School of Nursing and Midwifery

Accepting a Reduced Self after Acute Trauma

Mandy Lison-Pick

This thesis is presented for the Degree of
Doctor of Philosophy
of
Curtin University

April 2011

<u>Declaration</u>

To the best of my knowledge and belief this thesis contains no material previously published by any other person except where due acknowledgement has been made. This thesis contains no material which has been accepted for the award of any other degree or diploma in any university.

Signature: …………………………………...

Date: …………………………………..

Acknowledgement

Abstract

Disability associated with loss of limb function following major/minor trauma is a life-changing phenomenon of global significance which poses a heavy burden on healthcare systems, communities and individuals. While there is a voluminous and growing body of knowledge on disabilities and chronic illness, little attention has been given to the short and long-term experiences of those living with loss of limb function and disability following acute major and minor trauma. The aim of this thesis is to develop a substantive theory that describes the phenomenon of living with disabilities resulting from a loss of limb function from acute minor or major trauma. Data were obtained from face-to-face interviews with 15 consenting participants aged between 18-45 years who had lost limb function from acute major/minor trauma all of whom were attending the Pain Management Centre of a major teaching hospital in Western Australia. Four clinical practitioners (who were classed as experts in their field) were also interviewed to clarify the practices the participants discussed so an all round picture could be given and analysed. Data analysis was conducted using the constant comparative technique of the Grounded Theory Method. The results indicate that the basic social problem was Loss of Self and developed from either a sudden or gradual loss of limb function as a result of acute trauma. This trauma had a biopsychosocial impact as the participant's hospitalisations, surgical procedures, extended rehabilitation programs and resultant disability reduced the self. The basic social process experienced was recognised as Accepting a Reduced Self appearing in three stages: Floundering, Treading Water and Wading to Shore. However these stages were strongly influenced by various modifying conditions such as their persistent pain, the availability of a support crew, the type of trauma experienced and the length of time since injury. It was concluded that disabilities related to loss of limb function can occur following acute major or minor trauma. The impairment the participants experienced affected all aspects of their lives and that of their partners, family and friends as most of them continued to struggle with their disability, either biologically, psychologically or socially. The findings of this thesis point to the importance of more research into designing care and offering ongoing support services to provide long term care for this vulnerable, disabled population.

Table of Contents

List of Figures

CHAPTER 1

Introduction

Change and transition are common in an individuals' life, with physical, emotional and relationship development occurring throughout the lifespan. Along with this physical, emotional and psychological maturity societal roles usually change allowing for increased rights and responsibilities. Such change is common, often expected and planning for major transitional events (such as marriage) helps reduce stress and aids psychosocial adjustment to the new situation (Kiser, Bennett, Heston and Paavola, 2005; Janoff-Bullman and Timko, 1987). Parkes (1971 p113; 1993) acknowledges that preparatory training or advanced positive planning can influence a major life event (such as planning for retirement) thereby changing a major transition to a *'minor transition'*.

However when change is unexpected or a life transition is unplanned or unhappy then an individuals' life can be sent into turmoil. This turmoil can have a negative impact for the individual, as their personal expectations and life assumptions of their current situation and future goals are disrupted (Barton, 2007; Kiser et al., 2005; Janoff-Bullman and Timko, 1987; Bury, 1982). A common source of unplanned change in an individuals' life is acute trauma.

Trauma

The term trauma originates from the Greek, implying 'wound or injury' (Oxford Dictionary of English, 2003; Barrett, 2001; Worlock, 2001). Even though the term 'trauma' is universal, there is imprecision and confusion in the literature about the actual meaning of the word. Two recent reports commissioned by the World Health Organisation[1], (WHO) 'Guidelines for Essential Trauma' (Mock, Lormand, Goosen, Joshipura and Peden, 2004) and 'Prehospital Trauma Care' (Sasser, Varghese, Kellermann and Lormoand, 2005) both focussed on the impact of trauma but failed to give a definition, although the term was used repeatedly (Sasser et al., 2005; Mock et al., 2004). According to Royal Perth Hospital[2]

---

[1] World Health Organisation (WHO) is the directing and coordinating authority for health within the United Nations system, providing leadership on global health matters.
[2] Royal Perth Hospital (RPH) is Western Australia's premier teaching hospital with 885beds providing a full range of emergency services for adults (except obstetrics). RPH is the main provider of major trauma services in the state.

(RPH), trauma is 'an injury or wound resulting from an external force' (RPH, 2007 p17). This definition was based on Miller and Keane's (1983) dictionary description and seems somewhat limiting because it does not include injury from iatrogenic interventions. Therefore, for the benefit of this research, the definition of trauma will be expanded to include *any assault on the body from an injury, wound or infection due to an external cause including iatrogenic damage.* Incorporating iatrogenic damage allows the inclusion of elective surgery and repeated interventions/procedures and practices that can influence the disease process and loss of limb function. Acute trauma therefore is a medical situation that occurs with a fast onset with intense and severe symptoms (Oxford Dictionary of English).

Epidemiology of Trauma

Trauma resulting from an accident is one of the leading health issues of the twenty-first century and one of the leading causes of mortality and morbidity throughout the world (Sasser et al., 2005; Mock et al., 2004). Physical trauma is responsible for 16% of the global burden of disease and is on the increase (Halcomb and Davidson, 2005; Mock et al., 2004). Injuries are sometimes so severe that they cause death. For those aged 15-44 years, road traffic crashes, self inflicted injuries and interpersonal violence are in the top six causes of death for this age group (Australian Bureau of Statistics [1](ABS), 2008; Sasser et al., 2005; Mock et al., 2004). Other causes of preventable death, injury and disability include falls, exposure to chemicals, and poisonings (ABS, 2008; Sasser et al., 2005; Mock et al., 2004). Disability can be defined as 'any limitation, restriction or impairment, which has lasted or is likely to last for at least six months and restricts everyday activities' (ABS, 2004a p3). Survivors of trauma often have to manage a disability, for example Ketz (2008) estimates there were over 250,000 amputees worldwide due to machinery, wars and road traffic crashes. Since this time it is likely that the number has increased. If physical trauma does not occur, there is always the possibility of psychological trauma such as stress, anxiety and depression which can all cause disability (Casey, Greenberg, Nicassio, Harpin and Hubbard, 2007).

---

[1] Australian Bureau of Statistics (ABS) provides statistics on a wide range of economic, industry, environment and energy, people and regional matters, covering government, business and the community in general.

The word 'accident' implies that the occurrence is by chance, or haphazard, suggesting that nothing can be done to prevent the trauma or injury occurring, however this notion is incorrect (Barrett, 2001). There is a belief that accidents creating serious and fatal injuries are incidents with identifiable causes that can be acted upon and are therefore not considered accidents (Sasser et al., 2005; Barrett, 2001). For example, death and injury rates are higher in some countries because of poor road design or lack of compulsory vehicle maintenance, lack of safety equipment or occupational health and safety regulations (Ketz, 2008; Sasser et al., 2005).

The National Health Priority Area Budget in 2001 identified that the cost of injuries was 4,013 million Australian dollars (ABS, 2008). In 2004 to 2005, 16% of the population stated that they had long-term effects from acute traumatic injuries, with damage to lower limbs accounting for 2.6% (31,900) of all injuries in 2003 (ABS, 2008; ABS, 2007). Trauma to limbs is a major cause of injury-related disability and, when not managed well, will result in functional impairment, compromising one's ability to return to work (ABS, 2007; Mock et al., 2004). Injuries from trauma not only affects the victims but also their families/significant others and, ultimately, their communities (Sasser et al., 2005). The cost of these injuries is high and includes the personal cost to the individual (suffering and loss), the cost of their medical care to the community and the cost of premature death and permanent disability to society (Halcomb, Daly, Davidson, Elliot and Griffiths 2005; Sasser et al., 2005).

Financial problems resulting from loss of limb function commence from the day of the trauma, when the person is taken to hospital or sees a health professional (WHO, 2004). Relatives tend to reallocate their work within the family unit and frequently spend time away from their workplace to assist the injured person (WHO, 2004). Loss of limb function from acute trauma is an important worldwide phenomenon as injuries to extremities are a primary cause of global injury-related disability (Mock et al., 2004). Common sources of death and injury for the 18-44 age group are road traffic crashes, occupational injuries and recreational/sports trauma (ABS, 2008).

Road Traffic Crashes (Trauma)

Road traffic crashes (RTCs) are so named because they are often predictable and preventable (Barrett, 2001). It is estimated that up to 50 million people per year worldwide are injured or disabled because of RTCs and the WHO predict that RTCs will become the third largest global contributor to the burden of disease by 2020 (WHO, 2004). The annual the global monetary cost associated with these crashes is estimated to be US$518 billion. This places a significant strain on most international health care budgets (WHO, 2004, 2006). Congruent with international statistics, RTCs in Australia remain one of the leading causes of mortality and morbidity in people under 45 years and a major cause of disability (ABS, 2007). In 2004 to 2005, it was reported that two Australians in every 1000 were injured in a RTCs with prominence occurring in males aged 15-34 years (ABS, 2008). The ABS reports that in 2001 those injured in a RTCs significantly reduced their normal activities; 52% of them visited a doctor or another health professional and 495,300 were left with long-term health conditions resulting from their injuries (ABS, 2004a,b, 2003b). In 2003 approximately 13,000 people in Western Australia (WA) were involved in a RTCs, resulting in costs to the WA community of over $2 million (Hill, Marchant, Trafalski and Gant, 2007; Australian Transport Safety Bureau, 2004).

Injuries from RTCs

Lower limb trauma from RTCs resulting in loss of limb function can occur from damage to joints (particularly the knee), amputations, open wounds, spinal cord lesions and fractures (ABS, 2004a,b). In Western Australia, it has been reported that spinal cord injury, head trauma, burns and orthopaedic injuries can all be caused from RTCs, resulting in hospitalisation for approximately 15 to 40 days (RPH, 2008). Trauma to upper limbs from RTCs can cause damage to the humerus, shoulder, ulna, radius or hand from such injuries as fractures, lacerations or nerve damage and this occurred for approximately 4,500 Australians in 2002 (Australian Transport Safety Bureau, 2004).

Occupational Trauma

Occupational trauma are incidents connected with work that could result in personal injury, disease or death (International Labour Organisation, 2005).

Global collection of data for such incidents and injuries is difficult because most countries have either a fragmented reporting system or no system at all (International Labour Organisation, 2005; Leigh, Macaskill, Kuosma and Mandryk, 1999). Putting members of the workforce in danger can have serious implications for employers so they may decide not to report injuries hence data is not collected (International Labour Organisation, 2005; Leigh, et al., 1999). Statistics regarding occupational incidents are therefore often collated from secondary sources such as death reports, workers compensation claims and various health or workplace records, suggesting that any figures presented are an under representation of the true number (Leigh, et al., 1999). Australian statistics from July 2005 to June 2006 indicate that 6.4% of the working population aged 15 years and over experienced an injury at their workplace, with 58% taking time off work (ABS, 2008). In WA in 2002 to 2003, over 41,000 workers were identified as being injured at work resulting in the lodging of a workers compensation claim with their approved insurers (Fraser, 2007; Stansbury and Warr, 2005a; Stansbury and Warr, 2005b; Warr, 2005). It is evident in the existing research that people who experienced occupational trauma resulting in injury appear to use all available health services and the risk of hospital admission increases by 2.5 times compared to those who do not experience occupational trauma (Cameron, Kliewer, Purdie and McClure, 2006).

Injuries from Occupational Trauma

The most common type of injuries and illnesses experienced by Australian workers from June 2005 to July 2006 were sprains or strains occurring in the agricultural, forestry, fishing and the manufacturing industries, respectively (ABS, 2008). Cuts or open wounds mainly occurred in the electric, gas, water and mining industries (ABS, 2008). Approximately 19% of workers reported cuts or wound as their most recent work-related injury with fractures, amputations and crush injuries being responsible for a further 10% of injuries, all of which can cause loss of limb function (ABS, 2006a,b,c; ABS, 2008). In the underground mining industry, injuries to legs (specifically knees and ankles) were common. However, in surface mining, injuries to the arms (particularly shoulders elbows and wrists) were the leading cause of limb injuries (Department of Mines and Petroleum, 2009; Minesafe, 2009).

Sports Trauma

It has been reported that globally, in 2001 professional sport injuries cost approximately US $1 billion annually from reduced activity/work hours and medical expenses (Murphy, Connolly and Beynnon, 2003). When recreational sport is taken into consideration the cost is much higher, as approximately three to five million people injure themselves annually in the USA alone and their reduced activity, lack of work hours and medical fees needs to be acknowledged (Murphy et al., 2003). Again, estimates of sports injuries are complicated because of the different methodologies used to collect and analyse data and international comparisons are difficult, even though professional players are at an increased risk of injury during competitive games (Junge, Langevoort, Pipe, Peytavin, Wong, Mountjoy, et al., 2006; Murphy et al., 2003).

Australia is recognised internationally as a sports loving nation. Despite this reputation, sports-related injury data collection is poor (ABS, 2008; Department of Health and Ageing, 2004). In 2005-2006 there were over 10.5 million people aged 15 years and over who took part in a sporting activity (ABS, 2008). In WA, injuries incurred in sports such as Australian Rules Football, Netball, Basketball and Field Hockey cost the WA community approximately Aus$4.85 million annually (Stevenson, Hamer, Finch, Elliot and Kresnow, 2000). Injury rates from involvement with these sports are averaged at approximately 16.7 per 1000 matches. These rates increase if players have experienced a previous injury or back problem (Stevenson et al., 2000).

Injuries from Sports Trauma

The type of injuries causing loss of limb function in the sports arena varies from spinal cord injury, knee cartilage and anterior cruciate ligament damage and these are particularly common in rugby players (Brooks, Fuller and Reddin, 2005; Haylen, 2004). Other injuries to the lower limbs can occur at the groin, thigh, knee and ankle which all have the potential to cause a loss of limb function resulting in a loss in match and training times (Junge et al., 2006; Walden, Hagglund and Ekstrand, 2005; ABS, 2003a,b). Some sports can cause upper limb injuries, for example baseball, basketball and hockey, resulting in ligamental

ruptures or fractures of the hand; again limb function can be compromised (Junge et al., 2006).

One of the most common aspects of acute trauma is pain. Pain is identified as the most frequent reason for an individual to attend an Accident and Emergency Department (Australian and New Zealand College of Anaesthetists[1] (ANZCA), 2010).

Pain
Pain is also a common feature of acute or long-term illness and is defined as 'an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage' (Merskey and Bogduk, 1994 p210). Pain is experienced in some form or level of intensity by all trauma survivors but is often not captured adequately in data collection. Manias, Bucknall and Botti (2004) recognise that pain is complex, multidimensional and is always subjective, with these aspects being reinforced by the individual's cultural and linguistic development (Manias, 2002). Moreover, pain is more than an objective, measurable sensation (commonly expected by health professionals) because it has the power to destroy the individual biopsychosocially (Madjar, 1997).

Pain can be defined by duration, for example acute or persistent (chronic), or by the type of tissues involved, for example nociceptive or neuropathic (ANZCA), 2010). Acute pain is transmitted via nociceptive pathways signaling to the brain that pathology is occurring which requires diagnosis and treatment. This type of pain usually has a limited duration, reducing in severity as the body heals and returns to wellness (Macintyre and Schug, 2007; Therapeutic Guidelines, 2007). Unrelieved pain hinders recovery, increases hospitalization and causes mental health problems, interfering with sleep, appetite and activities (Phelan, Higgins, Summons, Douglas, Dobson and Hodson, 2010).

Should pain continue after tissue healing has occurred, it can be identified as persistent and may indicate that there is a change in the sensory processing network of the body (Henry, 2008; Hummel, Lu, Cummons and Whiteside, 2008;

---

[1] Australian and New Zealand College of Anaesthetist (ANZCA) promotes professional standards and patient safety in many areas of anaesthesia, intensive care and pain medicine.

Macintyre and Schug, 2007; Dolin, 2004; Merskey and Bogduk, 1994). Persistent pain is an ongoing worldwide issue affecting the health of countries, communities and individuals (Henry, 2008; Blyth, March, Nicholas and Cousins, 2005). When pain becomes persistent it can actually develop into an individual disease process because of the secondary changes caused in the body (Henry, 2008). According to Blyth, March, Brnabic, Jorm, Williamson and Cousins, (2001) approximately 17%-20% of the Australian population experience persistent pain. In their study of over 17,000 people, pain was the most common continual condition in Australia as opposed to diabetes, asthma or hypertension (Blyth et al., 2001). Persistent pain was a problem for those who attended the Multi Trauma Outpatient Clinic One[1] (MTOC1) at RPH in 2006 with over 61% of attendees stating that pain effected their physical, social and psychological wellbeing (RPH, 2007). A later study indicated that at three months following their initial injury, 82% of trauma patients reported persistent pain from their injuries (RPH, 2008).

Regardless of how limb function is lost people can experience acute and/or persistent pain. For instance, limb trauma causes tissue damage which requires surgery and this can result in nociepetive pain. However, limb trauma can also cause persistent pain. Spinal cord pain from spinal cord injury, phantom pain as a result of an amputation and complex regional pain syndrome[2] (CRPS) after trauma are all types of neuropathic (nerve) pain (Henry, 2008; Castillo, Mackenzie, Wegener and Bosse, 2006; Geertzen, van Wilgen, Schrier and Dijkstra., 2006; Mackenzie, Bosse, Kellam, Pollak, Webb, Swiontkowski et al., 2006; Urquhart, Williamson, Gabbe, Cicuttini, Cameron, Richardson et al., 2006; Eisenberg and Melamed, 2003; Siddall, McClelland, Rutkowski and Cousins, 2003; Lacoux, Crombie and Macrae, 2002; Birklein, Kunzel, Sieweke, 2001).

People who suffer continual pain can become disabled because of the impact pain has on the person. According to Castillo et al., (2006), pain is the most common cause of disability in the USA. In addition, if pain is experienced at three months post injury, those affected were likely to continue to suffer with this problem

---

[1] Multi-Trauma Outpatient Clinic (MTOC) is a clinic organised to provide follow up treatment for those who have experienced multi-trauma injuries.
[2] Complex Regional Pain Syndrome (CRPS) is a chronic progressive disease characterised by severe pain, swelling of the limb and changes in the skin, there is no cure.

throughout their lives. The reason for this was because pain affects daily living activities, influencing all personal functional abilities (Castillo et al., 2006). This research also revealed that people who experienced persistent pain often suffered from sleep disturbances and experienced high levels of anxiety and depression (Castillo et al., 2006). Aronoff and Feldman (2000) contend that psychiatric problems and psychological processes are intimately linked to the pain experience. Their paper indicated that if traumatic injuries cause chronic pain or Post Traumatic Stress Disorder[1] (PTSD) then these issues have a greater impact on the person (Aronoff and Feldman, 2000). Henry (2008) and Geertzen et al. (2006) report that persistent pain influences stress levels which impacts on coping abilities and ultimately influences mood and behaviour.

Purpose and Aims of the Study

Experiencing sudden, unanticipated physical restriction because of an acute injury influences how one performs in the world and the consequences can be devastating for the individual. Accessing and navigating the health care system and within society as a disabled person is foreign to most individuals and requires a significant psychosocial transition (Parkes, 1988). However, thousands of individuals a year are forced to undergo such experiences. It was with these considerations in mind that this researcher decided that the purpose of this study was to discover how these experiences shaped the lives and futures of those affected by loss of limb function from acute trauma.

