in their roles and social relationships either without difficulty or with assistance. These satisfaction-related findings are likely to be meaningful, particularly given that a systematic review following traumatic, life-altering injuries has reported relationships with family and friends are a patient priority and that they improve quality of life post-injury (Simpson et al., 2012).

Patients may benefit greatly from peer support with others that have sustained similar levels and severity of injury (Franzblau et al., 2014), and research indicates peer support can assist with regaining self-belief and a sense of autonomy assisting with adapting to everyday life (Lund et al., 2018). This thesis's qualitative data identified that while family and friends provided support, long-term health care providers also developed trusted relationships that positively contributed to patient recovery. The patient-therapist

relationship was explored in another study that included individuals with a BPI diagnosis; it found patients felt this relationship assisted with their re-engagement in participation (Janssen et al., 2019). Patients in this investigation (Chapter 7), also expressed that they continued to feel less comfortable meeting new people, as they felt they needed to explain about what happened to their injured arm.

While it was not specifically raised in the patient interviews, it would be reasonable to believe that such self-conscious feelings may reduce one's willingness to attend social events or work in jobs where they will need to regularly meet new people – ultimately limiting patients' social participation (Rumsey et al., 2004; Thompson & Kent, 2001). Regardless, positive social support following injury has been linked to adjustment following injury, including management of persistent pain and increased rates of return to work (Prang et al., 2015; White et al., 2019). Such challenges to re-engagement in daily life need to be considered when working with this population.

The current investigations and broader BPI literature (Sachar et al., 2020) indicates that patients report potentially maladaptive coping strategies (e.g., denial, self-blame, withdrawal) post-injury. Other upper limb trauma research has also found that maladaptive reactions that impacted psychosocial adjustment are common post-injury (Schaffalitzky et al., 2010). The likelihood of patients post-BPI using potentially maladaptive coping strategies combined with a low level of engagement with mental health services requires a more considered and nuanced response from treating health professionals than is currently being provided. Adaptive coping styles have been an affective enabler of well-being in other chronic conditions following traumatic injury (i.e., spinal cord injury) (Mackay et al., 2011). Health care providers need to consider the availability of positive social

support for individuals following pan-BPI and the related impacts on coping, adjustment, and health outcomes.

An important environmental factor for the patients with pan-BPI who participated in the investigations that are included as part of this thesis is that they were all covered under the Victorian Transport Accident Commission (TAC) comprehensive insurance scheme (Transport Accident Commission, 2018). Patients reported positively on this, as it provided access to: transport assistance for the numerous and long-term medical appointments they attended, private therapy appointments that had increased frequency, return-to-work services, and psychological services (Brito et al., 2019). This is not to say that the patients *availed* themselves of all these services but being compensable recipients of TAC coverage provided them with access - via the TAC funding their care and recovery needs.

While patients reported positive feelings and gratitude for the support received from the TAC, prior studies have demonstrated poorer outcomes for compensable patients and those seeking compensation for some injuries - orthopaedic trauma (Gabbe et al., 2007), spinal surgery (Cheriyen et al., 2015), and traumatic brain injury (Paniak et al., 2002). A report on the impact of compensation on recovery suggests why this might be the case. In this report, the authors suggest that some compensable systems may encourage the over medicalisation of patients whilst also failing to address the psychosocial factors inherent post-injury (Frost & Sheppard, 2017). While the impact of compensation on outcomes post-injury was beyond the scope of this thesis, most participants recognised the benefits of having the TAC assistance with a loss of wages and being able to access to private health services. Exploration of the impact of compensable schemes and seeking compensation on outcomes following BPI therefore warrants further examination.

The final environmental factor to be discussed, linked to society and culture, are gender roles. The influence of gender roles and masculinity on health seeking behaviour is an area that has been overlooked in relation to BPI recovery. The broader literature on men's health and masculinity reports that men are less likely to self-refer, adhere to recommendations of health providers, and are less willing to ask questions or share concerns (Addis & Mahalik, 2003; Courtenay, 2003). Further consideration of the influence of a person's gender role on recovery following BPI is warranted as this population is predominately young males (Ciaramitaro et al., 2010; Yang et al., 2012).

Additionally, in Investigation 5 clinicians discussed that there are some characteristics and considerations when working with young men (e.g., easily frustrated, felt young men did not want to take advice from a young female therapist, etc.). Many survivors of traumatic injury have psychological distress that can last for decades (Vincent et al., 2015). Strategies recommended to assist with the psychological distress following traumatic injury include: peer support from others that have had similar experiences and teaching self-management strategies to patients to assist with coping and adjustment (Vincent et al., 2015).

Given that we know that individuals who sustain pan-BPI need years of engagement with the health care system and will likely benefit from physical and psychosocial health and well-being services, this is an under-investigated area in the BPI literature. In future studies the environmental aspects of health and recovery should not be overlooked when discussing or planning rehabilitation following injury.

9.5.3 Occupation-related Findings

Occupational therapy is based on the belief that humans are occupational beings and there is a relationship between engaging in meaningful occupations and one's health

and well-being (Braveman, 2016; Moll et al., 2015). Occupation as conceptualised in the CMOP-E (Townsend & Polatajko, 2007) is the interaction of person on environment and environment on person, and is classified as having three main purposes for the person: self-care, productivity, and leisure (Polatajko et al., 2013). Investigation 3 (Chapter Six) highlighted the breadth of impact pan-BPI has on occupations. According to the findings, areas of paid work (productivity), home duties (self-care), and exercise/ sport (leisure) were the most negatively impacted even years after the surgery and reconstructive surgery.

Given that this injury most often occurs in men of working age, the poor outcomes related to return to paid employment is both important and the most often discussed occupational outcome following BPI (Bengston et al., 2008; Dodakundi et al., 2013). Of the eight pan-BPI participants who took part in Investigation 4, only half returned to paid employment following injury, with participants reporting low levels of satisfaction with their participation in productive roles (Chapter 7). Return-to-work with significantly limited use of the affected limb limits opportunity for any job that has a physical or labour-intensive component. Anecdotally, return to sedentary or office-based work was more likely but on-the-whole required retraining for most. The issue of return-to-work following pan-BPI would benefit from further consideration of the adjustment required post-injury and the timing of interventions. Selecting and planning return to work requires working with the individuals to identify opportunities congruent with their self-concept and occupational identity which has likely been altered following their injury. That said, occupational identity for this cohort is explored in greater detail below under engagement.

While the current research has identified that patients with pan-BPI are engaging in occupations (Investigation 3), “having occupations is not the same as perform[ing]

occupations...and as occupational therapists we are concerned with engagement” in occupation which takes into account meaning and satisfaction (Polatajko et al., 2013, p. 24). The findings of Investigation 4 (Chapter 7) found that over half of the participants reported they were able to engage in roles and social relationships without difficulty. Salient factors associated with occupational engagement and performance are explored next.

9.5.4 Occupational Performance and Occupational Engagement-related Findings

The term *function* is frequently used synonymously with *occupation* in a recent review of hand therapy literature (Burley et al., 2018); however, the concept of *occupation* is central to the practice of occupational therapy. Using an occupation-focussed model to discuss activity, participation, engagement in occupations, and participation in daily life provides a detailed framework to explore these concepts to better understand function in daily life. The CMOP-E (Townsend & Polatajko, 2007) proposes that *occupational performance* is the product of the interaction of the person, their occupations, and their environment. Occupational performance and engagement are a multifaceted constructs that considers the act of involving one’s self in a meaningful way in daily life (Polatajko et al., 2013). Occupational performance and occupational engagement goes beyond just the act of doing an occupation and accounts for the subjective experience of individuals as well as their objective ability to engage (Polatajko et al., 2013). This mixed methods thesis provides an original contribution to the literature and a deeper understanding of objective (quantitative) and subjective (qualitative) outcomes related to occupational performance (activities) and engagement (identity and loss) following pan-BPI. The finding suggest that satisfaction and meaning is found in some areas (e.g., close personal relationships), but lacking in others (e.g., employment).

9.5.4.1 Occupational Performance. The CMOP-E uses the Taxonomic Code for Occupational Performance (TCOP) to provide a hierarchy of terms by which to consider the domain of occupational performance (Polatajko et al., 2004). The TCOP consists of *occupations* that are composed of *activities*, which are composed of *tasks*, which are composed of *actions* which are in turn composed of *voluntary movement or mental processes* (Polatajko et al., 2004). These concepts are the foundations of occupational performance. While this may seem like semantics at first glance, the terminology in the TCOP provides terms and definitions that clearly delineate the components of concepts that are often referred to as function or functioning in the BPI literature. The term function has been reported in the BPI literature in relation to range of movement (Bengston et al., 2008; Dy et al., 2015; Kitajima et al., 2006), activities (Kretschmer et al., 2009) and quality of life (Ahmed-Labib et al., 2007). This hierarchy of terms allows the more precise consideration of activity-based outcomes following pan-BPI.

Investigation 2 (Chapter 5) provided insight into patients' occupational performance by reporting on activity-related outcomes that included data related to *voluntary movements, actions, tasks, and activities*. Specifically, voluntary movement, as conceptualised by the TCOP, was assessed using active range of movement and strength measurements. Using the TCOP classification system, the items in the two activity measures applied in Investigation 2 can be classified as *voluntary movements, tasks, or activities*. In particular, some of the Brachial Assessment Tool items (BrAT; Hill et al., 2016) measure *voluntary movements* (Subscale 3 – e.g., stabilise an object) with the remaining BrAT items more aligned with the concept of *tasks* (Subscales 1 & 2 – e.g., turn on a light switch, wash your armpit, do up shirt buttons, etc.). The Disability of Shoulder, Arm, and Hand (DASH; Hudak et al., 1996) also has multiple TCOP levels assessed with some items assessing *tasks*

(e.g., tie up shoelaces, turn a key, push open a heavy door) and some items assessing *activities* (do yard work, sexual activities, etc.).

The evidence from the qualitative investigation with patients found that the injured arm will only ever be a *helper arm* following pan-BPI (Brito et al., 2019). What the helper arm can assist with in daily life is better detailed in the outcomes of Investigation 2 (Chapter 5).

Specifically, participants reported that while fine motor is not restored to the hand the arm is capable of voluntary movement patterns including:

- stabilising objects,
- carrying items hooked over the forearm,
- carrying object under their arm (between the thoracic wall and the upper arm through shoulder adduction), and
- carrying items by placing the handle across their fingers (in a gross grasp - hook grip).