The aims of this research study were fourfold:

1. to explore the personal experiences, social processes and interactions that occur when a person loses limb function as a result of acute trauma;
2. to identify and analyse the factors that impact on their experiences;
3. to investigate the relationships between the hospital and community settings (continuing care as an out patient) when limb function is lost;
4. to propose a substantive theory that explains their experience of loss of limb function as a result of acute trauma.

---

[1] Post Traumatic Stress Disorder (PTSD) is an anxiety disorder that can develop after exposure to any event that causes psychological trauma and influences the individual's ability to cope.

Significance of Study

This study was designed to make a substantial contribution to the knowledge of the phenomenon of loss of limb function following acute trauma. An in-depth investigation was conducted into the experience of individuals with a wide range of traumatic injuries including amputations and spinal cord injuries and those who developed CRPS resulting from relatively minor conditions such as removal of a wrist ganglion or torn knee ligaments. Selection within such an eclectic group of injuries is rare, again making this study atypical. It is anticipated that the findings from this research will add to the body of knowledge regarding the experiences of trauma and loss of limb function. By including the experiences of people with acute major or minor incapacitating trauma and their long term experiences within hospital and community settings, the findings of this study will increase our understanding of this important phenomenon. The type of trauma studied (major/minor), the diverse injuries researched and the varied length of time from injury to interview all indicate the unique contribution this research makes to the body of knowledge regarding trauma and loss of limb function.

Thesis Structure

The introductory chapter presented the background of the study. The first section commenced with an overview of the epidemiology of trauma and its impact globally, nationally and locally. Included were some major causes of trauma, such as RTCs, work related injuries and sports/leisure trauma. Following this, the purpose and significance of the research were presented.

The research design and rationale for using the Grounded Theory method is in Chapter Two. This study used a constructivist Grounded Theory method as suggested by Charmaz (2006). Details regarding ethics approval, research design and data collection are outlined. Explanations of data and analyses with suitable descriptive examples to aid clarification are provided to expand and illustrate how the process of Grounded Theory is applied to this research study. Issues of reliability, validity, credibility, theoretical sensitivity and the usefulness of the study are also discussed. The chapter closes with a brief description of the participants and their injuries.

Chapter Three presents the basic social problem 'Loss of Self' that was conceptualised from the collected data. This chapter describes the events that resulted in loss of limb function and contextualises the participant's injuries. When limb function was lost the participants entered a world of biopsychosocial transition which many found hard to accept and difficult to manage, as it whittled away at the self.

Chapter Four presents the basic social process that was identified as 'Accepting a Reduced Self'. Three stages to the process of 'Accepting a Reduced Self' were identified as 'Floundering, Treading Water and Wading to Shore'. Other factors which influenced the individual's ability to cope with their reduced self was their pain experience, their support systems, the length of time they had been disabled and whether they received major or minor trauma.

In Chapter Five, comparisons are made between existing theories that have relevance to aspects of the substantive theory developed in this study. The findings are discussed in terms of implications for clinical practice, policies regarding welfare and ongoing support. Recommendations for future research are then presented.

CHAPTER 2

Methodology

Overview

This chapter describes the research method used in this investigation. The setting in which the investigation was conducted and how participant access was negotiated is explained. The research design, ethics, (including informed consent) and initial recruitment of participants is presented. The chapter outlines how the methodology of Grounded Theory was used to investigate how the participants experienced the phenomenon of loss of limb function from acute trauma. The sources of data and how they were used in this study are discussed.

A central part of the chapter concentrates on the data analysis, the use of the constant comparative method (integral to grounded theory), and open and selective coding. The chapter continues with a discussion regarding validity, credibility and the usefulness of the study. An introduction to the participants contributing to this study is provided.

Use of Literature

In Grounded Theory studies, it is disputed whether to conduct a comprehensive literature review of the phenomenon under investigation (Charmaz, 2006; Glaser and Strauss, 1967; Glaser, 1978). It is suggested that literature reviews are conducted on the themes, issues, categories and concepts that are identified in the data so they can be discussed in the relevant context of the text (Charmaz, 2006). The rationale for this is so that the researcher does not attempt to fit the data into preconceived ideas derived from the extant relevant literature (Charmaz, 2006). This was done in this thesis.

However it is important to determine what has already been done and what knowledge does exist. To this end before the study operationally commenced I undertook a literature review on trauma, pain and disability. The words, 'trauma AND pain AND disability' into the common database research engines for full text articles PUBMED, PROQUEST 'Health & Medicine', MEDLINE and CINAHL;

'Psychology and Behavioural Sciences Collection; Nursing and Allied Health Collection'. A review of the first 20 articles in each search engine identified that the use of the quantitative research method prevailed. The notable exceptions were Cartmill, Soklaridis, and David Cassidy (2011) who developed a grounded theory study focussing on transdisciplinary teamwork. Flanagin, Cruz, and Medvecky (2011), Muir, (2010) and West, Sangani and Toh (2010) published case studies or reports regarding patient management. Within these parameters no study was located that addressed the phenomenon of the current investigation.

However to emphasise the importance of this study in terms of the extent of trauma an epidemiological review was undertake. This is presented in Chapter One, therefore in this study the literature has been used in three ways:-

1. as recommended by Charmaz, (2006) Glaser, (1978) and Glaser and Strauss, (1967), on the concepts and themes developed in the theory in chapters three and four:

2. the literature was reviewed regarding the epidemiological background of trauma, it's consequences from a global, national and local perspective as presented in chapter one:

3. the use of search engines to establish and identify what has previously occurred (as discussed above) to ensure this study adds to the body of knowledge and not merely repeats what has gone before.

Research Setting

This study took place in the state of WA; the largest in Australia, covering approximately one third of the nation's land mass (ABS, 2008). There are over two million people in the state and over 1.4 million people reside in the state's capital, Perth (ABS, 2007). RPH (where this study was performed) was designated the major trauma centre in the state in 2006 and regularly admits people who have experienced RTCs, work and sport injuries (RPH, 2006).

At RPH in 2008, there was an increase of all trauma admissions to the hospital by approximately 10% from 4,490 in 2007 to 4,977 in 2008 (RPH, 2009). Throughout 2008, there was a monthly average of over 414 trauma admissions with an average of 37 classified as acute major trauma (RPH, 2009). Male

admissions were most prominent in 2008 with the majority of all major trauma admissions being men aged 15-44 years (RPH, 2009).

RTCs accounted for approximately 844 trauma admissions in 2008 at RPH and these crashes were responsible for over 50% (approximately 258) of all major trauma admissions; to the hospital (RPH, 2009). Speeding, the use of alcohol and not using a helmet or seatbelt were believed to influence the severity of the trauma sustained (RPH, 2009, 2007, 2006).

In 2008, over 8.1% (approximately 398) of all trauma admissions to RPH occurred from injuries in the workplace (RPH, 2009). This figure is conservative as injuries at 'farms', in 'public open spaces' or 'site not recorded,' and some RTCs could also be work related injuries but received an alternative recording (RPH, 2009 p31, 2007, 2006). Major trauma admissions from workplace injuries in 2008 consisted of approximately 22 people, equating to 5% of all major trauma admissions to RPH. Again this figure must be classed as conservative because of the above reasons (RPH, 2009). Sports injuries were responsible for 4% of all traumas treated at RPH in 2008. This accounts for approximately 199 people attending the hospital, with 13 of those injured, or 3%, experiencing major traumatic injuries (RPH, 2009). However, this number could be underestimated as traumas recorded in the 'miscellaneous' group and those in the 'cyclist/pedestrian' group could also have been sports related but not documented as such (RPH, 2009 p32).

Major trauma patients in 2008 tended to be admitted to RPH under the Trauma team, followed by Neurosurgery, Orthopaedic, General Surgery and Plastic Surgery/Burns (RPH, 2009). Over 61% of major trauma admissions required surgery and the second greatest number of procedures (317 operations) were performed on limb extremities (RPH, 2009). The patients with loss of limb function tended to be managed by either orthopaedic, trauma or by plastic/burns specialists because these specialists have more experience repairing damaged limbs.

People with spinal cord trauma totalled 478 admissions to RPH in 2008 and 137 of these were major trauma admissions. RTCs were responsible for over 50% of

spinal injuries, followed by falls which were responsible for a further 25% (RPH, 2009). Burns trauma resulted in 172 admissions with fire causing 59% of admissions and hot liquids responsible for 27% of admissions. Again, these types of injuries can cause limb trauma and loss of function (RPH, 2009).

Working within the hospital and liaising with the orthopaedic, general surgery, trauma, burns and spinal teams is the Anaesthetic Department's Pain Service. This Service consists of an Acute Pain Team that usually attends elective, traumatic and emergency patients experiencing pain problems and a Pain Medicine Centre that treats other persistent pain issues such as CRPS, phantom limb pain, nerve pain and those who require a slow reduction of medications after high use in the acute stage of hospitalisation. Approximately 4,000 new cases per annum are referred to these services for pain management matters (RPH, 2005).

Research Questions

The main research questions which formed the basis of this study were:

What was the basic social problem experienced by all participants?

How did loss of limb function impact on people's lives?

What was the basic social process used by participants to address the problem?

Ethical Considerations

Approval for the study was obtained from the Human Research Ethics Committee of Curtin University of Technology and the hospital concerned.

Confidentiality and Storage of Data

All information was treated in a confidential manner. Names were not used in the field diary or on the tapes or transcripts and in all instances codes did not link to names. Data were unidentifiable and stored in a locked cupboard at the researcher's home. Electronic files were password protected on a computer kept at the researcher's home. Once the study was completed, all electronic files and paper records associated with the study were stored and kept as per National Health and Medical Research Council protocol (i.e. for five years) at the relevant institution: the Curtin University of Technology School of Nursing and Midwifery.

Inclusion Criteria

Loss of limb function in this study referred to limbs that had been amputated or remained attached to the body but no longer moved appropriately. Participants who were eligible for inclusion were those who were outpatients and had been discharged from hospital after their initial treatment. This allowed for recent (one year since their trauma) and prolonged experiences of loss of limb function from acute trauma to be discussed so that both long and short term consequences of the phenomenon were investigated. Eligibility criteria were that the participant:

- had experienced loss of limb function from acute trauma (including surgery and infection);
- were attending a teaching hospital on an outpatient basis;
- were aged between 18 to 45 years old since this was the demographic group most at risk of acute trauma (ABS, 2004a,b);
- were a part of the hospital system as an outpatient;
- spoke English and did not require an interpreter to avoid errors in translation;
- were treated by practitioners who were experts in their field and could clarify the care and treatment that had been given to the participants.

Those who were excluded were individuals who had lost limb function but also had acquired a brain injury on the grounds that cognitive abilities could be impaired and this could create inaccuracies in the data.

Access to Participants

This was a twofold process involving health professionals and researcher.

Contact by the Health Professional

Initial discussion of the research was performed by a member of the multi-disciplinary team working with the Pain Medicine Centre which consisted of:

- o physiotherapists;
- o psychologists;
- o psychiatrists;
- o nurses;
- o social workers;

    o occupational therapists;

    o pain medicine specialists.

The patients who attended this Centre were classed as out-patients and had been referred by a medical colleague (usually a general practitioner or medical personnel from the hospital, including the Acute Pain Team). This meant that the patients were over the acute phase of their illness/injury and lived in the community. If a member of the team believed a potential participant met the inclusion criteria, they would advise them of the study and ask if they were willing to take part. If a positive response was given they would provide the researcher with the potential participant's contact details.

Contact by Researcher

The researcher contacted the potential participant and explained the nature and the purpose of the study (Appendix A). Potential participants were assured that their health care needs would be met regardless of whether or not they became involved with the study and it was emphasized that they could withdraw at any time. If the potential participant agreed, then they were asked to sign a consent form (Appendix B). This reiterated what was in Appendix A, and also informed them that only aggregated results would be used for research purposes and allowed the participant to ask questions about the research so full informed consent could be obtained. A copy of this was given to the patient and the original retained by the researcher. Before commencing, the interviewee's permission was sought to audiotape the dialogue.

The researcher ensured that all the participants set the pace of the interview, respecting their beliefs, rights and dignity. The researcher is an experienced General and Mental Health Nurse and was well-qualified in identifying if participants experienced anxiety or distress during the informal interview. Assistance was organised from the psychologist, psychiatrist and social worker working with the multi-disciplinary team if needed. However, no problems, anxiety or distress were experienced by participants throughout the interview process.

Four participants were health professionals who were known as 'specialists' in their field. The data collected from them was to seek clarification regarding specific aspects of care given to patients who had lost limb function. The researcher knew these interviewees and approached them directly for an interview, although all established strategies remained in place regarding interview consent and protocol.

Research Design

This was a prospective, qualitative, exploratory study. The researcher chose to use an interpretive qualitative methodology because it gave emphasis to the personal and social constructions regarding the participant's disability. Social construction is an interpretive, ongoing process which seeks to develop and understand people's personal perspectives and viewpoints of the phenomenon being studied (Denzin and Lincoln, 1998).

The Interpretive Paradigm

Interpretive researchers visualise the social world as an individual, subjective experience and their aim is to discover meanings as to what is happening, what behaviours are exhibited and what humans understand about their social situation (Wiseman, 1997). This is in contrast to the positivist researcher who would see their social world through an objective eye, seeking an empirical theory/law, or the testing of behaviours, to explain a hypothesis (Thomson, 2004; Richardson and Fowers, 1998; Wiseman, 1997). From the interpretive paradigm, actions have meanings and actors are able to reflect on their intentions or their actions. Therefore, the interpretive paradigm searches for an understanding of what people are doing and why they behave the way they do (Wiseman, 1997). It concentrates on seeking to understand the situation, though it does not seek to question what causes the conditions to occur or how to resolve them (Connole, 1997; Wiseman, 1997). A premise that is central to the interpretive paradigm is that qualitative research both concentrates on describing and understanding human behaviour (Wiseman, 1997).

Qualitative Research

Individual perspectives are used in qualitative research which explores everyday life issues in the social world of a particular phenomenon, as opposed to research which is conducted in a controlled laboratory situation (Stern, 2009). This type of inquiry allows overt and covert interventions to become theory driven so that recommendations can be made to improve the individual's situation (Morse, 2006). It has been suggested that qualitative research can be defined as collecting words as data rather than numbers and is identified by certain characteristics:

1. the researcher conducts the research within a natural setting;

2. designs can be changed or modified as concepts in the data are analysed to meet the needs of ongoing data collection and analysis;

3. studies focus on the meanings surrounding their social processes;

4. data collection and analysis occur simultaneously (Wiseman, 1997).

In this study participants gave personal accounts of their acute traumatic experience of losing limb function. Such data could not be collected by surveys or by reviewing case studies. After considering several methods, the researcher used the qualitative methodology of Grounded Theory as described by Glaser (1978), Strauss and Corbin (1998b) and Charmaz (2006), as it was believed this would be best able to explain the participant's experiences.

Symbolic Interactionism and Grounded Theory

According to Charmaz (2006), Grounded Theory has its origins in symbolic interactionism. Symbolic interactionism allows human group life and behaviour to be studied and processed using three propositions (Blumer, 1969):

- people act, react and interact with specific physical items, ideals or activities that have meaning for them;

- the meaning of which is determined by the social interaction that people have with fellow human beings;

- the meaning of these interactions alters through the interpretive process of everyday encounters.

Society, reality and the self are dependent on the individual's interactions, relying on language and/or other methods of communication (that can be studied and interpreted) to explain the process of what is occurring for them within that process (Stern, 2009; Charmaz, 2006). Therefore, symbolic interaction is

concerned with 'defining the activities of people as they interact' (with the world) so that meanings and transformations can be seen as processes of social changes and interactions within a given social context (Blumer, 1969 p5; Charmaz, 2006). Grounded Theory generates a theory from data that 'is systematically obtained from social research' (Glaser, 1978 p2) as opposed to the testing of a theory devised by another scientist (Stern, 2009). Grounded theory concentrates on identifying concepts that describe behaviours (actions, interactions and reactions) in a given context until they are eventually developed into a specific idea, or one single workable hypothesis is identified (Stern, 2009). This hypothesis is commonly known as a variable core process composed of psychological and/or social processes (Stern, 2009). Development of the theory occurs by identifying, describing and linking these processes so that they fit with the data (Stern, 2009; Glaser, 2002).

This study used the constructivist approach to Grounded Theory as suggested by Charmaz (2006). It did not adhere to either the Glaserian or the Strauss and Corbin 'way' of performing Grounded Theory. Rather it utilised the basic Grounded Theory processes of collecting data, coding, analysis (consistent use of the constant comparative method, writing detailed memos and creating diagrams of the relationships of the concepts). Adherence to these practices enabled the construction of a substantive theory grounded in the data.

In this study, the process the researcher was seeking related to how people responded to loss of limb function from acute trauma, paying particular attention how they and others acted, reacted and interacted towards them with their acquired disability. Obtaining data from face-to-face interviews gave the participants the opportunity to tell their individual stories and experiences, from being able-bodied, to becoming disabled. By allowing time for the participants to relate their narrative, recognition and acknowledgment of their loss of limb function, the suffering they experienced and the transitional processes they encountered, was obtained. All of the participants commented that it was the first time they had been given an occasion to recount their life-changing event from beginning to end to a health professional, with three of the participants keeping silent about their experiences for over two decades.

The Grounded Theory method was chosen for this study because it was considered to be the most appropriate methodology, ontologically and epistemologically, for exploring the research topic. Personal and societal processes regarding actions, interactions and reactions to health issues influence how people manage their health-related problems (Annells, 2004). Using the Grounded Theory method, it is possible to critically analyse situations but remain sensitive to the words and actions of the respondents (Strauss and Corbin, 1998a).

Putting this into context, in this study the researcher initially asked the participants, 'could you tell me how you lost your limb function and how this has impacted on your life?' The researcher wanted to explore the actions, interactions and reactions that the participants experienced when they lost limb function after acute trauma. As the data were collected and analysed a further question was asked, as initial data analysis indicated the idea of positive consequences regarding this loss which required further exploration. So a second was asked which was, 'has anything positive come from the experience of losing limb function?'

Grounded Theory is not without its critics. Thomas and James (2006) criticize Grounded Theory for three reasons: firstly, they argue that this method oversimplifies the complex relationships and interactions often present in the data. Secondly, they maintain that analysis is restricted through the use of Grounded Theory and suggest that the procedure of performing Grounded Theory is more important than interpretation. Thirdly, they indicate that the inappropriate methods of induction, explanation and prediction all occur in order to legitimize everyday personal knowledge (Thomas and James, 2006). However, the Grounded Theory method is commonly used, internationally recognized and has been used in multiple settings when theory generation is the objective (Morse, 2009a,b).

Data Collection

Multiple types of data can be used in Grounded Theory (Corbin, 2009; Charmaz, 2006; Irurita, 2001; Backman and Kyngas, 1999; Strauss and Corbin, 1998a). In this study, 15 participants who had lost limb function and four health professionals

were interviewed. A field diary was maintained and memos were kept. The literature, in the form of books, newspaper articles and digital video discs, was used to assist in gaining data that helped develop codes and categories regarding loss of limb function as a result of acute trauma. The primary source of data in this study, however, was tape-recorded, face-to-face participant interviews which, after completion, were transcribed verbatim.

Sampling Strategies

Two types of sampling were used in this study: focused/purposeful and theoretical sampling.

Focused/Purposeful Sampling

Sandelowski (1995) states that events, situations, incidents and experiences, not people are studied in focused/purposeful sampling. Focused/purposeful sampling is often used initially in Grounded Theory as it includes participants who are typical of the study group, having personally experienced the phenomenon (Stern, 2009; Irurita, 2001; Silverman and Ricci, 1990). In this study, focused sampling was used as those who were knowledgeable and could articulate their experiences of losing limb function from acute trauma were interviewed. These interviews were analysed and coded and tentative categories were formed. The identified codes and categories were then used to direct the researcher to other potential participants which promoted further exploration of the developed codes and categories. This second type of sampling is called theoretical sampling (Charmaz, 2006; Strauss and Corbin, 1998a).

Theoretical Sampling

According to Glaser (1978, p37) theoretical sampling allows data collection to be dependent on previous coded and analysed data, though where this will occur 'is never clear cut'. Charmaz (2006) argues that the process of theoretical sampling is to gain more data to allow codes and categories to become rich and full so their properties, relationships and variations have definition and depth (Charmaz, 2006). Thomson (2004) and Morse (1995) identify that when theoretical sampling is used, theoretical saturation is achieved more quickly and this will influence the sample size. This is because the researcher is gaining information from those most knowledgeable and experienced regarding the phenomenon, thereby providing

thick quality data for analysis (Thomson, 2004). In this research, several of the participants interviewed commented that their life would be improved if their limb had been amputated. The researcher then recruited several amputees to explore this proposition and gain insight into life without a limb (as oppose to the limb remaining attached to the body, but not functioning) to develop this dimensional aspect of the code.

Sample Size

Sample size in qualitative research can be 'scary' when ongoing analysis and theory development is occurring (Morse, 1995 p148). This is because the researcher does not always know when the results are complete or, 'when enough data is enough?' (Morse, 1995 p148). The answers to these questions are determined by the types of sampling used. For example, random sampling may never achieve saturation because the sample chosen may be theoretically unsuitable and focused, or purposeful sampling will require a larger sample than if only theoretical sampling is used in the study (Morse, 1995). Guest, Bunce and Johnson's (2006) evaluation of 60 African sex workers revealed that 73% of the codes used in the ongoing analysis occurred in the first six interviews and 92% of the codes were attained by the twelfth interview. In contrast to interviewing 60 participants, only seven people were used in Trainor and Ezer's (2000) study focusing on men rebuilding their lives after facing potential death from AIDS (though their participants gave one to four interviews). In a review by Thomson (2004), of the 50 Grounded Theory articles, 38 of them had a sample size between five and 30 interviews. These variations in sampling are reinforced by Charmaz (2006) and Guest, et al., (2006) who comment that sample size varies as it is dependent on theoretical saturation and the depth of the data collected.

Thomson (2004) identifies that when the scope of the research question is broad then sample size will be increased. This is because more data will be required to answer that question. The sensitivity of the research phenomenon will also influence the sample size (Thomson, 2004). For example, if personal aspects are needed to be revealed, such as beliefs, values or sexual activity, or if the population is stigmatized or difficult to contact, then several interviews may be required to build a relationship with the interviewees and for them to disclose their

views. In addition, more participants must be recruited as some may be reluctant to discuss such sensitive issues (Thomson, 2004; Guest, et al., 2006). However, if the sample size is small, predictions regarding behaviours or generalisability could well be challenged (Charmaz, 2006; Morse, 1995). Another factor that will influence sample size is if the researcher is accomplished and is competent at interviewing, as they will be able to encourage and support the interviewees in describing their experiences more quickly and fluently, resulting in fewer interviews. This is in contrast to a novice researcher with poor interviewing skills who may need more interviews to discuss the phenomenon (Thomson, 2004).

The researcher for the present study was a novice, however she had competent interviewing skills as she had been a mental health worker for many years. Included in the sample were participants who were typical of the study group, had experienced the phenomenon and were knowledgeable about the topic. For instance, they all suffered either acute major or minor trauma with the result that their lives were suddenly projected onto a different trajectory. Therefore, a focused/purposeful sample was used, followed by the use of theoretical sampling. The sample consisted of:

- males and females;
- major and minor trauma;
- recent and long-standing loss of limb function;
- amputees;
- those who retained their limbs but function had been lost;
- expert practitioners.

Interviews

Participant interviews in this situation were that which Charmaz (2006, p25) calls 'directed' dialogues, although Strauss and Corbin (1998a) reinforce that the interview is the participant's recall of events, processes and actions as they remember the situation from their perspective and particular sensitivity. In this study this meant that each participant gave their personal account of their experiences which allowed the researcher to gain a detailed knowledge of their loss of limb function from their viewpoint. The interviews occurred at a time and

place convenient to the participant; usually this was their home or the hospital. Often the interviews commenced over a cup of tea and 'small talk' to put the participant and the researcher at ease. Morse (1998, p147) discusses how the use of eating and drinking together is a 'communal equalizer,' as sharing food and drink can iron out any inequalities in the relationship between the interviewer and the interviewee. When both were comfortable, the researcher asked the participant to describe in detail their experience of losing their limb function. As the interview was semi-structured, with the use of an interview guide, the researcher therefore let the participant set the pace and course of the interview (Appendix C). When appropriate, the researcher asked questions about what the participant had discussed to clarify details on various points and asked them to expand on their thoughts, feelings and actions at an event in time.

The researcher usually interviewed the participant alone, although on two occasions partners and family members were present. These supportive others assisted in giving information regarding the difficulties the family had experienced since the participant's trauma and how they had behaved at a particular time. Often family members recalled events that had been forgotten and this gave extra depth to the data. The interview allowed observation of the participant and their physical abilities, particularly how they mobilized, how they managed in their home situation (when interviewed in the home) and the interactions they had with others as they discussed the impact their loss of limb function had on their lives.

Interview Closure

The interview usually concluded with the researcher asking if the participant had anything further to say about their injury, hospital admission and treatment in the past or present. Sometimes this question stimulated further discussion about what was problematic for them as affected persons personally, locally or universally. For instance one participant commented on how, personally, they had problems making their children understand their physical limitations. Another participant explained how, locally, it was difficult to obtain medications when their General Practitioner was away from their practice and, universally, one participant began to discuss the issue of stem cell research and how it could potentially help so many people. Before leaving, the researcher asked if the participant could be re-

contacted if the need arose to clarify any points that may arise at a later date. Social chat or 'small talk' always occurred before the researcher departed. Charmaz, Bowers and Stern (2009) discuss how interview closure and normal conversation must be resumed between the researcher and participant, especially when personal and painful information has been disclosed.

Generally, the interviews took approximately two hours. After the interview was completed, the researcher tape-recorded her recollections thoughts, perceptions and ideas about the interview and any noticeable behaviors, activities and manners the participants displayed. For example while interviewing PF, the researcher saw how independent he was as he managed his personal laundry and made a hot drink for them to have while he talked about his injuries. Such information was documented within the text of the interview and coded. To ensure that no ideas, thoughts and perceptions about the interview were omitted, this information was used as the basis for interview memos.

Once completed, the interview was transcribed by hand and then re-listened to as the researcher entered the data into a computer word document. These two transcriptions were then compared and any information omitted on the computer document, compared to the hand written transcription, was added. Listening and transcribing the interview several times aided the researcher to commence the process of being immersed and grounded in the data.

Documents, Literature and Other Sources
Field Diary
This researcher used a field diary as suggested by Spradley (1979). He indicates that field observations can be used in four ways. Firstly, as short notes so the researcher does not forget an incident, thought or idea regarding the phenomenon being studied. Secondly, expanded diary entries can be made as soon as possible following initial field observations of thoughts and ideas about an incident. These incidents could be informal conversations with people who were not participants of the study but whose information helps to describe the research phenomenon. Thirdly, as an on-going record of how the interviewed participants were progressing. Fourthly, a field diary can record feedback from associates about

various issues and problems related to the studied phenomena (Spradley, 1979). Names were not used in the diary, though dates and times were recorded. The field diary assisted with theory advancement as entries were compared and contrasted to other data sources to enhance the development of the codes and categories, giving them depth and variation as suggested by Charmaz (2006). In other words the field diary gave support and reliability to the concepts developed, acting as a secondary source of data to strengthen or weaken the researcher's concept development.

Memos

Memos are essential to the data collection process as they form an analytical record of the study's progress and theory development (Charmaz, 2006). Glaser (1978, p83) determines that memos are a 'core stage' in the Grounded Theory process and, if omitted, the researcher is 'not doing Grounded Theory.' Memos are detailed records of:

- thoughts regarding the data;
- interpretations about the data;
- theorising the researcher has performed from the data;
- analysis of the codes found in the data;
- and relationships between the codes (Charmaz, 2006; Strauss and Corbin, 1998a; Glaser, 1978).

Each memo, whether it is a sentence, a paragraph or several pages long, is documentation showing how theory development occurs on a step-by-step basis and assists with the linking of codes, categories and concepts of the emerging theoretical ideas (Charmaz, 2006; Irurita, 2001; Chenitz and Swanson, 1986; Glaser, 1978; Glaser and Strauss, 1967). The researcher continued to write memos as the study progressed. For example, when ideas emerged from working with the data, the researcher looked at the language spoken, the definitions of the words used by a participant and re-read the written memo to enhance the expansion of the code, category and developing concepts.

> Example Memo
> Marginalised! The participants appear to becoming marginalised as this seems to be occurring, these patients are also suffering.
> Is suffering the process that's occurring or do they suffer because they are marginalised?

Secondary Sources

The use of technical and non-technical literature assists the research process to develop an overall picture of the phenomenon being studied (Corbin, 2009; Strauss and Corbin, 1998a). In this study secondary sources served as a background and gave alternative perspectives to the discovered codes and categories, giving them depth and variation so that they aided concept development. The use of non-technical literature in this study took the form of media interviews, movies, TV programs, web pages by relevant groups and published works of people who have lost limb function as a result of acute trauma. The sources consisted of autobiographical accounts of how people managed their adversity when losing limb function as a result of acute trauma. For example, the actor Christopher Reeve wrote about his disability after a horse riding accident left him quadriplegic (Reeve, 2002). In addition, following an appearance on a national television program, Sam Bailey and his wife wrote a biography of Sam's struggle to regain his sense of self worth as a paraplegic (Bailey and Bailey, 2006), and the movie 'Murderball' portrayed the lives of the American wheelchair rugby team of 2004 (Rubin and Shapiro, 2005). These sources were not coded but similar categories were discovered in the data and they were compared and contrasted with the coded and categorized participant interviews. This data assisted in recognising and validating the concepts the researcher had developed regarding the problems the participants in this study experienced.

Data Analysis and Coding

Constant Comparative Method

The constant comparative method is a major feature of Grounded Theory which occurs through the continuous interplay of data collection and analysis (Strauss and Corbin, 1990). This entails that the researcher simultaneously collects and analyses data throughout the research process (Stern, 2009; Cutcliffe, 1999;

Annells, 1996; Strauss and Corbin, 1990). According to Strauss and Corbin (1998a) there are two types of comparisons to be performed. Firstly, that of comparing incident to incident and secondly, the theoretical comparisons which involves the contrasting of categories at an abstract level to search for dimensions and properties of those categories that are not obvious to the researcher (Strauss and Corbin, 1998a). Therefore, data are constantly being analysed against previously analysed data so that systematic and critical differences can be detected (Charmaz, 2006). To illustrate, in this study all of the participants were required to change the way they met their hygiene needs with their loss of limb function. This action was then analysed to discover:

- how each participant met their hygiene needs;

- what made the problem better or worse;

- how these changes in their routine made them feel;

- the impact these changes had on their families.

Each analysis was compared, contrasted and coded. Individual participant's activities, events and/or perspectives that had the same or similar codes were put into the same category. As the categories grew, they were analysed for similarities, differences, variations, depth and integrating properties as suggested by Charmaz (2006), Irurita (2001), Backman and Kyngas (1999) and Strauss and Corbin (1998a). The constant comparative method of analysis continues until a theory develops that has 'fit and grab' (Stern, 2009 p61). This means that the problem and process are not forced but emerge from the research data and they flow logically and are understandable.

Data analysis and theory generation occurs by coding the data in two stages (Glaser and Strauss, 1967). The first part of the analysis is open coding were the researcher opens up the data to thoughts and ideas about its individual meanings.

Open coding

Open coding allows the data to be examined and opened up for thoughts, ideas and meanings and can be referred to as open or substantive coding (Charmaz, 2006; Walker and Myrick, 2006; Irurita, 2001; Strauss and Corbin, 1998a,b; 1990; Glaser, 1978). Glaser (1978, p56) explains this technique as 'running the data'

open as it is coded in every possible way and directs the analyst to the relevant theoretical sample (Glaser, 1978). This style of coding gives words, lines and sections of the data a description that classifies, encapsulates and acknowledges it, highlighting the vital bond between data collection and theory development (Glaser and Strauss, 1967). To commence, open coding with a line by line approach is usually advocated, especially for novice researchers, to ensure essential information and meanings are not omitted from the data (Charmaz, 2006; Strauss and Corbin, 1998a; Glaser, 1978). When the participant's own words are used to name the initial codes, or to describe an incident thought or feeling, this is known as 'in vivo' coding (Charmaz, 2006 p55; Strauss and Corbin, 1998a).

Coding the data aids understanding of what has happened to the phenomenon under scrutiny as it gives verification to the data; each code becomes full and rich with data so that dimensions and variations can be developed for each topic as the codes become saturated, thereby authenticating the phenomenon (Charmaz, 2006; Glaser, 1978). Glaser (1978) and Corbin (2009) identify that coding moves the researcher away from an empirical level of process to that of conceptual, interpretive theory development. Strauss and Corbin (1998a) stress that such coding is a fluctuating, ongoing process. Charmaz, (2006), Parry (1997) and Strauss and Corbin (1998a) all suggest that as codes develop they can be subsumed into specific codes, categories and, eventually, into theoretical concepts. Open coding indicates where the gaps are in the data and illustrates any changes or refinements that are required in the current data collection process to aid future analysis and further theory development (Charmaz, 2006; Glaser, 1978).

In the present study, the researcher read the transcript and used a highlighting pen to indicate any in vivo codes they found in the data. The researcher then re-read the transcript line by line and wrote down key meanings they understood by those words. These in vivo codes and open codes were then compared and contrasted and all were entered into a coding book. Each interview generated approximately 130 codes. This process was carried out for the first three interviews as the codes of all three interviews were compared and contrasted, as the researcher looked for conceptual repetitions in the data. These concepts where displayed in a diagrammatic form (see example p.32) to assist the researcher visualise what was

happening to these participants. For the following 12 interviews, the researcher used in vivo and open coded searching for comparisons and contrasts in the data, creating diagrams in an attempt to visualise the complexity of the phenomenon. Following on from this stage of open coding, the researcher proceeded to the next stage of the analysis: selective coding.

Selective Coding

Selective coding is also known as theoretical or category coding (Charmaz, 2006; Walker and Myrick 2006; Annells, 2004; Glaser, 1978). This process links and synthesizes open codes and categories so they relate to each other in the form of a hypothesis (Stern, 2009; Charmaz, 2006; Annells, 2004; Cutcliffe, 1999; Strauss and Corbin, 1998a; Swanson, 1986). This type of coding integrates the codes and categories together from the initial open coding analysis to progress to theory development and identify a core process that affects all the participants (Charmaz, 2006; Strauss and Corbin, 1998a; Glaser, 1978). As a result, the multiple open codes are reduced to concepts and relationships that can explain what is happening with the phenomena (Strauss and Corbin, 1998a).

Example of invivo coding to opening coding to initial development of theory concepts

Patient	Dialogue	*In Vivo* Code	Code	Category
P C	I haven't got as much money to spend	haven't much money		
			Money	Financial Constraint
P G	I didn't have the money to get a new one	didn't have the money		
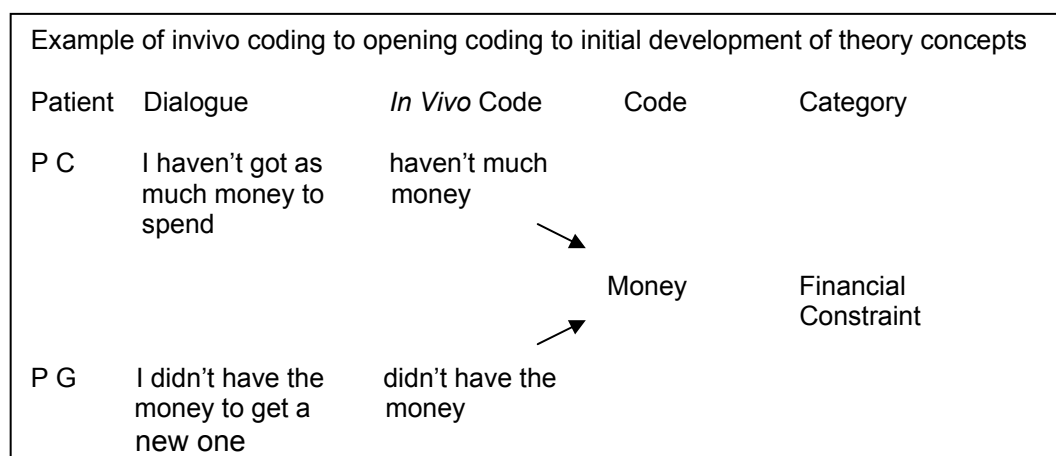
Progressing from open coding to selective coding is not a 'linear' process; the researcher open codes and then selectively codes the data (Charmaz, 2006 p58; Glaser, 1978). Returning to the original codes and categories as they move forward with selective theory coding assists the researcher in gaining a deeper understanding and greater knowledge of their data (Corbin, 2009; Stern, 2009; Charmaz, 2006; Glaser, 1978). Therefore, the process is synchronised so that both

types of coding, open and selective, occur simultaneously and aid theory development (Charmaz, 2006; Glaser, 1978).

Using a selective coding family assists with data analysis and helps determine the conditions which enable the categories to link together (Irurita, 2001; Glaser, 1978). This research utilised the six Cs coding family which refers to the causes, conditions, consequences, context, contingency and covariance of the analysed categories as it looks for variations, properties and components within that category (Charmaz, 2006; Glaser, 1978). For example, in this study the category 'pain' was found within the data. The researcher referred to the data to seek out:

- what caused the pain;

- in what conditions their pain occurred;

- the consequences of having pain;

- in what context/situation their pain was identified and found;

- the contingencies relating to how the participants managed their pain;

- the covariance i.e. identifying which variables made their pain better or worse.

Selective coding continues until each category is saturated; that is, each category is developed in terms of variation in range of dimensions, characteristics and the relationships between the categories are well-established and valid (Charmaz, 2006; Strauss and Corbin, 1998a,b).