However, it was also clear that participants were unable to do most task items including those used for the activity of dressing (BrAT Subscale 1) and other self-care activities such as eating or washing your face with their affected arm (BrAT Subscale 2). Reported ability to complete tasks included in the DASH (Hudak et al., 1996) were often rated substantially different than responses on the BrAT.

The exploratory investigation (Chapter 5) completed as part of this thesis indicates that while the BrAT (Hill et al., 2016) specifically measures the use of the injured arm in daily tasks, while the DASH (Hudak et al., 1996) provides a broader perspective of recovery that may also measure compensation and use of the uninjured arm to complete daily activities. This more nuanced understanding of what is being measured (using the reconstructed arm for tasks versus being able to complete tasks or activities in daily life by

any means regardless of the ability to use the affected limb) is an important clinical finding and represents an original contribution to the broader BPI literature.

9.5.4.2 Occupational Engagement. Using the TCOP assisted with the consideration of the activity-related findings of this thesis and their impact on occupational performance. This section will now consider the findings of this thesis in relationship to the concept of occupational engagement. Where occupational performance focuses more on the objective elements of occupation, occupational engagement considers the subjective experience of occupations, considering how self-identity, motivation, and meaning impact individuals' engagement in occupations (Polatajko et al., 2013). One study that considered engagement following spinal cord injury found that individuals prioritised social activities, life opportunities, accomplishments, and interpersonal relationships as most important (Viemerö & Krause, 1998). The occupational engagement areas of social activities and relationships overlapped some with this populations' areas of most satisfaction: family relationships, going out, and day trips/ outdoor activities (Chapter 6). Both the performance and the subjective experience of engaging in the occupations are other areas that are not accounted for in the ICF (Ennals & Fossey, 2017; Hemmingsson & Jonsson, 2005).

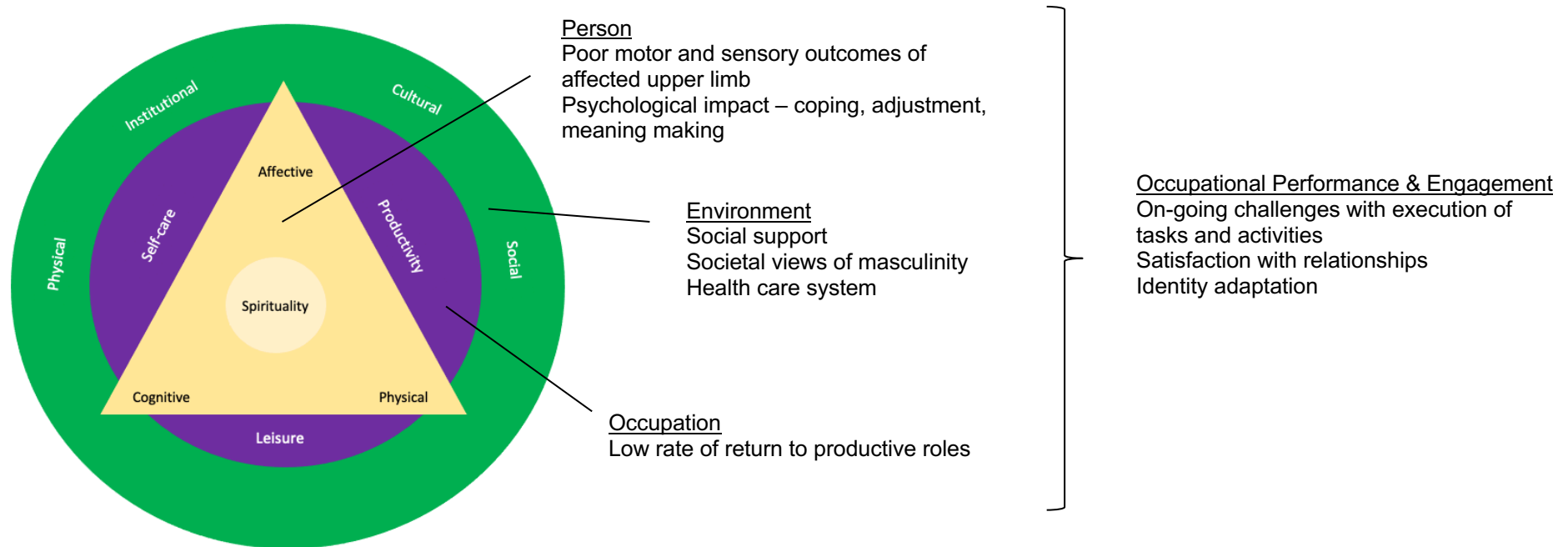
By comparison, occupational therapy utilises a client-centred philosophy and concepts of identity and these concepts are accounted for in CMOP-E (Townsend & Polatajko, 2007) in the domain of occupational performance & engagement. Identity has also been explored occupationally and is defined as how an individual “sees self in various occupational roles [and] has an image of the kind of life desired” (Kielhofner et al., 2001, p. 261). Findings from Investigations 4 and 5 (Chapters 7 & 8) also identified the process of adaptation and adjustment following injury, as well as an association with being able to

create a new identity. The concepts of self-identity, motivation, and meaning have been explored predominately in in Investigation 4 and 5, but to more fully understand their impact on occupational engagement following BPI further research is recommended.

Following pan-BPI, the severity of injury to the affected arm impairs patients' return to many pre-injury occupations. This impact is more acutely relevant to pan-BPI, as other BPI diagnoses have a greater likelihood of recovering arm function that allows them to return to pre-injury occupations. Therefore, individuals who sustain a pan-BPI are more likely to experience occupational loss. Occupational loss represents an "imposed, unanticipated transition" (Polatajko et al., 2007, p. 57), as such loss impacts individual's daily routines and occupations, what they can do, with whom they interact and the meaning of their occupations. This in turn can and often does negatively impact their health and well-being (Polatajko et al., 2007). Investigation 4 and 5 provided a deeper understanding of this change and loss. In these investigations, patients and health care providers highlighting the loss of occupation following injury and the process of creating a new concept of self and occupational identity that is needed to achieve re-engagement. A summary of key points from this thesis as applied to the CMOP-E are contained in Figure 5.

Figure 5

Pan-BPI Factors Applied to the CMOP-E Model (Townsend & Polatajko, 2007)



Note. Reproduced with permission (Appendix A, p.268).

9.6 Applying an Occupation-focussed Approach

Further exploration of occupational adaptation and occupational engagement in daily life following injury is needed and occupational therapists are well positioned to both measure and interpret participation and occupation-related data (Kielhofner et al., 2001). The CMOP-E provides a valuable framework to consider health and well-being from an occupationally-focussed perspective following pan-BPI as it includes the following aspects – it is client-centred, considers personal and environmental resources, and is enablement-focussed (Townsend & Polatajko, 2007). Whilst advances in surgical procedures are targeted at improving physical outcomes, self-perceived disability and well-being need to be assessing outcomes are meaningful to patients (i.e., participation in patient-valued occupations) (Dijkers, 1999; Schulz & Decker, 1985; Whiteneck et al., 1992).

While the increased adoption of biopsychosocial models (e.g., ICF Framework) has incorporated concepts such as activities and participation as domains relevant to health and well-being, occupational science provides a corpus of knowledge of definitions, concepts, and theories that are more nuanced consider the impact of participation and develop appropriate interventions (Whiteford & Hocking, 2012). As such the concepts of participation and engagement in meaningful occupations are central to occupational therapy practice (Rudman & Aldrich, 2017). Although the science of occupation is relatively new and requires further development, it provides a framework for deepening the understanding of engagement in activities and participation in relation to achieving and maintaining good health and well-being.

More recently, the therapy literature has also acknowledged an over-emphasis on the application of a biomechanical frame of reference over an occupational perspective by

occupational therapists working in upper limb rehabilitation (Burley et al., 2018; Robinson et al., 2016). A biomechanical frame of reference is a bottom-up approach that in hand therapy leads to a clinical focus on issues such as range of motion, physical modalities (i.e., massage and joint mobilisations), splinting, and exercises (Burley et al., 2018). Comparatively, an occupational perspective, central to occupational therapy, is a top-down approach that proposes that individuals engage in occupations and that engagement, in turn, impacts and informs their health and well-being (Kielhofner, 2009).

The existing BPI literature is primarily surgical and reports on biomechanical data (e.g., movement, strength, or sensation) (Maldonado et al., 2016; Yi Lee et al., 2019), with some psychological measures also having been applied (Landers et al., 2018; Wilson et al., 2016). Therefore, it is not surprising that there is a gap in the BPI literature appraising what physical gains *mean* in the patients' everyday lives. Insights on what is meaningful in the disability literature has noted that it is psychosocial function, not physiological functioning, that influences self-perceptions of disability (Eberhardt et al., 1993).

Occupational therapists are well positioned to deliver biopsychosocially-grounded treatment to support and enhance outcomes following pan-BPI given their training and involvement in both physical and mental health (Occupational Therapy Australia, 2021). Occupational therapists are trained to deliver occupation-focussed interventions through client-centred practice (Ripat, 2017) and to cultivate strong therapeutic relationships with their patients (Cole & McLean, 2003). A therapeutic relationship “is a trusting connection with rapport established between therapist and client through collaboration, communication, therapist empathy and mutual understanding and respect” (Cole & McLean, 2003, p. 44). It is through this therapeutic process that therapists understand the client's world, collaborate with them, and set occupationally-focussed goals (Price & Miner,

2007). In the research included in this thesis, patients (Chapter 7) and the therapists (Chapter 8) identified and valued client-centred goals and strong, client-therapist partnerships. While research on client-centred practice in outpatient mental health care units found that strong therapeutic relationships were linked to better rehabilitation outcomes (Gunnarsson & Eklund, 2009), there is a dearth of research in relation to post-BPI care.