Assisting with the large volume of data that the interviews created, the researcher used the computer program NUD*IST (Non-numerical Unstructured Data Indexing Searching and Theorizing). The software was used to store the interviews using a line by line basis. Having each sentence of the interview numbered assisted with data retrieval and analysis. As part of the ongoing analysis, relevant segments of the participants' stories were categorized within the software which made for easy recovery of the category and its contents. A comparison could then be made with another participant's interview. To aid theory development, the use of diagrams linking codes to categories and to theoretical concepts, is advised (Charmaz, 2006; Strauss and Corbin, 1998a).

Diagrams

Using diagrams helps to visualize the codes, categories and concepts that are developing to see the how they link together (Charmaz, 2006; Strauss and Corbin, 1998a). In this study the researcher used a whiteboard to visualize links between the codes, categories and concepts. The use of diagrams ceased initially after open coding of the third interview had occurred to prevent the researcher modifying ongoing data to fit any preliminary conceptual ideas that had been developed. When the fifth interview had been open coded, intermittent diagramming recommenced to visualise the developing ideas and aid theory development. The researcher found the use of a large whiteboard practical as when ideas emerged from the data they could be inserted into the diagram. Before the diagrams on the whiteboard were revised, a copy of the original was written in the researchers memos.
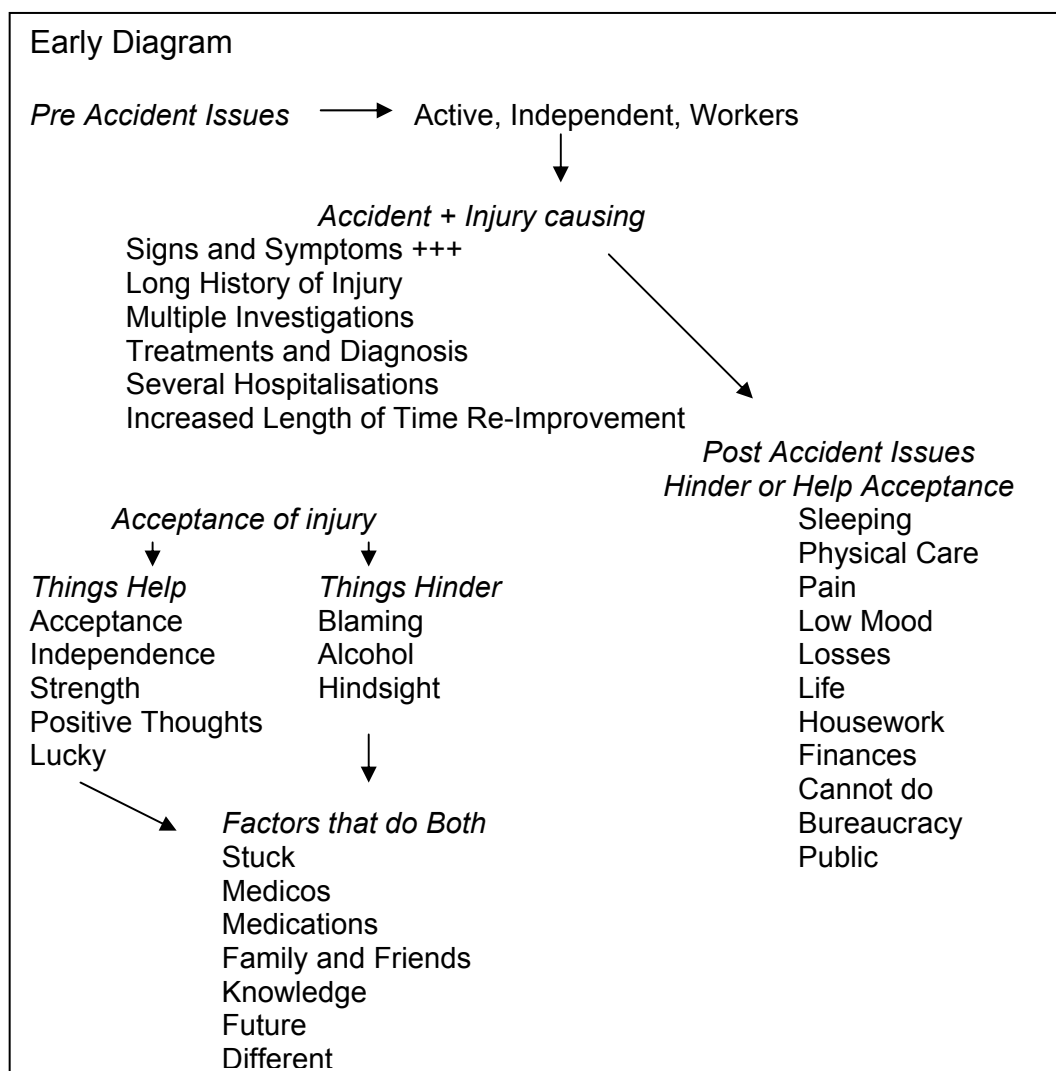
The diagram shown is a basic structure that helped develop a more complex theoretical perspective to the linking of the categories.

Linking categories together to see how they fit and relate to each other continues until a common core category or the basic social process is found (Stern, 2009; Annells, 2004). The core category is something experienced by all the participants, is mentioned frequently, is an issue for all and is associated to many of the other categories as theoretical ideas that have emerged from the analysis (Strauss and Corbin, 1998a, 1990). To illustrate, in this study the concept of losing limb function appeared to immerse the participants into unknown territory or, as identified in this study, Loss of Self, because of the physical, social, psychological and financial changes this phenomenon caused the participants. Subsequently, their behaviours changed because of the consequences of this immersion, resulting in the participant's Accepting to a Reduced Self which was the core process found in this study.

Theoretical Saturation

The main focus of theoretical saturation is theory development and, as such, it is an essential procedural requirement (Charmaz, 2006; Guest, et al., 2006; Irurita, 2001; Parry, 1997). If data collection ceases preemptively then the analysis is inadequate, as codes, categories and properties are incomplete and the core category/basic social process will be difficult to develop (Charmaz, 2006). Strauss and Corbin (1998a) identify that it is always a challenge to cease interviewing and they acknowledge that not every aspect of every code/category will be full, rich and detailed. Nonetheless, they do suggest that the categories should be developed enough to demonstrate a 'range of variability' and state that the use of theoretical saturation is essential to cease data collection (Strauss and Corbin, 1998a p158).

The process of theoretical saturation is completed when no new information, theoretical insights or developments are added to the data from any other data source and all the variations of the phenomenon under scrutiny are integrated into the emerging theory (Charmaz, 2006; Irurita, 2001; Parry, 1997). Therefore, the properties of the categories (that have emerged from the codes) cannot be developed any further even though data continues to be collected (Charmaz, 2006;

Guest, et al., 2006; Strauss and Corbin, 1998a). From Morse's (1995, p148) perspective, the 'quantity of data in a category is not theoretically important,' it is the 'process of saturation' which has significance.

Guest, et al., (2006) reports that even though they revised their codes (which they used to develop the theory) 10 times over the course of the 60 interviews, minimal changes occurred after the second round of code revision. This meant that of the 109 codes used for theory development, 100 of them were identified in the first 12 interviews (Guest, et al., 2006). These researchers looked at the internal consistency of the use of each code by their interviewees and found it had a Chronbach alpha score of .7048 from interview one to 12 and .9260 from one to 60 (anything above Chronbach alpha .7 indicates an acceptable degree of internal consistency) (Guest, et al., 2006). In the present study the 35 categories (that were used to develop the theory) were identified after ten interviews, however a further five interviews were performed to ensure that the data were full and theoretical saturation was complete.

A common category in this study that was important in developing the basic social process was that of meeting one's hygiene needs, particularly showering. All the participants developed ways of showering covering both extremes of a continuum. With participants being totally dependent, others being independent and the majority lying in between (i.e. they used some sort of aid to help them shower, such as a chair, shower hose, brush or seat).

Continuum regarding showering

_____

Totally Dependent	Use of Aids	Totally Independent

When all aspects of showering were explored, the following questions were considered:

- the cause of the difficulty in showering - was it access, pain, facilities, abilities?
- what conditions made showering better or worse?

- what were the consequences of showering/not showering?
- what context did showering occur, personally, socially, culturally, environmentally?
- what contingencies were involved, or how did the participants manage their shower?
- what was the covariance i.e. what variables made it worse or better?

When all these aspects had been investigated and no new data was found regarding the participant's ability to shower, this was then classed as being saturated and full.

Usually it is the outlier that is the key in assisting with theoretical saturation and this can often be ignored as an error, especially when quantitative methods are used (Morse, 1995). Morse identifies the rich, detailed description of the 'infrequent gem' which can give the data an alternative perspective that is often central to the analysis, thus enhancing theoretical saturation (Morse, 1995, p148). The researcher should also look for the extremes in variation of each category until word exhaustion (Thomson, 2004; Morse, 1995; Sandelowski, 1995). In this study the outlier was PO, as he was the participant to have most positively dealt with his loss of limb function. Upon code/category saturation, relationships between the categories are then determined and theory development progresses (Kendall, 1999; Strauss and Corbin, 1998a).

Triangulation

Triangulation is the use of multiple methods, sources and investigators to give an in-depth view of the phenomenon being studied (Denzin and Lincoln, 1998; Janesick 1998). By using multiple sources and methods and investigators rigor, intensity and richness are ensured that might otherwise be omitted if only one data source method or investigator is used (Denzin and Lincoln, 1998). This is similar to what Charmaz (2006, p182-183) labels as 'resonance' (i.e. deep and full data analysis). When a theory has 'resonance', all the categories identified describe all sides of the experiences and meanings within the data (Charmaz, 2006 p182-183). Links can be visualised between the individual, institutions and communities discussed in the data as the theory makes sense and offers a deeper insight to those interviewed (Charmaz, 2006).

Using data from various broad and rigorous approaches aids resonance in two ways:

- it can fill in potential gaps in the data that may have been omitted by primary sources;

- it gives credibility by reinforcing the point of concern. For example, if a code is mentioned in all data sources then it is an issue to all experiencing the phenomenon (Oliver, 2004; Adler and Adler, 1998; Fontana and Frey, 1998; Sandolowski, 1995).

In this study, the researcher used data from multiple sources that could be classed as either primary or secondary.

Primary Sources of Data	Secondary Sources of Data
Participant Interviews Practitioner Interviews Maintenance of a Field Diary Memos	Autobiographical Accounts Magazines and Newspapers articles Web sites (e.g. Amputees in Action) Media/Documentaries/DVD Hospital Trauma Reports Hospital Data Base Australian Bureau of Statistics Bulletins

The use of secondary sources added a further dimension to the discovered codes and categories as they reinforced and supported analysis of the primary sources. For example, the autobiographical account of the actor, Christopher Reeve living with his spinal cord injury (Reeve, 2002) offered similar experiences to the participants in this study who were not rich or famous but had lost limb function. Nevertheless, if a code had been discovered from a secondary source and not from a primary source then it would have been raised and discussed with the researcher's supervisor and included in subsequent participant interviews. In this study, this strategy was not required as all the codes and categories were discovered from primary sources.

The interviewing of expert practitioners assisted in triangulating the data and verifying the issues the participants encountered on a daily basis. The interviews with these experts occurred at their place of work and were recorded and transcribed in a similar way as all the other participant interviews. A typical question to start the interview with these practitioners was: 'what is your role in

managing an amputee, a spinal cord injured person, a trauma victim, or when they attend university?'

The researcher interviewed the practitioners to seek clarification and confirmation of the techniques and strategies that the participants who had lost limb function had discussed. For example PF expressed he was nursed in bed for 'so long' and PP explained how some with spinal cord injuries can spend the first six weeks nursed in bed because of the physiological changes that can occur with such an injury. PN was critical of the prosthetic team and PQ described the process of how the prosthetisis attends the ward meetings and interacts with the patients and their families as they try to build a new limb to meet their needs. Several of the participants complained that their care had been fragmented and disorganized. PS described how those who receive major trauma need to have their care consolidated and managed by one person and this was the focus of her new role as a trauma manager. PR explained how those who lose limb function continue to have problems, as society discriminates against them. Such information gave a more rounded and detailed story of what can occur for those who lose limb function. This allowed the researcher to more accurately conceptualise what was occurring for the participants.

The researcher analysed the practitioner interviews by looking for common themes that appeared to be developing. For instance, all the experts recognized themselves as advocates for those in their care, however this was in contrast to how some of the participants described their interactions with these types of practitioners. Aspects of acceptance of physical limitations and motivation were also dominant themes identified by the practitioners. Moreover, these themes were of significance to the participants in as much as most had problems accepting their loss of limb function and several demonstrated a degree of motivation to stay fit and healthy, but this was because they expected their limb function to be returned, not because they were accepting of their loss of limb function. Such themes added dimension to the categories that had been developed from the participants as it gave the researcher more knowledge and depth about each category.

Trustworthiness and Rigor

When research offers trustworthiness and rigor it indicates that if the study were to be reconstructed and replicated then the same results would occur (Lobindo-Wood and Haber, 1990). Thomson (2004, p6) identifies this trait as 'generalizability' and believes this is difficult to perform in qualitative research. Strauss and Corbin (1998a) agree that reproducing the social situations that the data were collected under and controlling the variables that influenced the original findings was likely to be impossible. Therefore, reproducing the exact work of Grounded Theory could not be performed as a new researcher may not always agree with the original interpretation (Thomson, 2004). However, should another researcher with a similar perspective as the original follow the general rules of sampling, data collection and analysis under similar conditions, then the second researcher should generate similar codes, categories and a similar theoretical explanation of what is occurring (Thomson, 2004; Strauss and Corbin, 1998a). The use of memos and keeping a diagrammatic trail allows an independent assessor to follow comparisons that develop in the study (Charmaz, 2006; Strauss and Corbin, 1998a), although it has been stated that some research students often do not like to write memos, they just want to analyse (Bowers, Morse, Charmaz and Clarke, 2009).

To aid rigor and trustworthiness in this study the researcher wrote memos to keep an accurate record of thoughts and ideas as the study progressed. These memos were thoughts, ideas and perceptions the researcher had about the data and they were dated creating an audit trail for others to follow. The use of diagrams depicting a visualization of the developing categories and concepts would help future researchers develop a similar study. The researcher also kept a field diary to aid their memory so they did not forget an incident that had occurred, expand on relative ideas and thoughts regarding how the participants were managing with their loss of limb function and also to document comments from other health professionals about the phenomenon. These notes assisted in code and category development as they supported the other data sources used. The representativeness of incidents and perceptions assisted in giving validation to the codes and categories developed. For example, one incident described feedback from a participant's mother who described how her son's mood had improved

since he had joined the wheelchair rugby team for the hospital. This incident reinforced that acceptance and the support of others can assist in managing loss of limb function.

The sharing of information at the Grounded Theory meetings organised by the relevant university allowed the researcher to present their ongoing findings. These findings were often challenged and the presenter was required to justify how and why they had reached such conclusions. During one of these meetings the researcher presented a preliminary finding of the basic social process, Attaining Normality. This was disputed, as some of the group members believed the analysis was superficial and more in-depth conceptualization was required. This aided the researcher to re-conceptualise and re-evaluate the data so a complete process that would fit the data more appropriately could be reasoned and described.

Credibility

According to Charmaz (2006, p18), data that yields intense, significant and considerable information about the phenomenon being researched gives it 'quality and credibility'. The relationships between discovered codes and categories should be identifiable so that an independent assessor could follow and agree with the comparisons found in the study (Charmaz, 2006). Strauss and Corbin (1998a) assert that concepts and categories should be linked and well-developed for the theory to be valid and have quality. Glaser (1978, p4) stresses the theory must have 'fit, relevance and must work.' This signifies that the theory categories fit the data and are relevant to the place of work, as it allows the problems of the phenomenon to emerge (Glaser, 1978). Thomson, (2004, p6) identifies this as 'theory validity' and, for this to be positive, the researcher must provide an accurate explanation of what is occurring with the phenomenon, displaying how the codes, categories and concepts fit together to convey a narrative of what exactly is occurring. For example, in this study the participants felt they were discriminated against because of their loss of function and this is evidenced in the data.

Thomson (2004, p5) also suggests that for a theory to be valid it must portray the accuracy of the data. Therefore, the data must accurately reflect what the participant has said or done and they identify this as 'descriptive validity'. Thomson (2004) implies that transcribing interviews verbatim is essential but could be inaccurate if tone, stress, pitch and actions are not included in the transcripts. However, Stern (2009) indicates that transcribing interviews verbatim is not compulsory because the researcher will develop a theory from their personal interpretations of the data. Other grounded theorists advise that listening/watching the tapes repeatedly (when available), assists in re-experiencing the interview so that the mood of the situation can be captured (Morse, Stern, Clarke, Bowers and Charmaz, 2009). For this research, the interviews were transcribed verbatim and sometimes actions and tones were inserted into the transcript. The researcher returned to the tapes on a regular basis, especially when developing the core process, so an accurate interpretation of the data could occur. Also, the researcher coded her tape-recorded recollections of the interview so perceptions and interpretations were not forgotten and could be used as data. Credibility can also be supported by acknowledging the researcher's theoretical sensitivity (Charmaz, 2006).

Theoretical Sensitivity

Theoretical sensitivity refers to the ability to see what is in the data, giving it meaning which is insightful and logical (Charmaz, 2006; Annells, 2004; Strauss and Corbin, 1998a). It refers to the researcher's personal knowledge, feelings, experiences and previous research regarding the phenomenon under investigation. Subjective ideas can influence how data is interpreted and when developing the theoretical constructs. Thomas and James (2006) advocate that grounded theorists cannot separate or disengage from their backgrounds, knowledge, prejudices and personal biases and not acknowledging these thoughts and behaviours will influence their interpretation of the data. Strauss and Corbin (1998a) agree that personal prejudices and biases will never be removed from a qualitative study. Theoretical sensitivity is what Thomson (2004, p6) appears to identify as 'interpretive validity' and they indicate that it is essential that the theory be based on the participants' perspective and not that of the researcher.

However, there are ways that the problem of theoretical sensitivity can be reduced. Keeping a written journal of the research process aids the reduction of personal bias (Strauss and Corbin, 1998a). Irurita (2001) suggests that alternative ideas, impressions and thoughts about the data should be gained using additional viewpoints. These opinions allow for a more rounded interpretation of the data, thereby reducing the risk of theoretical sensitivity (Irurita, 2001). Bowers (2009) advises that the researcher should ground themselves in the data first before they start conceptualising the data and the phenomenon, as this will reduce the impact of previous thoughts they have already conceived about what could be occurring with the phenomena. Strauss and Corbin (1998a) and Glaser (1978) state that theoretical sensitivity tends to intensify as the researcher becomes more in tune with the data over time, as more is discovered about the phenomenon.

For this study, the researcher used memos to expand various thoughts, perceptions, theoretical ideas and constructs that developed throughout the study. These memos were discussed with the researcher's supervisors so that personal biases could be confronted, discussed and challenged and a more rounded perspective of the data was given. The researcher presented the findings to fellow researchers and other supervisors to insure that personal influence was kept to a minimum. The local grounded theory group organized by the supportive institution offered alternative perspectives, as the members questioned assumptions that had been made by the researcher and challenged concepts if they did not fit with the presented data. Through interaction with this group, the researcher reduced the influence of her personal assumptions and biases and allowed other analysts to give their perspectives on the collected data, thus enhancing the theoretical interpretation of reality. For example, the group tested out the name given to the basic social problem when this was discussed at the group. Initially the researcher presented to the group that Loss of Limb Function was the name of the basic social problem. However, the group members suggested that the presented data was more about the self and suggested the problem was Loss of Life. After further analysis by the researcher this was initially refined to Loss of Self.

Usefulness

Glaser (1978) discusses that the identified theory should apply to the phenomenon under consideration and Charmaz (2006) indicates that to be valid the developed theory should be useful to current practice in a variety of ways. For instance:

- the theory should interpret what is occurring in current practice;
- categories should indicate the general process taking place;
- identify how the study contributes to the body of knowledge;
- specify general improvements that can be made for those affected by the phenomenon (Charmaz, 2006).

This study covered multiple aspects of losing limb function. For example, the research included those experiencing both major and minor trauma which is unusual for this field of research. Secondly, injuries received by participants were eclectic. Amputees, spinal cord injuries, infections and iatrogenic diseases were all included and, again, such inclusions are infrequent. Thirdly, this research is distinctive because the experiences of those who had lost limb function as a result of a recent event, as well as those who had lived with this phenomenon for years and sometimes decades, were also of interest. The reasons for encompassing such a variety of participants was to discover the initial and long-term problems that can occur with loss of limb function.

The Participants

PA was in her early forties. She was a single woman who damaged her knee in 2002 when playing recreational netball. After multiple consultations, treatments and surgeries from various doctors and surgeons it was confirmed she had developed CRPS. This was repeatedly mis-diagnosed. Though depressed, she refused to take any medications or seek help from a psychiatrist or psychologist.

PB was a single male in his early forties who lived in a platonic relationship with a female friend. A motorcycle crash in 1985 (in his early twenties) left him with permanent right sided brachial plexus injury and a *damaged leg*. This *damaged leg* caused weakness that left him with a risk of falling. One year after his crash,

he requested the surgeons remove his arm as the weight of the limb was altering the curvature of his spine. He suffered with neuropathic pain.

PC received his injuries in his early forties and was living with his girlfriend and her daughter. A motorcycle crash in 2003 damaged his tibia and fibula. After multiple treatments and surgeries his leg was placed in a plaster cast, with the proposition of an amputation being discussed. Since the original interview this procedure had subsequently been performed.

PD was a married middle-aged woman with two teenage children who had had a work accident in 2003. She tore her knee meniscus and, after two operations to repair the injury, she continued to walk with a limp. Her knee often became stiff if not exercised. She could no longer run or manage her pre-injury, daily walking/keep fit routine.

PE was a 40 year old married man with two sons in their late teens. In 2003 when working at home in the garden he damaged his knee. He tore the knee meniscus and had several operations to repair the tear. Subsequently, he developed a cyst on the meniscus. He also developed CRPS and became profoundly depressed and anxious. In 2008 he had a serious suicide attempt and was admitted into hospital as an involuntary patient.

PF was a divorcee who fell from a roof in 1991, aged 41, while working in the building trade. The fall damaged his spinal cord and left him a paraplegic. Despite his incapacity he lived alone, with pain his constant companion.

PG was in a de-facto relationship with several children. He had a motorcycle crash in 1988, in his mid twenties and received multiple traumas. Offered reconstructive surgery or amputation, he chose amputation and subsequently underwent a below knee amputation of his left leg.

PH was single and has two dogs for company. Her parents used to live with her but they had separated and moved out and now she rarely sees them. An infection as a toddler in the late 1950's resulted in her becoming a paraplegic. Though the

cause is still unknown, viral meningitis had been suggested. She does have an intrathecal pump inserted for pain relief but this makes her sedated and she was having problems functioning at work.

PI lived with his wife and had an aeroplane crash in his forties which left him an incomplete paraplegic. The crash occurred six years ago but he remains angry and blamed the co-pilot for the crash. Initially extremely motivated, he recently spent time in a mental health facility because of mood changes.

PJ lived with her partner and three children. At the age of 19 (in 1998) she had a wrist ganglion removed which left her with nerve damage to her hand and arm. She has undergone several more operations to repair the nerve without success and suffered with migraines and CRPS. In 1998 she had one child, however her pain medications interacted twice with her contraception and she now has three children. Her husband left his job to be with her and become the children's carer. She has frequently been admitted to her local mental health facility because the migraines she experiences cause her to 'fit'. Recently she received a medical insurance claim for a large sum against the surgeon who caused the damage.

PK was married with two sons who have families of their own. In 2001, while working in the Kimberley a region in the north of WA, he fell six metres. This fall caused spinal cord damage and paraplegia. He moved to the city because of on-going health issues associated with his paraplegia. He went into partnership with an ex-colleague and started a business similar to the one he was involved with in the Kimberley. He recently suffered a Myocardial Infarction and has subsequently sold his half of the business and retired.

PL lived alone and is estranged from his family. In 2001, at the age of 40 he had a motorcycle crash resulting in a shattered tibial plateau[1]. He could not walk without a stick. He received a total knee replacement approximately three years after his initial injury and had ongoing issues with CRPS.

---

[1] A tibial plateau fracture occurs at the top of the tibia and often involves the cartilage surface at the top and around the knee joint.

PM was single and lived alone. A motorcycle crash in 2004, when he was in his late twenties, had left him with a brachial plexus injury. He remained as independent as possible, using self-made gadgets to promote his independence.

PN was single, lived alone and was in his early thirties at the time of his accident. A motorcycle crash while working in 2004 left him with a traumatic amputation at the crash site. He had a cardiac arrest at the road side and again in an emergency department. He wished he had been left to die. He had developed a neuroma at stump site and experiences neuropathic pain.

PO was single, lived alone and was estranged from his family before his accident. He was a member of a bikie gang and was well supported by other members and their families. A motor cycle crash in 1979 at the age of 18 left him with multiple amputations and severe internal injuries.

The Expert Practitioners

PP was an expert practitioner of spinal cord injuries. She gave in-depth information about the problems that can occur with spinal cord injury. Her interview confirmed and explained why the participants who had experienced a spinal cord injury were managed in a particular way. She talked about the anger and the grief cycle that affect the patient and their families. PP discussed how essential it was for the nursing staff to be truthful about the injury and their ability to walk again and the usefulness of prognostic meetings with the medical staff to reinforce their future disability.

PQ was an expert practitioner who worked with amputees. She confirmed the problems that some amputees have with their loss of limb, the remaining stump, phantom pain and the use of a prosthesis. PQ explained that a prosthesis is not compatible for all amputees and some people were happy using a wheelchair for the mobility.

PR was a disability representative for a university in which she was also a student. She was disabled herself, having the full use of one arm and one leg. She discussed life on the university campus for the disabled and illustrated how the

university, either overtly or covertly, made it hard for those with disabilities to gain an education, giving detailed examples.

PS was an expert practitioner in trauma management. Her role at the hospital was new. She was primarily employed to coordinate the care of trauma patients in the hope that their hospital stay would be reduced. Her role allowed her to follow the patient through their hospital stay from the Accident and Emergency Unit to Intensive Care and then on to the wards. She did not see the patients in the rehabilitative phase of their care. The role she assumed was the education of the patients, staff and families about their injuries and their management.

Summary

Initially this chapter commenced with a snapshot of the research setting and the incidence of trauma related injuries at RPH. Ethical conditions were then discussed. Recruitment and access to the participants was then illustrated. The research design, particularly the use of an interpretive, qualitative approach was then outlined and the Grounded Theory method explained. Data collection was described, clarifying the use of primary and secondary sources of data such as interviews, field diary, memoing, books and media. Data analysis was then discussed with the subjects of the constant comparative technique and open and selective coding was detailed. To assist with the linking of codes and categories the importance of the use of diagrams was elaborated on and specific procedures required by the Grounded Theory method such as theoretical saturation were also explained. The issues of trustworthiness, rigor, credibility and usefulness of the study were then discussed. The chapter closed with a brief synopsis of the participants who were interviewed.

CHAPTER 3
The Basic Social Problem:
Loss of Self

Overview

The basic social problem experienced by all the participants who lost limb function as a result of acute, unexpected trauma was identified as Loss of Self. This chapter commences with a description of the contextual background and precursor events in which loss of limb function occurred and the basic social problem, Loss of Self was created. Loss of limb function from acute trauma occurred in two ways:

1   Sudden loss of limb function following a major acute traumatic event during which loss occurred immediately (sometimes at the crash-site) or hours/days later;

2   Gradual loss of limb function following a series of unsuccessful minor surgical procedures performed to correct limb damage or function causing deterioration over weeks and months.

In this research, Loss of Self was a consequence of the biopsychosocial changes that occurred when the participants lost limb function. Biologically (physically), their ability to manage normal activities of daily living became restricted; psychologically, their emotional state and mood changed significantly, influencing perceptions of themselves in the world; and socially they became isolated, as their actions, reactions and interactions were all impacted. The relationship between a sudden or gradual loss of limb function and the biopsychosocial impact causing the development of loss of self is portrayed in figure 1.
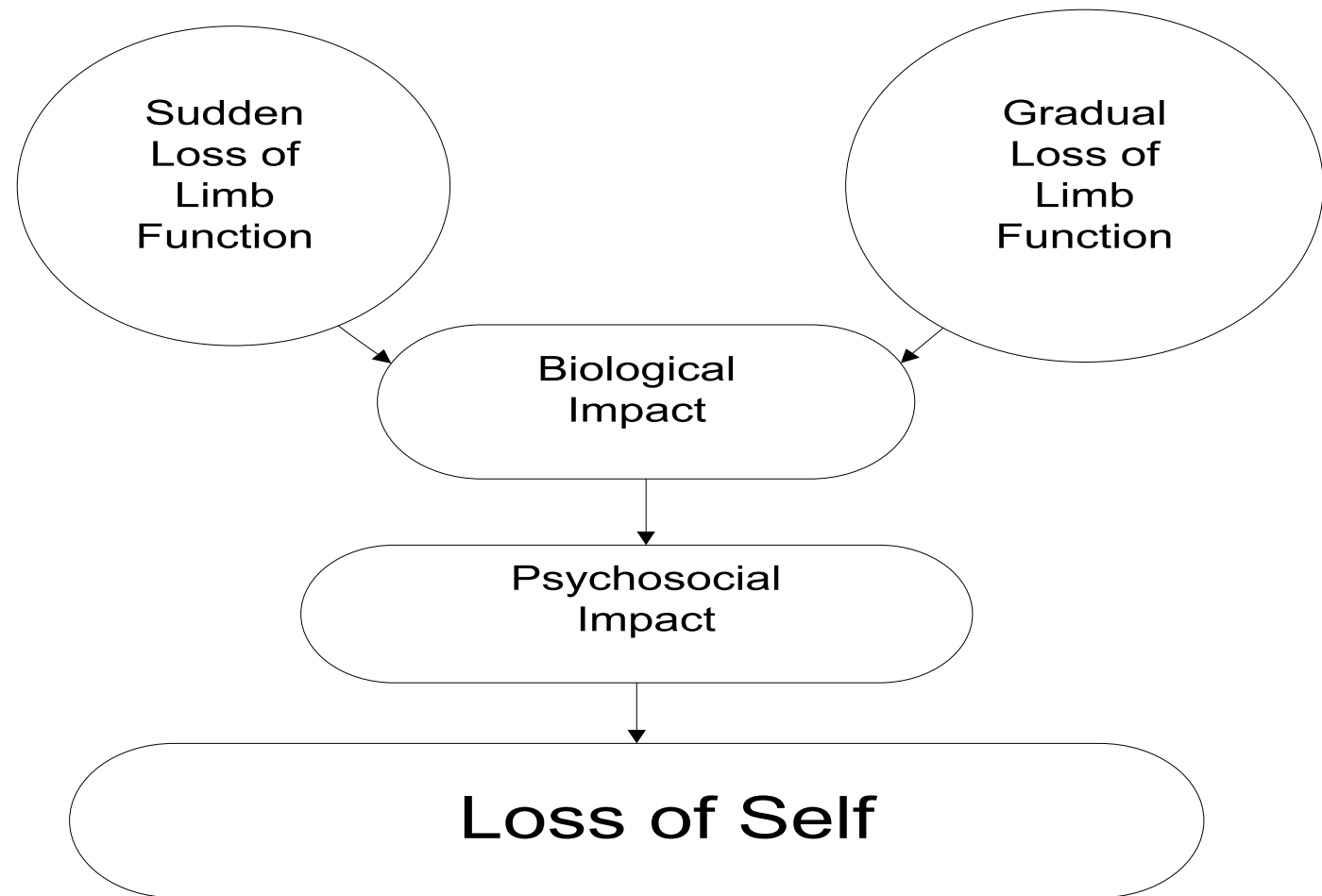
Figure 1 Basic Social Problem: Loss of Self

<u>Sudden Loss of Limb Function</u>

Ten of the participants encountered immediate, major trauma (four amputees, two with leg damage, three paraplegics and one with arm damage) that plunged them suddenly into, what was for them, the largely unknown domain of the health care system. For example, many needed medical interventions and specialised, acute and rehabilitative nursing as repeated hospital admissions and visits to operating theatres were required. PB explained his injuries:

> PB *I was on my way home from work, rode a motor cycle, and two cars where in front of me going towards X* (the nearest WA town). *A four wheel drive was coming towards me and of course he collected me on the bull bars.*

He further explained the length of time he was in the operating theatre as the medical team attempted to repair his injured body.

> *And I was in surgery for twelve hours, 6am to 6pm, just doing enough to keep me alive. Because the right hand side of the body, was completely demolished,*

He further described the damage:

> *Severed nerves, ripped nerves out of my spinal column, a full brachial plexus lesion. I tore all my nerves out of the spinal column. Smashed the radius and ulna but they put it back together with pieces held together with steel and repaired all the damage. Oh this* (points to his clavicle) *went through the aorta and burst the artery in my arm so I didn't get any blood flow for 12 hours or so. I was in hospital for a very long time. They did many more operations, I had muscle taken here, nerves taken from this leg cabled through to this leg trying to repair that. Because when I broke this femur it severed the branches of the sciatic nerve[1].*

PB detailed how his severe trauma initially required twelve hours of theatre operating time followed by multiple surgeries to treat other injuries. Most of the participants who experienced major trauma had similar medical experiences. For example, another participant, PF, suffered an occupational injury. According to PF:

---

[1] The sciatic nerve is a nerve that runs down the back of the thigh.

> PF *I fell through a skylight on the roof. The only thing I remember is over-balancing and I heard the breaking of the perspex of the old skylight. And I just kept falling. I landed into an en-suite that was underneath the double storey I was putting on the house. There was an en-suite in the main bedroom and my back landed on the wash basin. I bounced off there, apparently and hit my head on the hob of the shower. There was a lot of damage done. Well, I'd cut my spinal cord right through so the damage was massive and I busted three vertebrae.*

PL was involved in a motorbike crash which caused severe leg injuries:

> PL *I was riding a motorcycle. I braked and as the front wheel locked up I put my foot down to balance and I shattered the tibia plateau.*

PL returned to the operating theatre at least ten times for washouts of his knee wound. He elaborated further:

> *So what they* (the surgical team) *did was they patched the knee up, which took two years. My knee was infected and I kept going back for washouts and then they* (the surgeons) *washed it out, took wound swabs and blood tests, but they* (the hospital staff) *didn't test them for two days. Meanwhile they'd* (the hospital) *sent me home without checking that I was free from infection. This was on the Friday night* (the discharge) *and I was readmitted back on the Sunday morning with some obvious rip-roaring infection. After the two years* (of repeated admissions) *it* (his knee) *wasn't getting better it was getting worse. There was only one choice from there and that was to have a knee replacement.*

It was two years and several more operations before PL received a knee replacement that he believed should have been performed immediately after his accident. Another participant, PN (whose injuries were very severe) was able to recall his near death experience:

> PN *The next thing I remember is opening my eyes up and seeing myself getting wheeled into surgery and I blacked out. But before I blacked out I heard* **'He's having a cardiac arrest, he's having a cardiac arrest'.**

Another participant remembered how his accident was fatal to his pillion passenger and left him with very serious injuries:

> PO *It killed my mate*! *It left me smashed up.* *All he did was*
> *break his neck! I took all the impact, you see…*

This statement seems somewhat contradictory, as somehow PO believed he has suffered more than his friend, who died as a result of the accident.

The above participants all suffered major trauma which immediately forced them into the confusing terrain of the health care system, where they required multiple procedures and a lengthy rehabilitation process. Several other participants who shared their stories experienced a gradual loss of limb function.

Gradual Loss of Limb Function

Gradual loss of limb function for participants who took part in this study was a result of the undesirable consequences of minor surgical/medical interventions which caused such deterioration in their limb function that it was lost. When something is described as 'minor' in the health setting it refers to surgery performed to treat conditions that are not immediately or potentially life-threatening. The condition is relatively straightforward, involving little risk to the patient and requires no (or very brief) hospitalization (Oxford Dictionary of English, 2003). It should be acknowledged that what was once considered to be a semi-serious trauma or injury requiring admission and days of hospitalisation could now be considered as 'minor,' or a day case procedure (Boughton and Halliday, 2009). Though some limb trauma and surgical interventions are deemed as minor or insignificant loss of limb function and impairment may still develop (Holtslag, Buskens, Rommers, Prevo and van der Werken, 2006; Mackenzie, et al., 2006; Urquhart et al., 2006; Eisenberg and Melamed, 2003; Birklein et al., 2001).

Five of the participants experienced minor trauma (three received knee surgery, one the removal of a wrist ganglion and one experienced a childhood infection). As a result of repeated surgical interventions their limb function became impaired and, in some cases, completely lost. To assist and enhance the return of their limb function (so impairment would be reduced and their former routines and behaviours regained) they each underwent several more minor surgical/investigative procedures. These interventions were unsuccessful as their loss of limb function further deteriorated following each procedure they underwent

to correct their original disability. The experience of relatively minor trauma combined with unsuccessful procedures compounded their limb impairment. For example, PA suffered a torn knee meniscus during netball training:

> PA *One day at netball training my leg went on me. I thought it was my 'hammy'* (hamstring) *so I strapped up my hammy thinking that was right and I kept on playing! But I was doing more damage without knowing it and in an extreme amount of pain!*

PA explained how her pain persisted so she went to see a physiotherapist:

> *So I went to physio and they didn't know much so I went to the doctors. Straight away he said,* **'Your knee has gone. You need an operation'.** *I said,* **'No, no. No way am I having an op'.** *So he sent me to see a specialist* (a surgeon) *up there* (in the country town where she was living). *I went to see them* (the surgeon) *and he said* **'We must operate'.** *So he did an arthroscopy*[1]. *But he should have done a total knee construction. Well he did a lot of damage and my leg was in such a mess.*

New symptoms developed, so PA returned to another specialist:

> *I got DVT*[2] (deep vein thrombosis) *so got through that and it was really hard. I was still working and then my leg. Well I couldn't walk, I was on crutches at work. So I went back to see the specialist and he said,* **'I'm going to give you a knee reconstruction'.** *So I said,* **'OK'.** *I knew it would be 12 months before I could play any netball but I'd still go down the gym and do some workouts. Then I got another DVT which put me back again. I must have been to 20 specialists altogether and none of them could tell me what the hell was wrong, why I was getting these DVTs.*

Again, illness and symptoms persisted so PA visited another specialist:

> *Then I went to see another specialist and he said,* **'You've got RSD'** (reflex sympathetic dystrophy[3]). *I didn't know what that was. I was still under the physio and the physio explained what it was and, in the meantime, I thought I got to get my knee flexed so I went and saw an orthopaedic surgeon down here in the city.*

---

[1] Arthroscopy is a procedure to look in to a joint area.