9.7 Chapter Summary

The findings of this thesis represent both an original contribution to the research and significant findings for clinical practice. Individuals with pan-brachial plexus injuries experience high levels of disability (Ahmed-Labib et al., 2007; Novak et al., 2011) that significantly changes their participation and engagement in life roles. This change in participation is the result of a range of the interactions among multiple factors as discussed above, and can be appropriately understood by applying occupational therapy practice models such as the CMOP-E (Townsend & Polatajko, 2007). This current, in-depth, exploratory study determined that pan-BPI patients require a holistic, long-term treatment plan consistent with the severity and permanence of their disability. Participation across the lifespan is impacted following BPI including involvement in valued occupations (e.g., employment, exercising/ sport, home duties) and meaningful roles (e.g., parenting, volunteering, and intimate relationships). The next section will relate these findings to clinical practice and contains the conclusion of this thesis.

Chapter 10 - Translation to Practice, Future Research, & Conclusion

10.1 Chapter Introduction

The preceding chapter included an integrated discussion of the investigations that make up this thesis, their findings. It outlined a more complex and nuanced understanding of life post pan-BPI through the application of an occupationally-focussed model to better understand activity and participation outcomes. This chapter continues the discussion of findings as they apply to practice with patients following pan-BPI. In doing so, this chapter discusses the use of the Recovery Model (Repper & Perkins, 2003) as an alternative way of planning health care following FFMT for pan-BPI patients in order to achieve social inclusion, and maximise health, and well-being outcomes. The chapter will then outline the strengths and limitations of this thesis, make recommendations for further research, and provide some concluding remarks.

This thesis aimed to better understand the long-term outcomes for individuals following FFMT for pan-BPI patients in Australia. Assessment measures were chosen based on the measures identified in this thesis's scoping review using a biopsychosocial frame of reference (World Health Organization, 2001) to gather relevant outcomes that represent the breadth of domains linked to health and well-being. The overall findings demonstrate that life post FFMT is complex and challenging with the impact of injury still present even at long-term follow up. This thesis provided an original contribution to the literature by reporting on a comprehensive view of outcomes following pan-BPI including the psychosocial outcome of participation. It has considered the data collected alongside the findings in the literature as well as providing insight into patient and health care providers' perspectives of recovery and outcomes following BPI.

The reporting of this more comprehensive view of life and care post-BPI from both patient and health care provider perspectives, provides a much-needed understanding of the recovery process and the contribution to daily life that FFMT reconstructive surgery and subsequent rehabilitation can provide for this sub-population (pan-BPI patients). It also provides new insight into what daily activities a patient can do with the reconstructed arm. The findings from this thesis will now be considered in relation to practice with emphasis on re-framing the approach taken from one that focuses on rehabilitation to one that focuses on recovery.

10.2 Translation to Practice

The literature reports the exceptionally high median cost of BPI – US\$34,544/ annum (medical, surgical, and therapy costs in the first year of injury) (Felici et al., 2014; Wali et al., 2017) and an estimated lifetime cost of US\$840,539 per patient (including wage loss and disability payments) (Hong et al., 2019). The research undertaken in this thesis found that patients face significant consequences following pan-BPI, emphasising why this diagnosis deserves broader consideration of outcomes beyond simply biomechanical ones. Investigation 1, the scoping review, identified that some studies are beginning to measure psychosocial factors following FFMT reconstructive surgery for management of BPI, including quality-of-life measures, cosmesis, psychological, and activity outcomes. Analysis of these results from the existing literature remains fragmented, though.

While it is commendable that previous studies gathered data regarding a variety of outcomes that are commiserate with the profound impacts experienced following this type of severe injury, the lack of consistent employment of outcome measures, including study specific measures (e.g., single items generated by the researchers of the study), makes comparison among studies impossible. This is borne out by the fact that the scoping

review identified that nine different measures were applied across the 14 included studies. Health care providers working with this population need to work toward using common measures that are in-line with the set of core outcomes following traumatic BPI that are under development (Miller et al., 2019). Once a core outcome set is established (Miller et al., 2019), consideration will still need to be exercised as to how the findings from such studies are interpreted when used with the pan-BPI population. The primary reason for this consideration is that BPI is an umbrella diagnosis that includes a heterogeneous range of injury patterns. As such, while a core set of outcome measures will be helpful, further development may be required to ensure they are meaningful for different levels and severities of BPI lesions.

Clinicians and researchers need to consider the heterogeneity of the BPI population when reporting and considering outcome measures to allow for more equivalent comparison. While some studies can be identified that reported outcomes based on level or pattern of lesion (Bertelli & Ghizoni, 2011), many report all BPI lesions as a single population (Cole et al., 2020). This may be done due to the small number of BPIs seen in any one centre and reporting them together increases the sample size and therefore the ability to perform statistical analyses. However, this combining of all BPI injuries together is problematic, as the differing level of lesion results in variable patterns of motor impairment and expected long-term outcomes.

Clinically, an upper plexus injury (C5, C6 +/- C7) impacts the shoulder and elbow, lower plexus injuries (+/-C7, C8 & T1) – the wrist and hand, while pan-plexus injuries (C5-T1) results in global impairment of the shoulder, elbow and hand. When considering a patients' ability to complete activities of daily life, impairment of the proximal, distal or complete upper limb will have different impacts on an individual's ability. As such, further

exploration of patient cohorts by level and severity of injury is needed to better understand the nuances that exist among lesion patterns. This thesis has recognised this delineation and in doing so has narrowly targeted a specific diagnosis for deeper clinical understanding and application.

10.3 Reframing the Approach: From Rehabilitation to Recovery

The results of this thesis have practical implications for rehabilitation. For the patients who participated, FFMT reconstructive surgery was completed following pan-BPI to re-animate a flail upper limb, however, on-going physical impairment remained and impacted their participation and engagement in valued occupations. As discussed in Chapter 1 (pp. 5-6), the frameworks that are often used to guide therapy and improve patients' outcomes in completing activities and participating in meaningful occupations are biomedical and rehabilitative frames of reference (Pendleton & Schultz-Krohn, 2018). This approach is especially important following pan-BPI as individuals will have a permanent change in physical functioning and ability to use their arm in daily life (Chapter 5). Understanding that even with FFMT and other reconstructive surgeries an upper limb that has sustained a pan-BPI will only ever recover to the point where it will be a *helper arm* is a key point for health care providers to note when educating patients, setting realistic expectations, and goal setting.

This thesis reinforced the notion that patients need years to come to terms with consequences following pan-BPI - partly to do with the severity of the diagnosis and partly the years of ongoing reconstructive surgeries and therapy. The long period of adjustment needed to create a new self-identity needs to be considered when planning and delivering interventions for this population. Therefore, it is recommended an additional frame of reference be applied with individuals following pan-BPI. One approach that that would

assist in the delivery of direct care following pan-BPI is the Recovery Model (Repper & Perkins, 2003) approach. This model is traditionally used in mental health but is conceptually aligned with occupational therapy. The occupational therapist, Tina Champagne, summed up the alignment between occupational therapy and the recovery model as follows:

The practice of occupational therapy, like the recovery model, is based on the philosophy and evidence that individuals diagnosed with mental health conditions can and do recover and lead meaningful, satisfying, and productive lives. It is the profession's emphasis on a holistic approach to function, participation, and partnership that is used to help support people with mental illness to develop skills, engage in activities of interest, and meet individual recovery goals. (Champagne, 2016, p. 2).

The next section will consider how a recovery-informed approach and how it can be applied to the FFMT for pan-BPI population's health care delivery.

10.4 Recovery Approach

This thesis has identified objective and subjective challenges that are long-term consequences following pan-BPI. While pan-BPI is not a mental health diagnosis, there are shortcomings in reporting outcomes, with the literature predominately reporting on biomechanical outcomes. Biomechanical outcomes fail to adequately consider a number of salient factors including social context, psychological states, process of adjustment, and other relevant outcomes following injury. The recovery model uses a holistic approach to the individual and aims to restore health and well-being through developing a life with meaning and purpose, rather than just being cured (Repper & Perkins, 2003). It has been

predominately applied in mental health, but has been discussed for use in physical rehabilitation (Bennett et al., 2013).

This concept of not being cured, is consistent with the severe nature of pan-BPI and its impact on the affected upper limb. Recovery (Repper & Perkins, 2003) is based on concepts inherent in a strength-based approach to human health and well-being (Deegan, 1988) that actively uses an individual's strengths and resources to achieve their aspirations and desires. Additionally, the recovery model acknowledges that that recovery is not a linear process and the impacts of the illness (or in regard to BPI, the physical injury) remain and life is altered forever (Bennett et al., 2013).

Findings from this thesis can be applied to the Repper and Perkins (2003) Model of Recovery, which consists of three components: facilitating personal adaptation, promoting access and inclusion, and developing hope-inspiring relationships. These three components of the recovery model approach are not prescriptive, but instead are designed to be applied in a highly individual approach in order to assist individuals to rebuild meaningful and valued lives (Repper & Perkins, 2003). These concepts support recommendations from this current research regarding client-centred care for patients with pan-BPI.

10.4.1 Facilitating Personal Adaptation

Facilitating personal adaptation is the first component of the Recovery Model (Repper & Perkins, 2003) and emphasises the importance of helping the individual to make sense of what is happening to them by understanding, accepting and taking back control of their life decisions. In the broader health literature, understanding one's illness / condition has been linked to less pain (Hanusch et al., 2014) and better adherence to therapy (Mosleh & Almalik, 2016). In the current digital climate it is not surprising that

multiple studies have found that patients with BPI use online sources to provide information about their injury, emotional aspects of BPI, and about treatment and recovery (Franzblau et al., 2015; Morris et al., 2016).

One BPI study indicated that while doctors were the primary source of information for individuals with BPI almost half completed their own online research, with some gaining information from online media sources (Franzblau et al., 2015). Participants in the research completed as part of this thesis reported a preference to receive condition-specific information and treatment from health care providers with specialist knowledge in BPI, including their hand therapists. Given that rehabilitation therapists have more frequent appointments with patients than most doctors or surgeons, they provide an ideal opportunity to both repeat information and to slowly deepen patients' understanding of BPI, its longer-term impacts and how to better manage their lives post-BPI.