[2] Deep Vein Thrombosis (DVT) and is the development of a stationary blood clot in the leg often diagnosed by a painful limb, swelling, redness and heat at the calf of the leg.

[3] Reflex Sympathetic Dystrophy (RSD) is now identified as CRPS.

Reflex Sympathetic Dystrophy (RSD) is now recognized as CRPS and presents with varying signs and symptoms which may appear similar to those experienced by an individual suffering with a DVT (Eisenberg and Melamed, 2003; Birklein et al., 2001). Although not usually recognised as a condition in which limb function is lost, in certain situations CRPS can cause sensory and motor functions to deteriorate to the extent that limb function is severely impaired and the limb can no longer be used at all by the sufferer. It is common for CRPS to develop from minor injuries, as Eisenberg and Melamed's (2003) study details. Their research focused on five patients who developed CRPS from various types of minor ailments. For example, one person had a peroneal injury, two had sprained ankles, one had a fungal infection and one had an arthrodesis (Eisenberg and Melamed, 2003). For PA this led them to consult a second orthopaedic specialist:

> *He did an MRI[1]* (magnetic resonance imaging) *scan and mobility thing and said* **'I have got to operate to get the middle out of your leg and fix it up'**. *So I said,* **'OK no worries'**. *I didn't get another DVT, or haven't got one as yet, fingers crossed. But my RSD just got worse and worse and worse.*

PA saw multiple specialists to restore her leg function. She recalled, *I must have seen twenty (20) specialists*. Despite the multiple treatments, investigations and specialists involved in PA's care, her limb function remains limited and the pain has increased because of her CRPS.

Similar stories of repeated investigations, procedures and treatments occurred for the other three participants who expected their limb to be fixed and their problems to be resolved as they continued to attend various medical appointments to have their limb repaired and its function returned. Despite their initial traumatic event being recognised as minor, it had major life changing consequences for them. Charmaz (1995) suggests that the behaviour of seeking regular treatment and therapy is common for all those injured and disabled. She likens ones body to a broken machine that requires repair, so those affected endeavour to use different mechanics in order to mend their broken part. Bury (1991, p457) dubs this the 'medical merry go round,' which some patients use to search for a cure for their

---

[1] Magnetic Resonance Imaging (MRI) is a multi-dimensional Xray showing potential changes in the tissue structure.

physical ailments. Boughton (1997, p170) suggests that the sick or damaged individual 'alienates' the physical body. For these four participants in this study, their experiences with the health system were like a descending rollercoaster as their limb function never quite returned to its pre-operational/pre-investigatory level. These participants failed to develop the practical wisdom of learning from their experiences as it appeared they became habitual patients. Their desire to be fixed was foremost in their mind-set and this could be where their sense of self began to change. These ideas are supported by Bury (1991) and Charmaz (1995, 1983) who maintain that the individual's quest for a fixed normal body without pain and suffering is never ending. However, as Lupton (2003) points out, society expects those who are ill and disabled to seek appropriate treatment so they can return to a status of wellness and normality and rejoin society.

The participant who lost limb function because of a childhood infection told her story:

> PH *The cause is classified as unknown, unknown aetiology, unknown cause. She* (mum) *said* **'I was fine until I had this 24 hour virus when I was a kid'.** *That's when she started noticing things had changed. I was three months of age but I wasn't exactly diagnosed as having anything wrong with me until I was 18 months. Then at the age of 18 months they* (the authorities) *concluded I had some problem. The only time I could walk was when they gave me calipers and crutches. That was after 18 months and I was under the children's hospital there at that time.*

According to PH, these specialists had conflicting opinions:

> *Then somehow or other I got put under the Health Dept. They put me under a Dr X. We'd go to her private house and she resurrected these calipers from her basement. She also specialised in polio I think and she took me on because,* **'I had a good top piece'.** *She felt she could do a lot with me. So she put me in a 'strait jacket'.*

She described her *straight jacket*:

> *It was a jacket that I used to sleep in at night to stop me from turning over, so I had to sleep on my back. I hated it. I also had my feet in plaster bandage on just the casts and then I had these aluminium gutters that were like calipers. My*

> *knees were stuck down. I had to sleep like that and I hated it and my legs in those days wouldn't straighten.*

It seemed that the strapping of PH's limbs could have changed the muscle tone which influenced how she moved her limbs. Eventually a diagnosis of Cerebral Palsy (CP[1]) was given. Not having the ability to walk as a child had severe consequences for PH's education:

> *I went to a normal school initially but I couldn't handle the fact that I couldn't march like the other kids. I was actually in a standing frame. I had calipers, I had to stand up with my calipers and it had little things so I could ride. I was actually standing up while doing my school work rather than sitting down. I had to be pushed out at lunchtime by somebody. I didn't go out for morning tea. They (the teachers and pupils) left me at the back of the classroom because, **'It was only 15 minutes for recess, so it wasn't worth taking ME out'.** I had to stay in the classroom while all the other kids went out and played.*

Being unable to behave like other children and the nature of the treatment by authority figures in childhood clearly influenced this participant's psyche. Goffman (1963) indicates that being different and stigmatised is not good for one's psyche. PH continued:

> *It was having some sort of detrimental effect on my mentality, at the time. I wasn't sleeping very well, I was waking up and I was dreaming. I don't know. Mum would be able to tell you. Apparently it was having an effect on me. They decided I would be best going to a special school.*

This 'special' school was for children with disabilities:

> *It was a school with no normal kids in it. They all had things wrong with them. Burn victims, CP's. There was one little boy there that broke his bones just by knocking it on something. He was a dwarf. I was looked upon as one of the lucky ones. Well I looked at myself as one of the lucky ones. The ones like me and there weren't very many of them, but the ones like me were usually left to look after the ones that were worse off.*

PH stayed at that school for several terms and had to undergo a psychiatric review to leave the school permanently. When she was in her early twenties she and the

---

[1] Cerebral Palsy (CP) is brain injury that causes impairment of movement through non-progressive and non-contagious conditions

family moved to WA were she sought admission into the national games for people with disabilities:

> *They classed me as Cerebral Palsy (CP) in Melbourne, but when I came to Perth Dr X, who I met at the games in 1979, came to the conclusion that I'd had viral meningitis but there was no proof.*

In her late twenties, PH underwent a surgical procedure which left her totally wheelchair bound. Before this, she used her crutches and dragged her legs behind, though she does confess that her shoulders *were playing up* (they were causing her pain)*:*

> *Prior to seeing Dr X, I walked on crutches. I went into a chair in about 1986-87. The reason I think I went into the chair was because my shoulders were playing up. I also had surgery on my legs. Dr X did a neurectomy/tendonotomy and it was after that I had trouble standing and they* (the medical staff) *assumed then I must have stood on the tone of those muscles. Now they weren't there anymore because they (the surgeons) had cut them. So that put me into the wheelchair initially and I couldn't go back on crutches now. Though I would like, to I can't.*

As illustrated, PH's gradual loss of limb function occurred because of a combination of factors which included:

- mis-diagnosis and mis-management of her illness as a child;
- surgeons cutting the tendons in her legs which altered the tone of the muscles so she could no longer weight bear on them;
- problems with her shoulders that supported her crutches which she used to mobilize.

These contributing factors required her to permanently use a wheelchair to move around her world.

When people initially encounter trauma, illness or disability they are propelled into a world of hospitals and health professionals where recovery from injury or illness is often expected, though not always achieved (Halcomb and Davidson, 2005; Charmaz, 1991). Hospitals are places where a small number of individuals (the hospital board) have a considerable effect on the lives of many others (employees, patients and visitors) (Gibson, Martin and Singer, 2005). Admission in to hospital

is often foreign and frightening, leaving the patient feeling vulnerable as they attempt to negotiate the healthcare system in which they find themselves (Speedling and Rose, 1985). The presence and use of technological equipment, which is common in intensive or high dependency areas, creates a dehumanising environment for the patient (Fridh, Forsberg and Bergbom, 2009). When possible health professionals should spend more time with their patients, explaining who will be caring for them and what is happening regarding their care so that patients are more likely to have a positive hospital experience minimizing the negative aspects of hospitalisation (Ahmad and Alssad, 2004; Speedling and Rose, 1985). Fox (2002, p358) states that hospitalisation is 'a projection into otherness' where an individual's boundaries and territories are lost and the person becomes displaced from their current and past social worlds, similar to an itinerant searching for somewhere to anchor themselves. In this study, a comparable experience was described by the participants as their lives were put on hold until their bodies were repaired and they attempted to manage a new life with their loss of limb function and re-establish the self.

Loss of Self

For the participants in this study, their Loss of Self was magnified by preceding events, hospitalisation(s) and rehabilitation which resulted in dramatic, unplanned lifestyle changes caused by their loss of limb function. A simple definition of the self is 'a person's essential being and characteristics that distinguishes them from others' (Oxford Dictionary of English, 2003). Within this idea are subsumed the perceptions of self image, for example how one sees themselves, or self esteem i.e. having personal confidence in ones worth, as a unique individual' and self identity, which is defined as 'the recognition of one's potential and their abilities (Oxford Dictionary of English, 2003). Boughton (1997, p160) recognises that self identity and the body are 'integrally related'. However, the dictionary definition does not explain the complexity and the inherent multi-dimensional interactions that develop between a person and their social worlds that assist in the development of the self. Its complexity arises from that which Ricoeur (1992) refers to as the need to accept the conscious and unconscious self in order for it to be fully established and complete. According to Ricoeur (1992) there appears to be several selves. For example:

The self and ethical aim - requires the person to aim for their interpretation of the 'good life' or their 'true life' (Ricoeur, 1992 p172). This requires them to abide by their personal ethics to live a full, active life by working hard and being financially independent within the contemporary laws of society. When the self and ethical aims are lost, the participants can no longer be active and financially independent.

The self and narrative identity - helps the self focus on one's personal story which is the individual history of who they are, how they developed and who they want to become. It is important to recognise how one has developed through time and experiences so that they can reflect on and understand their current situation. Ricoeur (1992) stresses that although the narrator remains constant, the narrative is often re-crafted. Often when trauma, disability and chronic illness has occurred the current narrative identity is lost as the person tends to remember the upbeat and affirmative aspects of their past narrative (that is, they remember the good times and experiences in their lives) which makes loss more difficult to accept (Ross, 1989). Personal stories are created from memories and people learn from their memories who they are, where they have been and who they have met (Charon, 2002). Subsequently, narratives develop over time and often those with a damaged self will concentrate on how they performed in the past (when their self was whole), to how they are now (with the self damaged or lost) and how they will perform in their future (with a continued, damaged or lost self) (Chapman and Volinn, 2005; Charon, 2002; Charmaz, 1991, 1995; Ross 1989).

The self and the moral norm - is closely linked to one's ethical aims in life, though it centres on the individual's interpersonal, social and institutional interactions and relationships that are developed within their world. The basic premise of this self is that of self-respect which responds to self-esteem, which then enhances respect for those around them with whom they interact. As this respect extends to all contacts, this then guides positive communication at all levels, such as interpersonal, societal and institutional exchanges (Ricoeur, 1992). When disability occurs, their moral norm, self respect, esteem and confidence all are lost and this influences their relationships with the self, family, friends and communities.

The self and the practical wisdom - concentrates on how one learns about the self from past conflicts, tragedies and experiences in the hope that their future will be more positive and satisfying (Ricoeur, 1992). Some of the participants in this study lost their practical wisdom as they continued to undergo repeated investigations, procedures and surgeries in order restore their limb function.

The self and the body - describes how an individual usually feels secure and safe in their own physical presence as their body perform its abilities on command. Boughton (1997) and Madjar (1997) both acknowledge that experiencing the world biopsychosocially commences through the body. Ricoeur (1992) believes that control over the body is needed to enhance personal wellbeing, self-confidence and self-esteem and Boughton (1997) states that through the body a sense of self develops and knowledge is acquired about the world. Chapman and Volinn (2005) suggest that the self is intrinsically linked to the individual's body and that one's sense of self can be damaged or lost from suffering caused by chronic illness disability and loss, such that when the body is damaged, then the self is often lost.

It seems, therefore, that the self arises from interplay between:

- personal aspirations;
- personal history;
- inherent beliefs regarding self-respect, self-confidence and self-esteem;
- abilities to communicate with all levels of society and the individuals' subsequent response;
- control over ones own body (Ricoeur, 1992).

Changes in the self do not usually occur immediately, but over a period of time (Chapman and Volinn, 2005; Charon, 2002; Charmaz, 1991).

Loss of Self was the basic social process that developed from the data as all the participants appeared to lose the self when they lost their limb function. The elements of the self became unbalanced for the participants because of the biopsychosocial impact their loss of limb function had on their lives. This meant that every facet of their former existence was impacted so that they could

effectively manage their disability. The ensuing impairment changed the participant's lives and its consequences created an unscripted and unknown future as their personal narrative became dislocated and lost. The reason for this loss occurred as activities and events that were once natural and automatic could no longer be performed or achieved. When the self cannot see a positive recovery from disability, or suffers persistent pain, it becomes distorted and mutilated, as the demands of society on the mind, body and self outweighs the amount of energy and inner resources the individual has to meet the burden of this altered life path (Chapman and Volinn, 2005). This concurs with Agaibi and Wilson (2005) who acknowledge that when an individual senses that a life event is beyond their ability to cope, then it will be perceived as stressful. This stress leads to self-recriminations about an individual's competence, causing more stress and further thoughts of ineptitude which creates a vicious circle of negativity. Charmaz (1995) and Leder (1990) agree that both the mind and the body work cohesively to create the self and when one is unable to act or perform as required, or expected, then one's personal and social identity is undermined. They begin to perceive themselves as abnormal, to the extent that the self is threatened, lost and may even become unrecognisable. Therefore, the person changes on all levels, biologically (physically), psychologically and socially.

Biological (Physical)

The self is intrinsically linked to the body's performances and activities, such that when these are compromised by chronic illness, trauma and disability, then one's sense of self can be damaged or lost (Chapman and Volinn, 2005; Miles, Curran, Pearce and Allan., 2005; van Manen, 1998; Yoshida, 1993; Ricoeur, 1992; Leder, 1990). Paulson, Danielson and Soderberg (2002) recognise that one's body is used to conceptualise the self and self-esteem (I do therefore I am), so when the body is damaged so is the self, self-respect, self-confidence and the self esteem. Alongside their loss of limb function people also often experience changes in their personal routines, the demise of their previous relationships and a lack of control over their lives, the effects of which contribute to their personal misery. For example, participants PA, PC, PE, PF and PN described how particular activities had changed with their impairment, as what were once routine behaviours were now lost:

> PA *I was a very, very sporty person, gym every day, kept my self fit and healthy. I would work 12-14 hours a day. When I was working, it was my life.*
>
> PC *My life's not like it used to be. I can't do anything I used to.*
>
> PE *I've always been an active person. I go to the gym. I'm always out and about doing something and all that has come to a stop.*
>
> PF *I was a go-getting sort of a person. It's a hell of a difference to your life* (becoming a paraplegic) *especially when you were an active person, a very active person* (like me).
>
> PN *A typical Sunday* (before his loss of limb function) *I'd get up take my dog for a run then I'd go out riding on my motor bike with my friends…I wouldn't get back home until the evening.*

These participants were comparing their pre-injured lifestyle and abilities to their current situation with their disability. What was apparent was that the participants had lost their individual social practices (which supported how they defined themselves in society), and their previous, personal narratives (which were present when the self was whole) were now reduced because of their disability. Spaargaren and Van Vilet (2000) and Charmaz (1995, 1991, 1983) all indicate that for a person to remain credible, secure and safe in their social practices, personal routines, habits and rituals have to be maintained. The participants' disability required them to lose their old routines and activities in order to manage their loss of limb function. For those in this study changes to personal routines and activities commenced with the most basic, living activities, such as meeting hygiene needs or being able to reach a specific geographical destination. These actions were further influenced by their pain experience.

Hygiene

Meeting personal hygiene needs was a multi-faceted issue for the participants and some of the things that concerned them most were showering and their bladder/bowel functions. To manage these personal needs the participants were required to accept and adapt their behaviours and try to establish new routines.

For instance, despite being an amputee for over a year PN was still trying to find a practice which would allow him to shower with confidence and comfort:

> PN *The hardest part is actually having a shower. I tried a couple of times walking in the bathroom and then sitting down and taking my leg off in the shower, but it's too hard and awkward. Normally I take my leg off in the bedroom and then I use crutches to move into the bathroom.*

He explained how he had fallen when walking with crutches (he was not wearing his prosthesis) which had left him with a fear of falling:

> *I've fallen once. I landed straight on my stump. I was lucky!...I did have the hard dressing on but I still just sat there and cried because it hurt!...I then had to take the hard dressing off and look to see if I'd split it* (his stump wound) *again.*

PN's fear of falling was enhanced because he had already experienced the pain of a fall. Also, should he topple over, he would have damaged his stump wound, needing further medical care which would delay progress in using his prosthesis. The consequences of falling and splitting a stump was clarified by health professional PQ. She explained how open wounds delayed a patient's progress:

> PQ *If their wounds take some time to heal, or we're not getting the swelling down, if they live in the metro area* (live locally) *we actually send them home. When their wounds need healing we send them home because it's no good them sitting here when we could get some one else like a home nursing service to dress their wounds.*

When the patients were sent home with open wounds, their long term rehabilitation and recovery was delayed. This was because learning to use a prosthetic limb was time consuming and walking could not commence until the stump wound was healed, which for some could take months. It takes considerable time to comfortably wear and become accustomed to a prosthesis. During that time, sensory and motor cortex reorganisation is not occurring for the amputee, clearing the way for persistent pain to develop (Karl, Munlnickel, Kurth and Flor, 2004).

PJ, a mother of three, was embarrassed to rely on her husband for assistance with personal tasks. As she described:

> PJ *I can wash my body left-handed. I can't wash my hair because it's so long. I have to get him* (husband) *to put it up.*

Though her carer was her partner, she remained distressed that she had to involve him in meeting her personal hygiene needs. According to Ricoeur (1992) when any assistance is required then the self is damaged. Therefore, having difficulty or requiring assistance to shower reinforced that the participants' bodies were abnormal and this led them to perceive themselves as being less than whole, causing the self to be reduced. Miles, et al., (2005) and Charmaz (1991, 1983) describe how one considers certain habits and activities as contributing to a sense of independence which is whittled away through chronic illness.