Some individuals may require support to develop more adaptive coping strategies that empowers them to take control of their own recovery and facilitate personal adaptation (Repper & Perkins, 2003). In the current research, both individuals with pan-BPI (Chapter 7) and the therapists that work with them (Chapters 8) identified that maladaptive coping (e.g., social withdrawal, drug dependency, etc.) negatively impacts rehabilitation (e.g., poor attendance/ engagement in therapy). Active coping strategies following BPI that have been identified as beneficial (e.g., acceptance, active coping planning and emotional support) are similar to those employed following spinal cord injury (Franzblau & Chung, 2015). In a study by Franzblau and Chung (2015), it was determined that supportive therapeutic relationships between patient and therapist facilitated patients better utilising adaptive coping strategies. Identification of coping and adaptation as a key aspect of

recovery following BPI has also been identified more broadly following severe upper limb injury (Bates & Mason, 2014; Chan & Spencer, 2004).

The findings in this thesis indicate that transitioning from a physical, biomechanical frame of reference to a recovery and adaptation frame of reference is needed to better support improved patient outcomes. However, a deeper understanding of the relationship among body systems, participation, and real-world contexts following pan-BPI is still required.

10.4.2 Promoting Inclusion

The Recovery Model and occupational therapy both promote access and inclusion as a key component for individuals to engage in personally relevant and meaningful roles and occupations (Polatajko et al., 2013; Repper & Perkins, 2003). This aspect of the Recovery Model includes accessing resources (e.g., financial assistance, return-to-work supports), and maintaining and developing meaningful roles. The findings in this thesis indicate that both therapists and individuals with pan-BPI acknowledge the importance of adjustment and the need for adaptation following the injury and subsequent surgeries. Therapists also indicated the need to re-train individuals to use new patterns of movement, restored through surgery, in their day-to-day activities. For example, just because an individual with pan-BPI can now bend their elbow and lift weight following FFMT surgery, does not mean that they will use it to carry bags. Re-training and discussion around what the restored movement can assist with in day-to-day life is still required.

This thesis also found that while patients prioritised inclusion in their community, many do not return to productive roles. This has an impact on their self-image and represents an ongoing challenge. Despite the low rate of return to productive roles, patients identified that having roles and involvement in their community, including those

related to social roles with family members and friends, provided them with a sense of purpose and meaning. Studies have recommended that adaptation following hand injury be monitored by occupational therapists and that they offer intervention when required as adaptation does not always occur naturally as part of recovery (Bates & Mason, 2014; Chan & Spencer, 2004).

In the finding reported in this thesis, therapists reported that they prioritised interventions that were client-centred and restored engagement in daily life. This level of personalisation is enabled through trusting relationship with patients that is built over time. Patients, meanwhile, identified their on-going relationship and the unconditional positive regard – inherent in such relationships – as having contributed to improved adaptation and adjustment following pan-BPI and FFMT. This relationship was identified as important by patients with pan-BPI in the qualitative study of this thesis (Chapter 6) and needs to be considered more broadly when working with patients to plan both a return to work and leisure occupations.

10.4.3 Developing Hope-inspiring Relationships

The final component developing hope-inspiring relationships enables individuals to move forward in life. Health professionals, friends, and family need to be empathetic when providing support to patients with pan-BPI in order to provide a safe space for them to explore and accept their reality and experiences, tolerate uncertainty, problem solve, and to persevere (Repper & Perkins, 2003). The patients in the research contained in this thesis reported that their lives changed permanently and substantially regarding work, leisure, relationships, and sexuality following their injury. Some re-evaluated their relationships, with some ending and some changing (e.g., children they once looked after, were looking after them), and others deepening (Chapter 7). These patients underwent multiple surgeries and recovery periods, often for years following their injury. Each surgery

brings hope of improved functional outcomes, but gains are small, and the prolonged recovery commonly interferes with their daily life. Ultimately, adjustment takes time and an ability to both tolerate and navigate uncertainty.

Security and trust that allows for success and failure, without patients feeling bad about themselves, is essential during recovery (Green et al., 2008). Patients in the research noted that the continuity of care with their therapists across the years of injury, surgery, and rehabilitation created a strong therapeutic relationship that was acknowledged and valued. Continuity of care is “care over time by a single individual or team of health care professional and to effective and timely communication of health information” (Institute of Medicine, 1996, p. 43). The continuity of care offered to patients who participated in the current research may be unique given that all participants were insured by the same non-compensable insurance which funded their private hand therapy in a clinic specialising in BPI care. Given the value reported by patients in this study (e.g., trust, support, client-centred care), continuity in health care providers should be further explored and prioritised when possible.

While setting goals and hope were discussed in both the patients’ and therapists’ qualitative studies (Chapters 7 & 8), some caution needs to be considered. Hope is an important factor in the recovery model; however, individuals with pan-BPI also need to have a realistic expectation of what is possible post-BPI and come to understand they will have an on-going level of physical impairment. This is because unrealistic expectations of recovery and restoration have been found to negatively impact acceptance following severe BPI (Dy et al., 2020a; Franzblau & Chung, 2015). The second qualitative investigation with therapists noted very experienced therapists, who had been practicing for years and had years of BPI specific work experience, discuss the challenges of

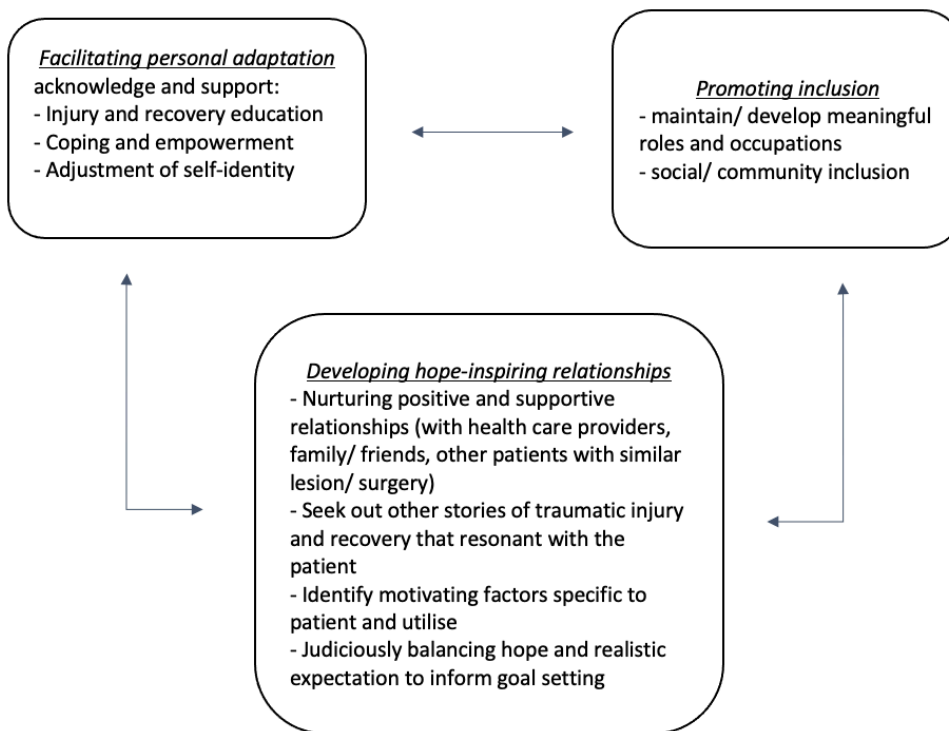
instilling hope for patients with severe-BPI when providing information for realistic expectations (Chapter 8). The therapists reflected there was a need to balance between honestly providing a pan-BPI prognosis whilst also creating space for the individual to see hope for the future (e.g., setting top-down goals related to returning to valued roles rather than focussing on range of motion or strength of the injured arm). This can be challenging but is easier with a thorough understanding of your patient and an ability to incorporate client-centred goals (i.e., adapting tasks to enable independent self-care, hobbies, driving, or playing with their children). This is arguably another benefit to having a strong therapeutic relationship built on trust and honesty to benefit recovery.

In summary, a combined approach that maximises surgical reconstruction techniques and enables patients to independently complete everyday activities of life through adaptation is required when working with individuals following pan-BPI. To best respond to this populations' needs for re-engagement and participating in valued daily occupations, psychosocial functioning and adaptation need to be considered and addressed. This can be done through application of an occupationally focussed perspective (Chapter 9, pp. 207-209) that aligns with a recovery perspective of functioning, health, and well-being (

Figure 6) When working with individuals following pan-BPI, it would therefore be beneficial for occupational therapists working in hand therapy to routinely work in conjunction with community health professionals (e.g., psychologists, pain clinics, general practitioners) and to further explore how a recovery framework can optimise client-focussed outcomes.

Figure 6

Components of the Recovery Model Applied to Pan-BPI Diagnosis



Note. Adapted from Repper & Perkins, 2003.

10.5 Limitations

This thesis has focussed on a very small and clinically complex population which limits the generalisability of the findings. While additional attempts were made to recruit additional participants, this did not yield any increase in numbers. However, the small sample size allowed for an in-depth, exploratory examination into the findings reported and is of similar sample size to other psychosocially-focussed BPI studies (Franzblau & Chung, 2015; Wellington, 2010). The cross-sectional nature of the research undertaken limits the ability to analyse and explore the gains and improvement achieved by patients over time. It also limits analysis to only reporting associations and does not provide evidence of causal relationships. While a longitudinal study would have been preferable, the very small

incidence rate of these injuries together with the long recovery period and time restraints with a doctoral program precluded such a design.

Another factor that limits generalisation is all pan-BPI patients in the current research were insured by the comprehensive, TAC insurance (Transport Accident Commission, 2018). It is unknown how similar or different the experience or outcomes are for those that are treated as public health or WorkCover insurance patients. Given some of the discussion by the therapists in the qualitative study, it seems that there are differences to access and frequency of therapy between compensable patients and public patients. Therefore it is recommended that further studies should be conducted to explore if and how funding for services relates to accessing services and ultimately outcomes.

10.6 Future Research

Future BPI-related health care literature needs to better explore outcomes beyond biomechanical for this diverse diagnosis (Dy et al., 2020a). This research should measure and continue to report on the psychosocial factors inherent in a BPI, as well on interventions, and outcomes both cross-sectionally and longitudinally. Additional research that reports pre- and post-operative data and outlines therapeutic interventions such as those in the Cole et al. (2020) study are needed to support the use of evidence-based interventions following BPI. Additional research will also provide health professionals with a greater understanding of what might be achievable for this population and will assist with providing better education, feedback, and goal setting. Future studies may also benefit from gathering additional data from patients' personal and work relationships (e.g., partner, family, friends, work colleagues, etc.) through completion of time-use diaries to better understand the impact on daily life, roles, habits, and routines.