Washing was not the only challenge for the participants in this study. Five of them had bladder/bowel problems resulting from their accident. PI was an incomplete paraplegic, indicating that he may have some sensation or motor function but not enough to walk unaided and bladder and bowel function may or may not be affected. For PI, bladder and bowel functions were deficient:

> PI *I have no bowel and bladder functions. That was another issue to come to terms with. In the beginning the bowel movement got a bit easier, the bladder got worse.*

One participant explained how the routine he devised to address this was workable at home but could not be maintained when he left the house. PM had received a brachial plexus injury and had lost the use of one arm. As a consequence, he experienced considerable difficulty dressing himself. A particular dilemma for him was using a bathroom outside of home, as he expressed:

> PM *But the thing is if I need to go to the toilet* (drop his trousers outside of home) *how am I going to get myself dressed afterwards?*

This again necessitated a change in his routines and lifestyle and, consequently, his sense of self, as the fundamental practice of using the bathroom outside the home was compromised. Also, common household chores were often lost. For instance PJ expressed how little she did around the home:

> PJ *I can't do a lot around the home, I can't make beds, vacuum, do the dishes, cook. I can't dress my own child! X (her partner) is my fulltime carer of me and the children.*

She complained further:

> *Washing dishes and folding clean washing are his downfall. He hates doing dishes so they pile up until he has to do them. And the folding of the clothes, well you should see the lounge room. There's usually eight loads of washing before it gets folded. I wasn't a clean freak! But I used to keep my home reasonably clean. Now it frustrates me to see it a mess because I can't deal with it.*

Participant PH (who was wheelchair bound) had attempted to have a non-government/non-profit making agency, Silverchain, manage her housework.

> PH *Mum and dad usually do the housework. Silverchain will do it but they'll only clean their half of the house, they wouldn't do my half For me to do my half well I'd have to pay for it to be done, so I'd may as well pay to get the whole bloody lot done. It's totally ridiculous getting half a house cleaned.*

This failed, so her parents were left to clean the house. These excerpts illustrate how the participants became frustrated and upset as their worlds were compromised and constricted because of her loss of limb function. However, should any of the participants complain about housework not being done, there was the risk that goodwill will be withdrawn and the housework would be left.

It was the female participants who tended to worry about what they could not do in the home because of their physical restrictions. When these women were dependent on others to do their chores they usually lowered their standards, as those cleaning for them tended to not work in a way preferred by the participant's way or in a way that met their standards. Charmaz (1983, 1991) and Miles et al. (2005) discuss how people with disabilities concede that their standards regarding their housework diminish because of their physical limitations. Another physical problem experienced by the participants was their difficulty moving around and reaching a destination.

Reaching One's Destination

Having the ability to move about quickly and efficiently to reach a destination is essential in the world today. Loss of limb function commonly causes problems meeting this need (Smith and Sparkes, 2005; Lacoux et al., 2002). Holtslag et al.'s (2006) investigation of participants with lower limb trauma found that, a year after injury, 35% of them believed they were fully recovered, though moving around was still difficult for 60%. Precarious movement reduced the participant's self-confidence and self-esteem and impacted on the self because they were no longer safe and secure in their bodies' abilities. Ricoeur (1992) acknowledges that part of a stable self is being safe, comfortable and confident in one's own body. Paulson et al. (2002) indicate that the body aids one's self-esteem, as it helps to define the self for the individual. Therefore, when movement and the ability to reach one's destination were impeded, as it was for the majority of participants in this study, stress and frustration occurred. As PC recounted:

> PC *I didn't realise how bad it was going to be until I tried* (to move around). *I thought I'd be right when I had that Ilizarov frame on. I thought,* **'Great, I've got the Ilizarov frame on I'll be able to walk'.** *Because they said* (the healthcare staff) **'You'll be able to walk on it'.**

An Ilizarov frame is an external frame fixed to the bone with pins protruding from the skin surface. Such frames are not uncommon as they are used when the fracture cannot be fixed opened and reduced internally. Nonetheless, there is the potential for the pin sites to become infected if not cleaned regularly. The frame allows the person to partially weight bear on the limb when using crutches, however this was not successful in PC's case:

> But it wasn't like that for me. I never, never could walk on it. I was always in pain!...It (the frame) was always getting infected, the pin sites and everything (so the doctors removed it and replaced it with a new full limb cast).

This participant's problems were complicated because the frame did not allow him to walk as anticipated. PI was an incomplete paraplegic, was wheelchair bound and his disability influenced how he moved about as illustrated below:

> PI *Mobility!... The sheer frustration at not being able to do what you used to. You have to rely on people, too! I can*

> *push myself alright but it's hard at my place because everything is so small. I've got no room to move around at all. If this chair was an inch longer I couldn't even get into the kitchen. As it is, if I misjudge it a bit I scrape the foot rest on the fridge door.*

Having a suitable house or residence to accommodate the needs of people with wheelchairs and other disabilities is essential. Usually patient's residential domains are assessed by qualified staff from the hospital and altered as required by either the Health Department or the Disability Service Commission before they are discharged home. In PI's case, this appeared not to have occurred as his home environment was clearly unsuitable for wheelchairs. The doorways of his home were too small to be safely negotiated by a wheelchair so he regularly knocked his hands or damaged the furniture. PN also experienced difficulty navigating his world while using his prosthetic limb:

> PN *I can't walk upstairs I virtually fall!...As I go to walk downstairs, I'm falling.*

PN's ability to walk on the flattest of surfaces was precarious and he found negotiating stairs even more hazardous. The participants all developed restrictions in their physical capacity as they could no longer perform common tasks because of their loss of limb function. It seemed that they had lost control of their bodies as they would not perform how the participants used to or in a way that they now desired. Some could not wash or walk because of their disability and, in addition to these challenging issues, was the problem of persistent pain.

Pain

Pain is always an individual experience and for this reason the influence it has on people and their lives is unique (Macintyre and Schug, 2007; Therapeutic Guidelines, 2007; Kleinman, Brodwin, Good and Good, 1992). For most of the participants, their physical inability was also influenced by their pain experiences and in some cases their pain was more of an issue than their injury. While the severity of pain fluctuated, its persistence was evident, as many had suffered on a daily basis from the time of their accident. PB had experienced pain since his accident over 20 years ago and others acknowledged that they sensed pain most of the time:

> PB *A lot of days I don't have <u>the pain</u>. They are what I call pain-free days. There's still a lot of pain there but it's gone from there to there* (signals with his hand to a lower level).

> PD *Whether it's a niggling pain or a sharp pain it just is there all the time, each day!*

> PJ *I have a continual ache, 100% of the time. I have learnt to deal with that. I get like a sharp, burning, stabbing, electric pain. That's pretty full on.*

> PL *My foot has got nerve damage from whatever. It's always colder that everything else. It's always got a level of pain.*

Pain is undoubtedly stressful and coping with pain was a major issue for some participants. Often the most simple of activities could cause pain for the participant which placed limitations on basic living skills. For example, PD explained how her pain aggravated her ability to tackle stairs, reinforcing how difficult it was to move between the levels of her home:

> PD *I have difficulty climbing stairs. If I had to come downstairs all the time it would be an absolute nightmare. It's so painful getting up and downstairs.*

PE described how the mundane actions of covering himself with blankets or using an air conditioner created pain:

> PE *If the blankets or sheets of the bed touch me it hurts, physically hurts. Like in summer we had the air-conditioner on and if it blew on me, on my leg or just breezed past that would hurt. Just physically hurt.*

Experiencing sensitivity and pain from stimuli such as the wind, a breeze, an air conditioner or blankets is known as allodynia and is a form of hyperalgesia. Hyperalgesia is a pain response to previously non-painful stimuli (Loeser and Treede, 2008). A diagnosis of allodynia is confirmed when stroking the skin with a camel hairbrush causes pain (Loeser and Treede, 2008).

It appeared pain influenced every aspect of PN's life, including the wearing of his prosthesis, as he explained:

> PN *I start having pain doing simple things. They become such a struggle and things start getting me down. I can't seem to do anything in comfort. If I don't have to do anything, I won't do it. I can't keep that* (his prosthesis) *on all day, it's hurting. What's actually made it worse is that I've got a neuroma.*

The wearing of a prosthetic limb should not cause pain but, rather, aid one's ability to walk. Those who have pain in their stump from neuromas or suffer with phantom limb pain often experience more hospital admissions, slower rehabilitation and repeated prosthetic fittings (Murray and Fox, 2002). PN's prosthesis was fitted later than usual because of the severity of his injury and the subsequent neuroma that had developed. Both of these events contributed to the problems he experienced with his prosthesis. The use of prosthesis among amputees varies. Some studies have shown less than 40% of amputees wear their prosthesis for more than eight hours per day. Despite this result, most health professionals will advocate the use of a prosthetic limb (Murray and Fox, 2002; Kooijman, Dijkestra, Geertzen, Elzinga and van der Schans, 2000). Research has shown that issues such as anxiety, depression and body image disruption are not as common in limb wearers as opposed to those who do not wear their prosthesis (Murray and Fox, 2002; Wetterhahn, Hanson and Levy, 2002). PN was distressed and frustrated at the lack of understanding and knowledge shown by the team who made his prosthesis:

> PN *You see I don't think the people who make the prosthetics understand. When they say,* **'This leg is just 2.5 kilos. It's the same weight as your leg'.** *It's the same weight as a dead leg!...*

PN acknowledged that his prosthesis replicated the mechanics of his former leg, but not the physiological biofeedback.

> *OK your real leg doesn't weigh 2.5 kilos because you've got muscle and everything holding it up and taking the weight. Now they've got a leg that's been chopped off and they've weighed it. But it's a dead weight, you know. They don't understand!... And you can feel a difference in the weights. Well, walking is different, you've got to remember to lift your leg and if you don't lift your leg you trip*

PN attempted to explain to the team that the synergistic relationship between his former leg and body had gone. If he wanted to walk using his prosthesis then he must carry its weight, but the team had difficulty comprehending this issue. It has been suggested that amputees who are unhappy with their prosthesis could be denying their injury and using their perception of an ill-fitting prosthesis as an excuse, which prevents them from coping with their injury (Murray and Fox, 2002).

Participants with persistent pain found their suffering difficult to describe and most tried to convey their pain with the use of similes to make their experience more realistic and concrete for the researcher. By likening their pain to a familiar objective experience, or by giving it a name, the participants were trying to reify their pain, making a subjective experience more objective and understandable to others. PE used the metaphor of a corkscrew to describe his pain:

> PE *The worst one* (type of pain) *was when the whole knee and shin felt like a corkscrew was turning your leg. It obviously wasn't. It felt like everything in your leg was turning in a circle. Afterwards, I have this tremendous pain.*

Goffman (1963) suggests that if people can understand another's torment then they become more tolerant and will taper their expectations of them. PK named his pain *neuropathic* and likened it to being *opened up with a Stanley Knife*. A Stanley Knife is the trade name for a box-cutting knife that has a sharp, retractable blade and is commonly used by store/warehouse workers:

> PK *Even now I get terrific pain. It's enormous, that neuropathic pain. It just is. I mean the pain I get now is like from the end of my toe right up there and goes to up to the backside* (draws a line up the outer side of his left leg from his calf to his buttock)*. It is like someone opening me up with a Stanley Knife. And mate that hurts!...*

Pain mediated all aspects of the participant's lives as it influenced their abilities to perform all their activities. Both Miles, et al. (2005) and Charmaz (1991) discuss how activities are limited when persistent pain is present. Moreover, it was not only the participant's physical capacities that were restricted by their impairment and persistent pain. The data indicated that their psychological perspective, mood

and self worth also changed significantly when they experienced a loss of self as a result of their loss of limb function.

Psychological

The participants perceived that their impairment and persistent pain made them abnormal in relation to the rest of society and that their altered image and activities supported this change in their thoughts and behaviours. To be 'normal' is to not deviate or behave differently from society's standards and expectations. No special requirements are needed for acknowledgement because accepted standards of communication are achieved and maintained (Goffman, 1963 p7). Impairments as a result of some event causing disability can alter self-identity and body image (Wetterhahn et al., 2002; Parkes, 1971). Body image is the 'combination of an individual's psychological experiences, feelings and attitudes that relate to the form, function, appearance and desirability of one's own body which is influenced by individual and environmental factors' (Taleporos and McCabe, 2002 p971). Changes in body image and self-identity can impact on the person's self confidence and communication skills as they have to learn to accept their different body image, abilities and activities (Sparkes and Smith, 2003; Smith and Sparkes, 2002; Taleporos and McCabe, 2002). Body image is a common issue for those who have an amputation and spinal cord injury, as problems of psychosocial adjustment and stigma can occur (Sparkes and Smith, 2003, Smith and Sparkes, 2002; Murray and Fox, 2002). For the participants, the acute, catastrophic events of losing limb function resulted in their present and future plans becoming disrupted as their personal, narrative of self identity and body image were altered, defective or lost because of their impairment. They tended to focus on their past lives, when the self and the body were whole, as their contemporary and future selves were lost, unattainable because of their newly-established, abnormal and disabled state. They struggled daily with the mundane actions of everyday living and when performing past behaviours. The following excerpts illustrate how some of the participant's current plans were focused on returning to normality. For example, PD was trying to motivate herself into 'normalcy' by keeping as active as her injury would allow:

> PD *I've got to get on with it* (her life) *and be normal!... And not down tools altogether regardless of this!...* (points to her affected limb).

> PC *I just want to walk around without crutches!... I just want to be normal, that's all I want to do!...*

PC grieved for the loss of his impaired mobility as he yearned for a return to 'normalcy' and being able to walk without crutches. PJ had similar yearnings but their reasons for wanting to be normal differed. For example:

> PJ *I want to be normal. I want to just be able to do whatever I like!... I want to do everything for my kids but I can't.*

Lack of normality was sometimes constant so strategies were put in place to manage this problem. For example, PG avoided sexual encounters because he was averse to be seen without his artificial limb as he believed this diminished him as a person:

> PG (Long pause) *I didn't change partners regularly or anything. Because I didn't want to deal with the psychological aspects of getting into bed and taking my leg off. It made me less of a person, because in the bedroom I'm not what you see standing in the door way.*

His lack of self-confidence in his body caused him to restrict the numbers of potential lovers. Ide (2004) acknowledges that such intimacy requires sensitivity from both partners and indicates that sexual performance is composed of physical and psychological aspects. Reactions by a sexual partner are highly influential to an individual's sexual activity and functioning. Having a participating, understanding partner is usually a major part of an intimate/sexual relationship and being sexual. Some people will be embarrassed or reluctant to show their damaged limb to a partner and this will influence their sexual relationships. However, when these intimate relationships are severed, loneliness, isolation and changes in mood are compounded (Ide, 2004). PE acknowledged that not being able to perform sexually caused him more anxiety and stress, as this was abnormal for him:

> PE *And also intimacy with your wife is just a no go! What sort of things have been happening there? Because I know*

> *all the nerve endings down there are connected to each other.*

PE was searching for answers regarding his reduced sexual performance. He questioned the potential for complications regarding his knee operation. He admitted that he was worried about this situation but did not acknowledge that this worry could be contributing to his reduced sexual performance. PI explained how since his accident left him paraplegic he could not perform sexually: *Sexually I can't function anymore.* Losing these intimate relationships influenced their actions, reactions and interactions with significant others, as it reinforced their altered body image and physical losses. Sometimes it was partners' and not the participants', who had problems with intimacy, as PF explained:

> PF *I'm divorced* (long pause). *But that's the way it goes, eh? She couldn't handle what happened to me. I mean I've got no animosity against her about that. She's still a nice person, she's a very nice person. But it got too much for her. She just couldn't handle what happened to me anymore. She wasn't happy anymore. So she kind of, she had to leave. Otherwise she'd never be happy and I don't think that was fair on her.*

Losing these intimate relationships augmented the participant's perceptions of their abnormality and loss of present and future narratives.

When the participants experienced body impairment and persistent pain they were not only physically drained but mentally and emotionally exhausted by their condition. Such emotional exhaustion results in chronic stress and burn-out which is the development of a lack of control and emotional exhaustion (Larsson and Scanner, 2010). The participants often described themselves as *low, down* or *depressed*. Clarification of these terms obtained during interviews indicated that they generally meant low in mood. Research indicates that similar neuro-biological changes occur at brain cell level when people suffer persistent pain, depression or anxiety (Symreng and Fishman, 2004; Wörz, 2003). That is, people with persistent pain feel and behave similarly to those who have the mental health problems of anxiety or depression because of the brain cell changes that occur. As PD explained:

> PD *It does, at times, yes* (her pain and disability made her feel low in mood). *Just thinking that you can't do what you could do. And you get jacked off not being able to do* (her usual activities) *and being in pain.*

> PN *I never used to be depressed!... I have never been a person who gets depressed. People would come to me and tell me all their problems all the time. I get depressed quite easily* (now). *This* (his accident) *has changed me. I'm not comfortable. I'm embarrassed!... I'm ashamed!... I still have pain. It's not as if I can go to work and be happy about what I'm doing.*

Depressed was how PN described himself because of his altered physical appearance. He was tormented by becoming an amputee. Not only had his physicality changed, but mentally his mood had altered. He had gone from being an active member of many groups (he did lots of physical activities including martial arts, running and playing soccer) to staying home and isolating himself, because he was ashamed of his impairment. His self-respect, esteem and confidence were poor. According to Ricoeur (1992), when this occurs the moral norm of the self becomes fractured. Changes to physical abilities and mood reinforced to the participants the perception that they were abnormal. The perception of becoming different to others influenced the actions, reactions and interactions of the participants as it reinforced how their self and their moral norm became dislocated. For example, since his loss of limb function PC identified himself as *grumpy* when he had issues concentrating:

> PC *My mood!... Oh I think that's all changed too! I don't stick at anything too much, I just get grumpy!... I get all ratty.*

PF described, with sadness, what he had lost since he became a paraplegic:

> PF *You know, for example, say a hot night, you want to get out of the house. It's a hot night, you want to go for a walk along the beach. You can't do it!... It's just not there anymore. It's been taken away from you!... Just feeling the cold sand, feeling the water on your feet, it's not there anymore.*

PF's description of the sand and water were quite sensual, portraying his sense of tactile loss and potential need. He continued to despondently discuss the experiences he missed:

> *Little things like that. You miss a lot of little things in life which are important, I think. But all those little things together, they make one big thing don't they? And I think it's the simple thing that you used to do easy and the things you used to enjoy, you can't even do them any more…*

PE acknowledged how emotionally labile he had become:

> *PE I can't believe how emotional I am. I get so emotional, I breakdown crying and think nothing of it. I don't know why I could cry now, just lose it, now!...*

He likened the feelings he experienced to those he had when his mother died:

> *The only other time X* (his wife) *has seen me like that was when my mum died. But now I could breakdown at the drop of a pin. That even gets me down more!... I'm really tired and depressed. Everybody's feeding off your energy and they're all coming down* (in mood).

PE was aware that his low mood influenced the rest of the family, as was PJ:

> *PJ The emotional side is just as debilitating I guess, because I feel I've let my family down with my depression. I'm always moping.*

PJ was concerned about the impact her mood was having on the family and this seemed to reinforce her emotional debilitation. PI also acknowledged how his mood affected his wife:

> *PI I suppose I've gone down a touch* (in mood) *these last few months. The fact is, my wife has gone down a touch too.*

These participants were aware that their emotional state influenced not only themselves, but also other members of the family and this seemed to add to their emotional burden and physical impairment.