Additional research is also required to gain better understanding of how the reconstructed arm can be used to assist with daily activities and participation. Such studies could start to create *arm use profiles* of various levels of injury (e.g., upper plexus, lower plexus and pan-plexus injuries) with corresponding outcomes. This information would assist treating health care providers and improve education and expectation setting for patients and their significant others. It would also inform health professionals of the expected adaptations and modifications necessary to complete activities of daily living.

Other conditions such as spinal cord injury (Noreau & Fougere, 2000; Sezer et al., 2015) and upper limb deficiency and amputation (Postema et al., 2016) have explored associated sequela such as musculoskeletal complaints and its impact on participation. Such outcomes remain poorly understood following BPI and requires further research. Long-term follow up studies (beyond the first 2 years), such as this thesis' results, are required to build on the preliminary findings contained in this thesis to improve understanding of the long-term, psychosocial outcomes for patients who have FFMT for management of pan-BPI.

10.7 Conclusions

Patients that undergo FFMT reconstructive surgery for management of pan-BPI have ongoing physical limitations of their affected upper limb and meaningful changes in their occupational engagement and participation. While surgical reconstruction improves upper limb ability, factors that positively influence patients' adjustment and recovery are poorly understood. Pan-BPI care should prioritise the development of a strong therapeutic alliance that fosters client-centred care in an environment that promotes normalisation and adjustment. Researchers and health care providers need to consider factors beyond physical recovery when working with individuals with pan-BPI to enable optimal recovery.

The ICF (World Health Organization, 2001) and occupational therapy practice models provide a theoretical basis for such care, that emphasises a holistic approach to health and well-being. Occupational therapists are trained in both physical and mental health practice and are well positioned to restore health and well-being by helping to facilitate reengagement with occupations and meaningful participation. Application of a recovery-focussed approach to treatment shifts the goal from a deficit-focussed, curative approach to a strengths-oriented approach that aims to return patients to meaningful lives that contributes to their communities.

Care and treatment interventions should consider working within a recovery model frame of reference to increase focus on psychosocial aspects following pan-BPI to restore optimal health and well-being. Treating therapists therefore have an important, needed, and meaningful role in aiding patient's adaptation and adjustment following injury. This thesis has provided an in-depth review of long-term psychosocial outcomes following pan-BPI, and identified the on-going impact experienced in daily life including reduced participation and involvement in valued daily roles and occupations.

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Appendices

Appendix A

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ICF Model Permission

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Permission to Reproduce the Free Functioning Muscle Transfer Anatomical Images



June 2, 2021

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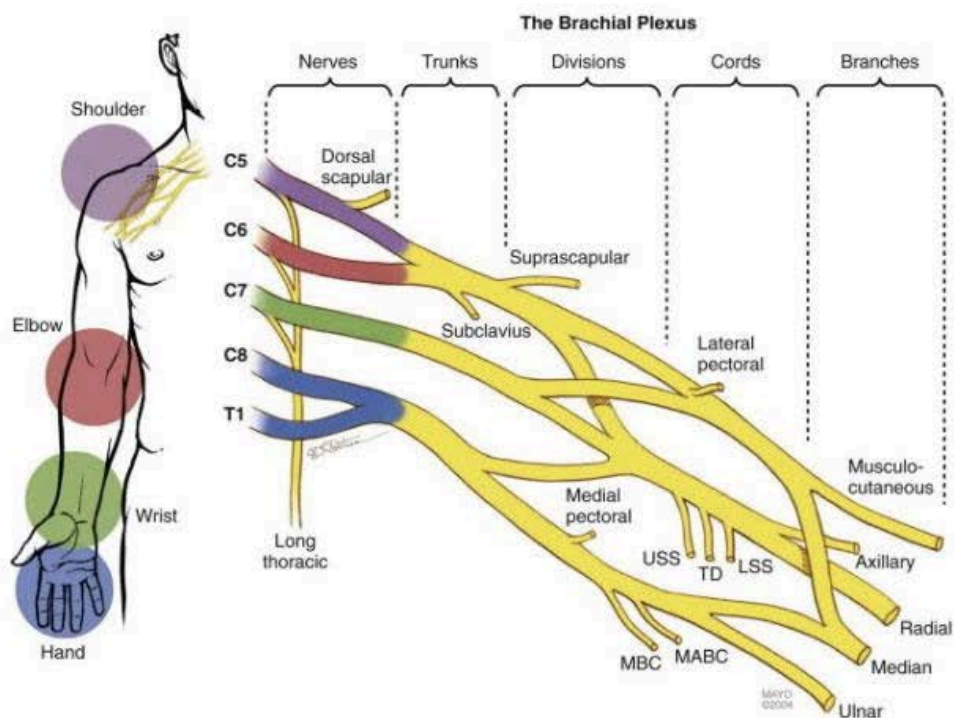
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Thursday, September 2, 2021 at 08:47:34 Australian Eastern Standard Time

Subject: Gracilis Clinical Briefing Art
Date: Friday, 13 March 2020 at 1:09:33 am Australian Eastern Daylight Time
From: Baker, Mark
To: Sara Brito
Attachments: Gracilis Art.jpg

Sara,

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Thank you,

Mark Baker
Senior Medical Writer
Penn Medicine Web Group
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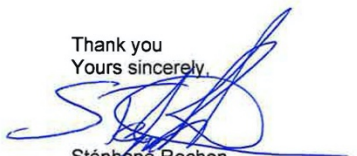
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Appendix B

Ethics Approval for Investigations 1-4



Monash University Human Research Ethics Committee

Approval Certificate

This is to certify that the project below was considered by the Monash University Human Research Ethics Committee. The Committee was satisfied that the proposal meets the requirements of the *National Statement on Ethical Conduct in Human Research* and has granted approval.

Project Number: 0392

Project Title: Outcomes of free flap muscle transfer following brachial plexus injury: Impacts on clients' daily participation

Chief Investigator: Dr Nikos Thomacos

Expiry Date: 28/10/2021

Terms of approval - failure to comply with the terms below is in breach of your approval and the *Australian Code for the Responsible Conduct of Research*.

1. The Chief Investigator is responsible for ensuring that permission letters are obtained, if relevant, before any data can occur at the specified organisation.
2. Approval is only valid whilst you hold a position at Monash University.
3. It is responsibility of the Chief Investigator to ensure that all investigators are aware of the terms of approval and to ensure the project is conducted as approved by MUHREC.
4. You should notify MUHREC immediately of any serious or unexpected adverse effects on participants or unforeseen events affecting the ethical acceptability of the project.
5. The Explanatory Statement must be on Monash letterhead and the Monash University complaints clause must include your project number.
6. Amendments to approved projects including changes to personnel must not commence without written approval from MUHREC.
7. Annual Report - continued approval of this project is dependent on the submission of an Annual Report.
8. Final Report - should be provided at the conclusion of the project. MUHREC should be notified if the project is discontinued before the expected completion date.
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Thank you for your assistance.

Professor Nip Thomson

Chair, MUHREC

Ethics Approval for Investigation 5



Monash University Human Research Ethics Committee

Approval Certificate

This is to certify that the project below was considered by the Monash University Human Research Ethics Committee. The Committee was satisfied that the proposal meets the requirements of the *National Statement on Ethical Conduct in Human Research* and has granted approval.

Project ID: 12210
Project Title: Outcomes following traumatic brachial plexus injury: Health professionals' perspectives
Chief Investigator: Dr Nikos Thomacos
Approval Date: 01/05/2019
Expiry Date: 01/05/2024

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Kind Regards,

Professor Nip Thomson

Chair, MUHREC

CC: Mrs Sara Brito, Assoc Professor Ted Brown, Ms Bridget Hill

List of approved documents:

Document Type	File Name	Date	Version
Focus Group questions	investigation 5 focus grp questions	24/03/2019	v1
Consent Form	Participant consent form v2	03/04/2019	2
Supporting Documentation	Therapist Email Invite	03/04/2019	2
Explanatory Statement	Part expl statement health prof focus grp v2	26/04/2019	3

Appendix C

Scoping Review Search Strategy

Below is the initial search undertaken in OvidMedline to review existing journal articles written on the topic of post-operative care following traumatic brachial plexus injury. Looking narrowly for journal articles about individuals who have had a TBPI to all nerves innervated from C5-T1 and subsequent FFMT produced a small number of journal articles. The search strategy was widened to gather a broader set of journal articles relating to the topic of traumatic brachial plexus injury, therapy, rehabilitation and outcomes. The initial search was conducted using the following search terms (Figure A.1, Figure A.2, Figure A.3, and Figure A.4).

Key words outlined below were run in OvidMedline and Scopus. OvidMedline found 1846 articles and Scopus 2871. The same search terms found 492 articles in CINAHL. The only exclusion parameters were that the article be in English and published after 1994. These three lists were then compared for duplicates that found 1174 duplicate journal articles to remove leaving 4036 articles. Systematic review of these articles is recommended in the future; however, for the purpose of literature review it was not conducted. Additional referenced articles were found using in-text citation and hand searching.

Figure A.1

Boolean Search Strategy for Investigation 1: Scoping Review

Brachial plexus/ or brachial plexus injury.mp or	and	Reconstructive surgical procedures/ or surgical flaps/ or free tissue	and	Pan plexus or flail limb or complete	and	Rehabilitation or “physical and rehabilitation medicine” or
--	-----	---	-----	--	-----	---

brachial	flaps or free	injury or	rehabilitation
plexus	flap muscle	full injury	or post-
neuropathies	transfer.mp. or	or trauma	operative
	free		treatment or
	functioning		physical
	muscle		therapy
	transfer		modalities/ or
			physical
			therapy or
			physiotherapy
			or
			occupational
			therapy

Figure A.2

CINAHL Search Strategy for Investigation 1: Scoping Review

"brachial plexus" OR "brachial plexus neuropathies"
 OR
 free muscle transfer OR free flap muscle transfer OR FFMT
 AND
 physical therapy modalities OR recovery W2 function
 OR
 "outcome assessment" OR "patient satisfaction" OR "quality of life"
 OR
 treatment W2 outcom* OR "postoperative care" OR rehabilitat*
 OR
 physiotherap* OR "occupational therapy*" OR "hand therap*"

Figure A.3

Scopus Database Search Strategy for Investigation 1: Scoping Review

☐ (((TITLE-ABS-KEY (**physical therapy modalities**) AND PUBYEAR > **1994**) OR (TITLE-ABS-KEY (**rehabilitat***) AND PUBYEAR > **1994**) OR (TITLE-ABS-KEY (**postoperative care**) AND PUBYEAR > **1994**) OR (TITLE-ABS-KEY (**postoperative treatment**) AND PUBYEAR > **1994**) OR (TITLE-ABS-KEY (**physiotherap***) AND PUBYEAR > **1994**) OR (TITLE-ABS-KEY (**occupational therap***) AND PUBYEAR > **1994**) OR (TITLE-ABS-KEY (**treatment outcome**) AND PUBYEAR > **1994**)) AND ((TITLE-ABS-KEY (**outcome assessment***) AND PUBYEAR > **1994**) OR (TITLE-ABS-KEY (**patient satisfaction**) AND PUBYEAR > **1994**) OR (TITLE-ABS-KEY (**quality of life**) AND PUBYEAR > **1994**) OR (TITLE-ABS-KEY (**recovery w/2 function**) AND PUBYEAR > **1994**) OR (TITLE-ABS-KEY (**treatment w/2 outcome***) AND PUBYEAR > **1994**) OR (TITLE-ABS-KEY (**hand therap***) AND PUBYEAR > **1994**))) AND ((TITLE-ABS-KEY (**brachial plexus**) AND PUBYEAR > **1994**) OR (TITLE-ABS-KEY (**brachial plexus neuropath***) AND PUBYEAR > **1994**) OR (TITLE-ABS-KEY (**free muscle transfer**) AND PUBYEAR > **1994**) OR (TITLE-ABS-KEY (**ffmt**) AND PUBYEAR > **1994**) OR (TITLE-ABS-KEY (**free flap muscle transfer**) AND PUBYEAR > **1994**)))

20 May 2015 2,871

Figure A.4

OvidMedline Database Search Strategy for Investigation 1: Scoping Review

<input type="checkbox"/>	# ▲	Searches	Results	Search Type	Actions
<input type="checkbox"/>	1	exp physical therapy modalities/ or exp rehabilitation/	247978	Advanced	Display More »
<input type="checkbox"/>	2	rehabilitat*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]	121402	Advanced	Display Delete More »
<input type="checkbox"/>	3	Postoperative Care/	52862	Advanced	Display More »
<input type="checkbox"/>	4	(postoperative adj (care or treatment)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]	57550	Advanced	Display Delete Save More »
<input type="checkbox"/>	5	(post operative adj (care or treatment)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]	937	Advanced	Display Delete Save More »
<input type="checkbox"/>	6	(physiotherap* or physical therap*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]	45980	Advanced	Display Delete More »
<input type="checkbox"/>	7	Occupational Therapy/	10541	Advanced	Display More »
<input type="checkbox"/>	8	occupational therap*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]	13314	Advanced	Display Delete More »
<input type="checkbox"/>	9	exp Treatment Outcome/	701341	Advanced	Display More »

<input type="checkbox"/>	10	"Outcome Assessment (Health Care)"/	51662	Advanced	Display More »
<input type="checkbox"/>	11	Patient Satisfaction/	61654	Advanced	Display More »
<input type="checkbox"/>	12	quality of life.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]	194317	Advanced	Display Delete More »
<input type="checkbox"/>	13	(recovery adj2 function*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]	47263	Advanced	Display Delete More »
<input type="checkbox"/>	14	(treatment adj2 outcome*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]	699964	Advanced	Display Delete More »
<input type="checkbox"/>	15	hand therap*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]	503	Advanced	Display Delete More »
<input type="checkbox"/>	16	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15	1297677	Advanced	Display More »
<input type="checkbox"/>	17	Brachial Plexus/	7490	Advanced	Display More »
<input type="checkbox"/>	18	exp Brachial Plexus Neuropathies/	2885	Advanced	Display More »
<input type="checkbox"/>	19	brachial plexus.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]	11453	Advanced	Display Delete More »
<input type="checkbox"/>	20	free muscle transfer*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]	208	Advanced	Display Delete More »
<input type="checkbox"/>	21	FFMT.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]	20	Advanced	Display Delete More »
<input type="checkbox"/>	22	free flap muscle transfer*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]	0	Advanced	Delete Save More »
<input type="checkbox"/>	23	17 or 18 or 19 or 20 or 21 or 22	11621	Advanced	Display More »
<input type="checkbox"/>	24	16 and 23	2247	Advanced	Display More »
<input type="checkbox"/>	25	limit 24 to yr="1995 -Current"	1847	Advanced	Display More »

Combine selections with:

Appendix D

Recruitment Documents Sent to Private Practice Patients

Participant Email Sent to Private Clinic Patients for Recruitment



Correspondence: PO Box 2320 Hawthorn VIC 3122
Telephone: 1300 99 66 90 Fax: 1300 99 66 60

Survey No: _____

28 June 2021

Dear ,

I am writing today to tell you about a study being conducted at Monash University. As a care provider, I am involved in treating my patients and promoting research in order to understand and find better ways to treat medical conditions.

I am not a member of the research team, however, I am contacting some of my patients to let them know about the research in case they might be interested in learning more.

It is important to know that this letter is not to tell you to join this study. It is your decision. Your participation is voluntary. Whether or not you participate in this study will have no effect on your relationship with Re-Wired Hand Therapy as a patient.

If you are interested in learning more about this study, please review the enclosed information from Sara Brito. You can contact Sara via email at Sara.Brito@monash.edu or phone on 03 9904 4412.

Or if you wish to take part, you can complete the Consent Form and attached survey. When you have completed both please return via post using the postage-paid envelope enclosed.

Or if you would prefer, you can complete both online at:
<https://goo.gl/forms/CxKAtU3X13cgsqfN2>

You do not have to respond if you are not interested in this study. If you do not respond, you may receive a follow up call just to confirm if you are or are not interested in taking part.

Thank you for your time and consideration. We look forward to hearing from you.

Sincerely,

Melanie McCulloch
Occupational Therapist
Full member AHTA

Enclosed:
Participant Explanatory Statement
Consent Form

St Francis Building Level 5, 166 Gipps Street East Melbourne 3002	Berwick Specialists Suites Suite 2, Level 1, 50 Kangan Drv Berwick 3806	Sunbury Consulting Suite Suite 11, 33-35 Macedon Street Sunbury 3429	Waverley Plastic Surgery 169 Waverley Road (cnr Huntingdale Rd) Chadstone 3148
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Participant Information Statement Sent to Private Clinic Patients for Recruitment



MONASH University

Survey No: _____

PARTICIPANT INFORMATION STATEMENT (Quantitative Study- Part 2)

Project Title: Outcomes following traumatic brachial plexus injury: Impacts on client's daily participation'

Project Number: (Project number: 2016-0392-826)

Chief Research:

Dr Nikos Thomacos
Senior Lecturer
School of Primary Health Care
Faculty of Medicine, Nursing and Health Sciences
Monash University - Peninsula Campus
Phone: 03 9904-4873
Email: nikos.thomacos@monash.edu

Associate Researcher:

Associate Professor Ted Brown
Department of Occupational Therapy
School of Primary Health Care
Faculty of Medicine, Nursing and Health Sciences
Monash University - Peninsula Campus
Phone: 03 9904 4462
Email: ted.brown@monash.edu

Associate Researcher:

Ms Bridget Hill
Research Fellow.
Epworth Monash Rehabilitation Medicine Unit
Epworth Rehabilitation
Phone: 03 9426 8785
Email: Bridget.Hill@epworth.org.au

Student Researcher:

Ms Sara Brito
PhD Candidate
Department of Medicine, Nursing and
Health Sciences
Phone: 03 9904 4412
Email: sara.brito@monash.edu

You are invited to take part in this study. Please read this statement in full before deciding whether or not to participate in this research. If you would like further information regarding any aspect of this project, you are encouraged to contact one of the researchers above via the phone number or email address listed.

Why were you chosen for this research?

Your name was found following a database search conducted at Re-Wired Hand Therapy (which includes previous Resolve Hand Therapy clients). The search was based on diagnosis (traumatic, brachial plexus injury). A total of 50-100 people will be invited to participate in this project.

What does the research involve?

Investigation into the outcomes of traumatic brachial plexus injury is critical for patients and health care providers. The proposed research will provide an opportunity to report outcomes across broad measures of health including physical, mental and functional. The information gathered will add depth to how brachial plexus injuries affect your ability to participate fully in everyday life activities. It will also inform third parties such as insurance companies regarding the complexities of recovery following reconstructive surgery.

Procedures

The assessment will take approximately 30-60 minutes. You will be asked to complete a questionnaire designed to gain a better understanding of your mental health, satisfaction with outcomes, and participation in life roles.

Possible benefits and risks to participants

The aim of the research is to report on the outcomes for individuals following reconstructive surgery for traumatic brachial plexus injury in Australia, as well as to consider how the outcomes following surgery impact an individual's participation in life roles. Data gathered from this project will provide information for health care providers regarding outcomes following surgery.

There will be minimal risk to the participants. However, some of the survey questions may pose a risk of emotional discomfort. If this occurs, you are able to cease participation at any time.

Services on offer if adversely affected – if you feel very upset, the interviewer will stop the interview to ask you whether you would like to keep going. You can either stop or continue after a short break. If you continue to feel distressed after the interview is finished, you can either go to your own GP, or phone one of the following helplines:

1. Lifeline provides 24/7 crisis support at 13 11 14.
2. Beyond Blue at 1300 22 4636

Payment

No rewards or payments will be given for participation in the study.

Consenting to participate in the project and withdrawing from the research

You are invited to take part in this research project. You are under no obligation to participate.

The purpose of this Participant Information Statement is to explain to you as clearly as possible all the procedures involved in this research before you decide to take part in it. Please ensure you have read this information closely and ask any questions you have. You are free to discuss this project with family, friends or health care providers.

Your decision to participate or refrain from involvement in this research will have no impact on relationships or the care provided by your health care professionals.

After you have read and understood the Participant Information Statement, you can indicate your interest to take part by signing the enclosed Consent Form. When you sign and date the Consent Form you are indicating that you understand this information and are taking part of this research of your own free will. Please keep this Participant Information Statement for your records. You may request a copy of your signed consent form at any stage from one of the researchers listed at the top of this document.

If you change your mind, you may withdrawal from this project. You will need to inform one of the researchers that you wish to withdrawal.

Privacy, Confidentiality and Storage of Data

Data for this project will consist of physical measures taken as well as answers to questionnaires. These data will be stored for a period of seven years, after which time, they may be destroyed. Data will be stored for a minimum of 5 years.

Data from questionnaires will be gathered by an electronic survey provider (e.g. Google Surveys or Survey Monkey), but they will not have any of your personal details.

Individual participants will not be identifiable in any publication or presentation that may be submitted. If you give us your permission by signing the Consent Form, we plan to publish our finding in health care and medical journals. All information will be collated, analysed and reported on a group basis.

Use of data for other purposes

It is not anticipated at this time, but if there is a future use of data it will only be used for projects where ethics approval has been granted. Your privacy and confidentiality will again be ensured by using only aggregate, de-identified information will be used.

Results

As part of this research project, it is planned that a written summary will be written. Please contact the student researcher if you wish to receive a copy (contact details can be found at the top of this document).

Reimbursement

You will not be paid for any costs related to this project.

Invitation to participate in a second, interview-based study

You are also invited to participate in an interview as part of a second study. This will allow us to further examine the information collected in this study. You can indicate your willingness to participate by ticking the appropriate box in the accompanying, consent form.

Again, you are invited to take part in the second, interview-based study. You are under no obligation to participate – and you are free to participate in only this study should you so choose. Your decision to participate or refrain from involvement in this research will have no impact on relationships or the care provided by your health care professionals.

Should you choose to participate in the second, interview-based study, you will be forwarded additional information and another consent form.

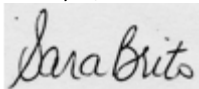
Complaints

Should you have any concerns or complaints about the conduct of the project, you are welcome to contact the Executive Officer, Monash University Human Research Ethics (MUHREC):

Executive Officer
Monash University Human Research Ethics Committee (MUHREC)
Room 111, Building 3e
Research Office
Monash University VIC 3800

Tel: +61 3 9905 2052 Email: muhrec@monash.edu Fax: +61 3 9905 3831

Thank you,

A handwritten signature in black ink that reads "Sara Brito". The signature is written in a cursive, flowing style.

Sara Brito, Nikos Thomacos, Ted Brown & Bridget Hill

Participant Consent Form Sent to Private Clinic Patients for Recruitment



MONASH University

CONSENT FORM

Project: Outcomes following free flap muscle transfer following traumatic brachial plexus injury: impacts on client's daily participation

Student Researcher: Sara Brito (Senior Occupational Therapist/ Hand Therapist)

I have been asked to take part in the Monash University research project specified above. Please read below and select 'yes' or 'no'.

	<u>Yes</u>	<u>No</u>
I have read and understood the participant information statement and I hereby consent to participate in this project	<input type="checkbox"/>	<input type="checkbox"/>
I consent to the following:		
Participating in a physical assessment to measure the movement, strength and sensation of my injured upper limb.	<input type="checkbox"/>	<input type="checkbox"/>
Completing questionnaires about my feelings and thoughts, as well as, engagement in social, vocational and leisure activity.	<input type="checkbox"/>	<input type="checkbox"/>
Data will always be reported in a way to protect my identity and personal details. My confidentiality will be maintained if this project is published or presented in any public form.	<input type="checkbox"/>	<input type="checkbox"/>
The data I provide during this research may be used in future research projects. The data will only be used with the same level of confidentiality as discussed in item above.	<input type="checkbox"/>	<input type="checkbox"/>
As part of this research project, we will also be conducting one-on-one interviews. They are expected to last approximately one hour. This will be an opportunity for participants to share their experiences in their own words. Please indicate 'yes' if you would like to be contacted to take part.	<input type="checkbox"/>	<input type="checkbox"/>

Name of Participant _____

Participant Signature _____ Date _____

Please contact me using the following information:

Telephone(s): _____

Best time and day to call: _____

Email: _____@_____

Appendix E

Recruitment Documents Sent to Clinicians for Distribution and Recruitment *Cover Letter Sent to Other Therapists to Assist with Recruitment of Patients*



MONASH University

Survey No: _____

28 June 2021

To whom it may concern:

I am writing today to tell you about a study being conducted at Monash University. As a health care provider and member of the research team, I am involved in both treating patients and promoting research in order to understand and find better ways to treat medical conditions.

I have asked other health care professionals to help me reach individuals that might be interested in learning more about or taking part in this study.

It is important to know that this letter is not to tell you to join this study. It is your decision. Your participation is voluntary. Whether or not you participate in this study will have no effect on the relationship between you and your health care providers.

If you are interested in learning more about this study, please review the enclosed information from Sara Brito. You can contact Sara via email at Sara.Brito@monash.edu or phone on 03 9904 4412.

Or if you wish to take part, you can complete the Consent Form and attached survey. When you have completed both please return via post using the postage-paid envelope enclosed.

Or if you would prefer, you can complete both online at:
<https://goo.gl/forms/CxKAtU3X13cgsqfN2>

You do not have to respond if you are not interested in this study.

Thank you for your time and consideration. We hope to hear from you.

Sincerely,

Sara Brito, Nikos Thomacos, Ted Brown, & Bridget Hill

Enclosed:

Participant Explanatory Statement
Consent Form
Questionnaire

Participant Information Statement Sent to Other Therapists to Assist with Recruitment



MONASH University

Survey No: _____

PARTICIPANT INFORMATION STATEMENT (Quantitative Study- Part 2)

Project Title: Outcomes following traumatic brachial plexus injury: Impacts on client's daily participation'

Project Number: (Project number: 2016-0392-826)

Chief Research:

Dr Nikos Thomacos
Senior Lecturer
School of Primary Health Care
Faculty of Medicine, Nursing and Health Sciences
Monash University - Peninsula Campus
Phone: 03 9904-4873
Email: nikos.thomacos@monash.edu

Associate Researcher:

Associate Professor Ted Brown
Department of Occupational Therapy
School of Primary Health Care
Faculty of Medicine, Nursing and Health Sciences
Monash University - Peninsula Campus
Phone: 03 9904 4462
Email: ted.brown@monash.edu

Associate Researcher:

Ms Bridget Hill
Research Fellow.
Epworth Monash Rehabilitation Medicine Unit
Epworth Rehabilitation
Phone: 03 9426 8785
Email: Bridget.Hill@epworth.org.au

Student Researcher:

Ms Sara Brito
PhD Candidate
Department of Medicine, Nursing and
Health Sciences
Phone: 03 9904 4412
Email: sara.brito@monash.edu

You are invited to take part in this study. Please read this statement in full before deciding whether or not to participate in this research. If you would like further information regarding any aspect of this project, you are encouraged to contact one of the researchers above via the phone number or email address listed.

Why were you chosen for this research?

You were identified by one of your health care providers as meeting the criteria for this research project including a diagnosis of a brachial plexus injury and having a subsequent surgery (free functioning muscle transfer). A total of 50-100 people will be invited to participate in this project.

What does the research involve?

Investigation into the outcomes of traumatic brachial plexus injury is critical for patients and health care providers. The proposed research will provide an opportunity to report outcomes across broad measures of health including physical, mental and functional. The information gathered will add depth to how brachial plexus injuries affect your ability to participate fully in everyday life activities. It will also inform third parties such as insurance companies regarding the complexities of recovery following reconstructive surgery.

Procedures

The assessment will take approximately 30-60 minutes. You will be asked to complete a questionnaire designed to gain a better understanding of your mental health, satisfaction with outcomes, and participation in life roles.

Possible benefits and risks to participants

The aim of the research is to report on the outcomes for individuals following reconstructive surgery for traumatic brachial plexus injury in Australia, as well as to consider how the outcomes following surgery impact an individual's participation in life roles. Data gathered from this project will provide information for health care providers regarding outcomes following surgery.

There will be minimal risk to the participants. However, some of the survey questions may pose a risk of emotional discomfort. If this occurs, you are able to cease participation at any time.

Services on offer if adversely affected – if you feel very upset, the interviewer will stop the interview to ask you whether you would like to keep going. You can either stop or continue after a short break. If you continue to feel distressed after the interview is finished, you can either go to your own GP, or phone one of the following helplines:

1. Lifeline provides 24/7 crisis support at 13 11 14.
2. Beyond Blue at 1300 22 4636

Payment

No rewards or payments will be given for participation in the study.

Consenting to participate in the project and withdrawing from the research

You are invited to take part in this research project. You are under no obligation to participate.

The purpose of this Participant Information Statement is to explain to you as clearly as possible all the procedures involved in this research before you decide to take part in it. Please ensure you have read this information closely and ask any questions you have. You are free to discuss this project with family, friends or health care providers.

Your decision to participate or refrain from involvement in this research will have no impact on relationships or the care provided by your health care professionals.

After you have read and understood the Participant Information Statement, you can indicate your interest to take part by signing the enclosed Consent Form. When you sign and date the Consent Form you are indicating that you understand this information and are taking part of this research of your own free will. Please keep this Participant Information Statement for your records. You may request a copy of your signed consent form at any stage from one of the researchers listed at the top of this document.

If you change your mind, you may withdrawal from this project. You will need to inform one of the researchers that you wish to withdrawal.

Privacy, Confidentiality and Storage of Data

Data for this project will consist of physical measures taken as well as answers to questionnaires. These data will be stored for a period of seven years, after which time, they may be destroyed. Data will be stored for a minimum of 5 years.

Data from questionnaires will be gathered by an electronic survey provider (Google Surveys), but they will not have any of your personal details.

Individual participants will not be identifiable in any publication or presentation that may be submitted. If you give us your permission by signing the Consent Form, we plan to publish our finding in health care and medical journals. All information will be collated, analysed and reported on a group basis.

Use of data for other purposes

It is not anticipated at this time, but if there is a future use of data it will only be used for projects where ethics approval has been granted. Your privacy and confidentiality will again be ensured by using only aggregate, de-identified information will be used.

Results

As part of this research project, it is planned that a written summary will be written. Please contact the student researcher if you wish to receive a copy (contact details can be found at the top of this document).

Reimbursement

You will not be paid for any costs related to this project.

Invitation to participate in a second, interview-based study

You are also invited to participate in an interview as part of a second study. This will allow us to further examine the information collected in this study. You can indicate your willingness to participate by ticking the appropriate box in the accompanying, consent form.

Again, you are invited to take part in the second, interview-based study. You are under no obligation to participate – and you are free to participate in only this study should you so choose. Your decision to participate or refrain from involvement in this research will have no impact on relationships or the care provided by your health care professionals.

Should you choose to participate in the second, interview-based study, you will be forwarded additional information and another consent form.

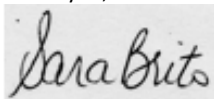
Complaints

Should you have any concerns or complaints about the conduct of the project, you are welcome to contact the Executive Officer, Monash University Human Research Ethics (MUHREC):

Executive Officer
Monash University Human Research Ethics Committee (MUHREC)
Room 111, Building 3e
Research Office
Monash University VIC 3800

Tel: +61 3 9905 2052 Email: muhrec@monash.edu Fax: +61 3 9905 3831

Thank you,



Sara Brito, Nikos Thomacos, Ted Brown, & Bridget Hill

Consent Form Sent to Other Therapists to Assist with Recruitment of Patients



MONASH University

Survey No: _____

CONSENT FORM

Project: **Outcomes following traumatic brachial plexus injury: impacts on client's daily participation**
(Project number: 2016-0392-826)

Principal Researcher: Dr Nikos Thomacos
Co-Researchers: A/Prof Ted Brown & Ms Bridget Hill
Student Researcher: Ms Sara Brito

I have been asked to take part in the Monash University research project specified above. Please read below and select 'yes' or 'no'.

	<u>Yes</u>	<u>No</u>
I have read and understood the participant information statement and I hereby consent to participate in this project.		
I understand that:		
- data will always be reported in a way to protect my identity and personal details. My confidentiality will be maintained if this project is published or presented in any public form.	<input type="checkbox"/>	<input type="checkbox"/>
- the data I provide during this research may be used in future research projects. The data will only be used with the same level of confidentiality as discussed in the item above.		
- I will be completing questionnaires about my feelings and thoughts, as well as, engagement in social, vocational and leisure activity.		

If you have chosen **not to participate**, you do not need to do anything else. Thank you for your consideration.

If you have answered '**yes**' to the above questions, and wish to participate in this study please complete your details below and sign. You may scan and email this form back to Sara.Brito@monash.edu or return via post to:

Attn: Ms Sara Brito
School of Primary and Allied Health Care
Peninsula Campus
Monash University
PO Box 527
Frankston, VIC 3199

You may scan and email this form and the completed questionnaire back to Sara.Brito@monash.edu.

Thank you for your time and consideration.

Appendix F

Critical Appraisal of the articles

The Joanna Briggs Institute (19): Critical Appraisal of case series

	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10
Addosooki et al. (22)	Y	U	U	U	U	Y	Y	Y	N	Y
Coulet et al. (26)	Y	U	U	U	N	Y	N	Y	N	Y
Dodakundi et al. (23)	Y	U	U	U	Y	Y	Y	Y	N	Y
Elzinga et al. (35)	Y	U	U	Y	Y	Y	U	Y	Y	N/A
Estrella et al. (27)	Y	U	U	Y	Y	Y	Y	Y	N	Y
Gillis et al. (30)	Y	U	U	Y	N	Y	Y	Y	N	Y
Kitajima et al. (24)	U	U	U	U	U	Y	Y	Y	Y	Y
Maldonado (31)	Y	U	U	Y	U	Y	Y	Y	N	Y
Maldonado (32)	Y	Y	U	Y	Y	Y	Y	Y	N	Y
Potter & Ferris (33)	Y	Y	Y	Y	U	Y	Y	Y	N	Y
Satbhai et al. (25)	Y	Y	Y	U	Y	Y	Y	Y	N	Y
Yang et al. (34)	Y	Y	Y	U	Y	Y	Y	Y	N	Y

Note:

N/A= not applicable; N=no; Y= yes; U=unclear

Q1= Were there clear criteria for inclusion in the case series?

Q2= Was the condition measured in a standard, reliable way for all participants included in the case series?

Q3= Were valid methods used for identification of the condition for all participants included in the case series?

Q4= Did the case series have consecutive inclusion of participants?

Q5= Did the case series have complete inclusion of participants?

Q6= Was there clear reporting of the demographics of the participants in the study?

Q7= Was there clear reporting of clinical information of the participants?

Q8= Were the outcomes or follow up results of cases clearly reported?

Q9= Was there clear reporting of the presenting site(s)/ Clinic(s) demographic information?

Q10= Was statistical analysis appropriate?

Mixed methods

		Franzblau et al. (2014)	Franzblau & Chung (2015)
Methodological quality criteria		Responses Comments	Responses Comments
Screening questions	Are there clear qualitative and quantitative research questions (or objectives*), or a clear mixed methods question (or objective)?	Y	Y
	Do the collected data allow address of the research question (objective)? E.g. consider whether the follow-up period is long enough for the outcome to occur (for longitudinal studies or study components)	Y	Y
	<i>Further appraisal may be not feasible or appropriate when the answer is</i>		
	<i>'No' or Can't tell' to one or both screening questions.</i>		
Qualitative	1.1 Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question (objective)?	Y	Y
	1.2 Is the process for analysing qualitative data relevant to address the research question (objective)?	Y	Y
	1.3 Is appropriate consideration given to how findings relate to the context, e.g. the setting, in which the data were collected?	N	Y
	1.4 Is appropriate consideration given to how finding relate to researchers' influence, e.g. through their interactions with participants?	Y	Y
Quantitative descriptive	4.1 Is the sampling strategy relevant to address the quantitative research question (quantitative aspect of the mixed methods question)?	Y	Y
	4.2 Is the sample representative of the population under study?	Y	Y
	4.3 Are measurements appropriate (clear origin, or validity known, or standard instrument)?	Y	Y

	4.4 Is there an acceptable response rate (60% or above)?	N	52%- clearly explained the other 48%	N	52%- clearly explained the other 48%
Mixed methods	5.1. Is the mixed methods research design relevant to address the qualitative and quantitative research questions (or objectives), or the qualitative and quantitative aspects of the mixed methods question (or objective)?	Y		Y	
	5.2. Is the integration of qualitative and quantitative data (or results*) relevant to address the research question (objective)?	N	Poor integration of qualitative and quantitative data.	Y	
	5.3. Is appropriate consideration given to the limitations associated with this integration, e.g. the divergence of qualitative and quantitative data (or results*) in a triangulation design?	N/A		Y	
<i>Criteria for the qualitative component (1.1 to 1.4), and appropriate criteria for the quantitative component (2.1 to 2.4, or 3.1 to 3.4, or 4.1 to 4.4), must be also applied.</i>					

Note:

C= Can't tell, N= No, Y= Yes

*These two items are not considered as double-barrelled items since in mixed methods research, (1) there may be research questions (quantitative research) or research objective (qualitative research), and (2) data may be integrated, and/ or qualitative findings and quantitative results can be integrated.

Appendix G

Outputs and Achievements of The Author

Publications During Enrolment

Brito, S., White, J., Thomacos, N., & Hill, B. (2019). The lived experience following free functioning muscle transfer for management of pan-brachial plexus injury: Reflections from a long-term follow-up study. *Disability and Rehabilitation*, 1-9.

<https://doi.org/10.1080/09638288.2019.1668970>

Significance: Qualitative research methodology - development of semi-structured interviews of health professionals, conducting interviews, and data analysis.

Brito, S., White, J., Hill, B., Thomacos, N., Hill, B. (manuscript under review). Effective long-term management of brachial plexus injury following surgery: What is needed from hand therapists' perspectives. *Journal of Hand Therapy*.

Significance: Qualitative research methodology - development of semi-structured interviews of health professionals, conducting interviews, data analysis, and use of NVivo software.

Brito, S., Brown, T., Thomacos, N. (manuscript under review). Participation following brachial plexus injury: An Australian case series. *Hong Kong Journal of Occupational Therapy*.

Significance: Quantitative data methodology using SPSS statistical software. On-line survey instrument development, administration, and analysis.

Brito, S., Thomacos, N., Hill, B., & McCulloch, M. (manuscript under review).

Measuring activity following free functioning muscle transfer for pan-brachial plexus injury: A case series. *To be confirmed*.

Significance: Quantitative data methodology using SPSS statistical software. On-line survey instrument development, administration, and analysis.

Brito, S., Thomacos, N., Hill, B., & Brown, T. (manuscript under review). Psychosocial outcome measures following free functioning muscle transfer for management of adult brachial plexus injury: A scoping review. *International Journal of Rehabilitation Research*.

Significance: Background work of a scoping review undertaken. Content expertise for the proposed research.

Presentations

Brito, S., Thomacos, N., White, J., Brown, T., & Hill, B. (2019, July 10-12). *Patients' experiences following severe, brachial plexus injury: A long-term, qualitative follow-up* [Short presentation]. Occupational Therapy Australia Conference, Sydney, NSW, Australia.

Brito, S., Thomacos, N., & Hill, B. (2020, March 11-14) *Outcomes following free functioning muscle transfer for management of pan-brachial plexus injury: An Australian sample* [Invited speaker - Presentation]. 8th Asia Pacific Federation of Societies of Hand Therapy Conference, Melbourne, VIC, Australia.

Other Achievements

Balint-style, BPI special interest group. As a follow up to the requests for a support and education group, a BPI Special Interest Group was started. Meeting 5-6 times a year. All are welcome, but primary attendance is therapists who regularly treat clients with BPI. We have been joined by a couple of therapists who were seeking support in managing their first BPI client, education, case study discussions.

Non-PhD Related Work

Newton, F., Lee, A., Brito, S., Haines, T. (under review). A co-created conceptualization of supplementary support services for CALD allied health students and their fieldwork supervisors. *Advances in Health Science Education*.

Significance: Grounded theory methodology and analysis.

Grant. Porter, J. E., Reimers, V., Barbagallo, M., Prokopiv, V., James, M., Dabkowski, E., Mesagno, C., Peck, B., Jones, J., Missen, K., Bailey, C., Snell, C., & Brito, S. (2020). The Latrobe Health Assembly Community Programs Evaluation. Department of Health and Human Services (DHHS), Latrobe Health Assembly (LHA) - \$143,866.