Mood changes and psychological distress in the form of depression or phobic anxiety states are common with loss of limb function (Halcomb et al., 2005; McCarthy, Mackenzie, Edwin, Bosse, Casillo, Starr and The Leap Study Group, 2003). Andy, one of the 2005 American Olympic wheelchair rugby team, comments that overcoming the mental anguish associated with disability is bigger than the physical issue of paraplegia (Rubin and Shapiro, 2005). Charmaz (1991,

p195) explains that when people have chronic pain and attempt to recapture their old self it causes 'endless sorrow and depression' which indicates that pain, mood changes, disability and illness are interlinked. Geertzen, et al. (2006) also discuss how persistent pain, depression, stress and learning to cope are all intertwined. Differentiating between each of these experiences is difficult. The issue of developing mental health problems after limb injury is further highlighted by McCarthy et al.'s (2003) investigation which discovered that over 40% of 545 participants screened two years after a lower limb injury showed some psychological distress. Approximately one fifth of participants in their study described severe anxiety or depression at their two-year review, with 20% having contacted mental health services for assistance. Factors associated with their poor mental health included reduced physical function, being younger in age, belonging to a non-white race, alcohol issues, low socioeconomic factors, poor self efficacy and inadequate social support. Such findings are supported by Mackenzie et al. (2006) who acknowledge that psychological distress is a predictor of one's ability to return to work. A pilot study at RPH indicated that 35% of patients reviewed at three months, post major trauma reported depressive symptoms and 17% experienced post traumatic stress disorder (RPH, 2008).

Three of the participants in this study indicated that their mood had become so low that they had contemplated suicide as a way of ending their misery:

> PA *A lot of people commit suicide and stuff because it just gets too much!... And it does!... Because, believe me, don't think I haven't thought about it. I had a couple of days there that I thought I just wasn't going to make it!...* (continue to live).

PA indicated that she had thought about suicide. PB explained that he had once attempted to kill himself.

> PB *Yes, occasionally I get depressed and upset about what could have been. What might have been!... I was actually on my own at one stage in a hotel. I got a bit depressed so I took a whole bottle of methadone. Three days later I went to see my GP and I said,* **'I got depressed and took the whole lot'** (the remaining tablets in the bottle).

It is not uncommon for people to become tolerant to some medications, especially the opioid group and clearly PB had developed a high level of tolerance. This is an adaptation process which occurs with increased drug exposure. As time passes more of the drug is required, either as an increase in dose or the same dose is taken more frequently to obtain the same effect (ANZCA, 2010; Therapeutic Guidelines, 2007). PE also seriously considered suicide:

> PE *Even my sons have said, **'Gee you're so down'**. You don't realize, it's a slow process. But everyone says **'You're so down.'** You just don't want to do anything. Even now my best friend he comes up and says, **'You know I was worried that you would do something silly'.** .*

A clarification of *silly* was sought:

> *Oh, he thought I was going to hurt myself. And those thought do cross your mind, sometimes. Just fed up with the pain and the lifestyle change. Where's the light at the end of the tunnel?*

Four years post injury, PE was admitted to hospital after a serious suicide attempt which required that he be admitted as an involuntary mental health patient. For the first two weeks of this admission he was on 'suicide watch,' meaning he was accompanied by a nurse at all times to ensure no self harm occurred. Alterations in mood and the perception of being abnormal were also enhanced when the participant's social outlets were reduced, which is common when loss of limb function and persistent pain are present (Miles et al., 2005).

Social

Individuals often personally identify themselves by validating their experiences and being recognised in society because of their personal abilities and achievements, such as their employment, athleticism or social activities (van Manen, 1998; Goffman, 1963). Cast and Burke (2002) indicate that personal identity is tied up with the notion of self-esteem and social groups as particular behaviours contribute to self-esteem, self-efficacy and self-verification. These qualities can buffer negative life events as they act as a resource and offer protection to the individual. Schrag (1997) comments that an ethical life is constructed in accordance to how one's life meets their personal goals within the

notions of responsibility, duty, obligation and a concern for human rights. The participant's personal ethics for living a positive, productive and true life were intertwined with being physically active and working hard for their employers. As the participants explained:

> PA *I would work 12-14 hours a day… when I was working, it was my life. All I did was work and go to the gym. This has practically ruined my life!...*

> PC *I'd work 10 hours a day and I work night shift and all… I used to just get up and go. But I can't do that now!...*

> PE *I've always been a conscientious worker too…*

> PI *Yes, I sometimes worked 7 days a week...*

Several participants in this study also justified their existence by being an active member of some group (usually the gym), as the following excerpts showed:

> PD *I used to do like, walking, running. I used to do outside work. I just feel a bit more de-conditioned, walking or running every day for years to not at all.*

> PE *I've always been an active person. I go to the gym, always out and about doing something. All that has come to a stop!...*

> PK *Always* (doing) *never stopped…*

> PL *I was always doing things; yes I mean that's the only way I lived. My entire existence is about doing things!... I mean, I don't know what other people do, but for me I'm either going out, or I'm going to do the Avon Descent or I'm going to do this or that or whatever!... And if I'm not doing things then that's the end of my existence from my perspective!...*

The Avon (River) Decent challenges competitors from around the world to a two day, 134 kilometre race of grueling water trials, using varying paddle dinghies and power crafts. This race offers competitors varied experiences, such as stretches of flat water that will test the endurance and fitness of the competitors, to the rapids which challenges the negotiating skills of the competitors because of the unknown contours of the waters. To take part in this race, the competitors must be physically fit, having the ability to competently swim in moving water, be able to

manage their vessel and eddies and wade through fast moving waters, often carrying their boats. PL obviously previously had a high level of fitness to enable him to participate in such an event, prior to his leg injury.

In order to adjust to loss of limb function, the individual is required to lose their old vision of the self and change their assumptive world so they can develop a new self, one which incorporates their disability caused by their trauma (Parkes, 1971). This could be what Yoshida (1993, p223) identifies as the 'disabled identity', which is a part of a new total self. However, when personal abilities change because of disability the person behaves differently to the self, to the family, to friends and society, causing them to be stigmatised as defective, odd or unusual. This is especially true when impairment is visible to society (Goffman, 1963). Since the development of their individual injuries, the participants had been forced to re-evaluate their sense of self and their ethical aims. What had once constituted a 'good and true life' could no longer be continued because of their limited abilities and reduced work performance.

Harrison and Kahn (2004) and Smith and Sparkes (2002) suggest that society is unsure of how to communicate, act, interact and react with those who have a disability. According to Parkes (1971), when one loses limb function they find it hard to discuss their injury as they grieve for their loss, increasing communication difficulties. Difficulties with communication increases the individual's pain, isolation and suffering which results in reduced self-confidence and poor self-esteem, fracturing the self and the moral norms (Asbring and Narvanen, 2002; Hentz, 2002; Ricoeur, 1992; Charmaz, 1983; Goffman, 1963). Alongside alterations in personal and social identity, those who have lost limb function usually experience changes in their self-image, self-esteem and self-efficacy, again influencing the moral self. As these changes create problems in communicating and when forming relationships with others, this personal suffering further reinforces their disability and loss of self (Horgan and MacLachlan, 2004; Hugenberg and Bodenhausen, 2004; Taleporos and McCabe, 2002; Arnstein, 2000; Frank, 1995,1991, Yoshida, 1993).

The data identified that it was not only the participants' physical limitations and mood that restricted them from rejoining their previous social groups; the participant's were now seen by others as disabled and no longer normal, hence they had become 'discredited,' 'the other' and 'different,' concepts which are discussed by Goffman (1963, p 4). These ideas are supported by Bury (1991) and Charmaz (1983, 1995) who both confirm that the integration of the personal self is maintained through individual and social relationships. On the one hand, the participants in this study could not communicate effectively because of their disability but society was also reluctant to communicate with them because of that same impairment. This poor communication mediated through all aspects of their relationships with their friends, colleagues and communities.

Friends

Prior to his accident, PB received regular invitations to parties and social gatherings with his friends but now they have ceased:

> PB *Yes I used to go to X and Y's house for BBQ's when they were having one. We'd all go, the whole gang would go. I'd go. But by 9 o clock* (at night) *I'm saying to X, **'I've got to go home'.***

PB found he could not stay when invited to a party and he would ask his host (or someone) to take him home earlier than anticipated, causing inconvenience to the other partygoers. Ultimately, the invitations stopped and *the gang* ceased socialising with him. PJ explained how friends would no longer visit her because they did not understand her condition: *Friends have gone because they don't understand. I've lost so many friends.* PG indicated how *the boy's* interactions changed towards him after his amputation:

> PG *I used to go to the pub and the boys used to throw darts at the foot* (his prosthesis). *I went for a while but then they began to miss* (his prosthesis) *and that hurt!...*

It was indicated that his friends were deliberately targeting his flesh and not his prosthesis. Whereas PN's friends could not cope with his amputation and their response was to not visit and avoid contact:

> PN   *You know I lost a lot of friends. Because a lot of them were horrified at what's happened. I can't get out and visit them. They find it hard to cope with how I am* (an amputee). *So they don't visit. I've become a hermit!...I have and that's being honest.*

The lack of socialisation with his friends caused him anxiety and misery. It reinforced his physical differences as he was no longer considered one of *the crowd.*

Socialisations and interactions were also influenced by financial pressures which usually made the cost of entertainment too expensive for the participants. The primary cause of limited finances for them was their lack of employment because of their disability. Being employed is important in Western society as it promotes self-worth and personal satisfaction, although returning to work after losing limb function can be difficult (Mackenzie et al., 2006; Halcomb, et al., 2005; Rose, 1999; Charmaz, 1983).   Unemployment is associated with poor psychological well-being, higher incidences of depression, lack of satisfaction with one's life, reduced social activities, material deprivation, a negative future outlook and an increase in stress levels (Creed and Klisch, 2005). Having a lack of a viable income compromises one's ability to pay for goods and services they need to meet daily living costs, encountered in today's consumerist society.   Most of the participants had financial issues which negatively influenced their socialisation. For example:

> PH   *No, I don't have any social life.   I know people in wheelchairs that do. I have the added burden that I don't have a lot of money. So maybe if I had money and I had the friends I'd maybe have a different social life altogether.*

PH was living on a limited budget and could not afford to socialise. PI had a similar story. He and his wife rarely went out together as 'a couple' because of monetary restrictions, as he explained:

> PI   *But I think most of all it is financially we cannot do a lot of things because of the cost. We can't afford to go out any where. Financially, it's very difficult. We virtually live on the 'specials' because we can't afford to go out anywhere*

Specials are reduced price items that supermarkets advertise on a weekly basis. While people may be able to survive on 'specials' this limits the choice of other food and goods which are not otherwise promoted in the stores. Not being able to go out and socialise with others created tension in their marriage as it reinforced that their world had diminished because of their financial limitations. PJ acknowledged that all of her immediate family was dependent on various government pension schemes as the participant and her husband were not able to work.

> PJ *He's* (her partner) *a first class sheet metal worker so he's got a trade and he was earning good money. Now he's on a carer's pension and I'm on a disability pension…*

PJ continued to explain how their restricted income was a source of ridicule. Her partner was now identified as a *skirt* (someone who is dominated by their female partner) by his friends because he could not afford to socialise with them:

> *And also people's attitudes, his mates are saying,* **'Come on you skirt, come out with us, or can't you leave your bloody kids for 5 minutes and come and have a beer'?** *And it's like* **'No we haven't got the money',** *we just don't have the money for X* (her partner) *to go and have beer with his friends.*

Financial problems caused by people experiencing loss of limb(s) function usually commence on the day of trauma, when the person is taken to hospital (WHO, 2004). Reduced social outlets and activities because of restricted finances augment one's psychological distress and reduce one's well-being (Creed and Klisch, 2005). Being financially compromised transforms lifestyles, as deciding where vital, limited finances are to be spent is stressful, according to Charmaz (1991). It was not only the lack of finances that reduced socialisation. As most of the participants did not work they were unable to associate with work colleagues.

Work Colleagues

Remaining employed was difficult when the participant had lost limb function. Workplaces are considered a major source of status and socialisation (Goffman 1963). Most people spend several hours a week working, therefore, when one is unemployed, this avenue of socialistation is lost. Holtslag, et al. (2006) reports

that, 75% of those who were working at the time of their trauma do not return to their previous job after lower limb injury. Ten of the fifteen participants in this study were not working at the time of interview.

PA lost her job and her home after acquiring her loss of limb function and her former salary had encompassed food and accommodation expenses. She acknowledged how lonely she was, *I had to move, that was hard. So it's been a bit lonely. It's been very lonely!*

After PF became paraplegic he could not return to the building trade:

> PF *You see them* (your workmates) *a bit for the first couple of years, or first year or so. But after a while, I found that they've got their lives, especially if they've got a family. They've got their lives and they move on. Because your life has changed and you're not out there.*

He pragmatically accepted his loss of contact with former workmates. Losing work colleagues reinforced their differences and feelings of loneliness. Loneliness causes sadness, stress, mood changes, despondence and a reduced interactive social world (Lund, Casertra and Dimond, 1993; Stroebe and Stroebe, 1993). Social interactions for the participants were also compromised when they perceived that the general community discriminated against them. Taleporos and McCabe (2002), Charmaz (1991) and Goffman (1963) discuss how those with a disability are often given a negative image and are isolated from society as they receive off-putting interactions from their communities. These interactions caused more damage to a fragile self-image, esteem and confidence.

Community

Negative situations within the community occurred for the participants in this study as they could not perform as expected. Goffman (1963) acknowledges that communities have little respect or acceptance for those who cannot behave in a way that is considered normal by the community. For instance PA explained how shoppers at her local supermarket stared and avoided her while she dealt with an unexpected bout of severe pain:

> PA *Going in to the supermarket you get in to one of the aisles and you just can't move any more because of the pain. So you're stuck there!... You've got your leg like this and your **'Umming and arring'** and you're rubbing it, trying to get it going. People are looking at you as if you're having a fit or something.*

PA was stared at but offered no assistance when affected by a spasm of pain. PH believed seeing the wheelchair attached to her car influenced the general public's reaction towards her:

> PH *The disability plays a bit of a part. I still reckon people see my car, see the wheelchair on top, I'm hoping I'm wrong here but I reckon they see that chair and think **'No I couldn't be doing with that'** and then they switch of.*

PH's perception was that when people saw her wheelchair they either ignored her or, if they decided to interact with her, they treated her as if she had reduced intelligence. The notion of being *different* was reinforced by PF:

> PF *You know they* (the general public) *just they think, well you're different!... You're not a lot different, it's just that you don't work and you do things a little bit different.*

PF recognised his loneliness and rationalised his physical changes and others reactions towards him:

> *You get lonely occasionally; probably because people shy away from you after a while. A lot of people get their own picture in their head* (about the disabled) *I suppose, they picture things differently, I think.*

PF believed that his difference (being a paraplegic) influenced public reactions when offering him advice:

> *Able bodied people come up and talk to you. But they don't really know what you're going through. Words are cheap. They don't really understand. They don't know. They haven't got the foggiest of what you're going through. But people have a lot of advice for you.*

Advice from others appeared to irritate him as he suggested that it showed they had little insight into his paraplegic world. PK explained how people's reactions towards him influenced his mood:

> PK *If we're going to have a beer somewhere and somebody* (the waiter) *looks at me and then talks to X* (his wife). *I say* **'Excuse me mate what's you're problem? What is your problem, why aren't you asking me, why are you looking at X just because I'm sitting a bit lower than my wife here?'** *It gives me the shits!...*

PK became angry when people ignored him and preferred to talk to his wife. When people are different from those in mainstream society they are often given an altered image, stared at, discriminated against, segregated and avoided (Smith and Sparkes, 2002; Goffman, 1963). Discrimination, poor communication and lack of understanding were also apparent within the institutional setting.

Institutions

Some welfare institutions dealing with the injured were reported to have communicated poorly with the participants in this study. For example, PC had been registered on sick leave for several weeks as he had fractured the bones in his lower leg. He received a letter from the government employment agency, threatening him with non-payment of his benefit if he did not attend a meeting regarding his sick leave payments:

> PC   *X* (his partner) *rang up Centrelink* (the government employment agency) *and tried to explain that I'd just had a bone graft but they said,* **'It was policy'.** *I have to go or they'd stop my benefits!...*

PC had left the hospital a couple of days earlier, after having a bone graft applied to his leg and was wheelchair bound. He telephoned the relevant authorities and explained his situation but was told that he must comply with *policy* and attend this interview or his financial support would be suspended:

> *So we get there, there is no way into the building except twenty steps up at the front. We get in and as we walked* (his partner walked, he was wheeled) *in the woman took one look at me and said,* **'What are you doing here?** *She sent us home. You get that sort of stuff all the time.*

PC had to get out of his wheelchair and use his arms, good leg and support from his partner to 'hop' up these steps. It is not uncommon for bureaucratic government systems to be incompetent, inefficient and only offering fragmented care, as they

tend to focus on their own area of policy and not the collective care of the individual (Miller and Rose, 2008). Moreover, physical access to health and welfare services for those who are disabled is often limited (Lumby, 2001). PH explained how she suffered discrimination at the hands of her co-workers, including her boss, because of her disability:

> PH *It's the way I'm treated* (at work)*, I don't like it. It doesn't happen everyday. It's just like they have a bad day and they take it out on me! I have had one actually have a go at me a bit below the belt. That was a direct hit at my disability. I wasn't happy with that cause the big boss was there with her at the time and he didn't tell her to stop!... He just let her go!... I didn't think that was very ethical.*

Those who were educated were not excluded from the socially discriminatory practices. PR worked as a disability representative with the Student Guild at one of the local universities and spoke of the issues experienced by some of the disabled students:

> PR *I have had a lot of reports of discrimination really by some of the lecturers* (from the students who have a disability)*. I don't think they* (the lecturers) *have an understanding!... Even though they might have a theoretical understanding and say* **'Oh we have to meet the needs of the disability service plan at the University'.** *But when it comes down to it, I don't think they really have an understanding, or they're too busy for it.*

PR recounted one student's experiences:

> *For example one student came to me and stated* **'The lecturer had made me perform a different assessment to everyone else because I was disabled'.** *But it was much harder than what everyone else had to do!...*

She described how some lecturers ignore the needs of the students with a disability:

> *Some lecturers, when they have visually impaired students, the lecturers are required to give handouts. Because the students can't see the overheads or power point or whatever!... So they require the handouts to follow the lecture or they sit there listening to someone blab on. Not getting anything out of the lecture, as there's no substance to it. It's a bit tricky when somebody would rather you die than give you an extension!...*

Students with a disability also suffered at the hands of the able-bodied students. PR explained how those with wheelchairs could wait several minutes to gain access to an elevator because other students would discriminate against them:

> *I think there needs to be attitude changes in the general student population as well. It's not just teaching. Like the lift in the library. Obviously there are cultural differences, but some students will jump in a lift altogether, there will be a person in a wheelchair waiting there and they won't let them in. They say to them* (the disabled person), ***'Oh no wait for the next lift'.***

It was not only the welfare and educational facilities which offered poor communication and different treatment to those with disabilities. There was also evidence that interactions and communications with health care professionals became problematic at times. Usually such relationships can be a source of safety and comfort but for some of the participants these contacts generated frustration, anger and distress. For instance, PC presented to an Accident and Emergency unit which was in the public sector and explained how, in that environment, he was ignored by two nurses in that unit:

> PC *And I sat there for about an hour and a half with the Triage nurse. Well, two of them stood and discussed **'Where they get their hair streaked'.** That really pissed me off!... So then they asked the question **'Have you had an operation in the last seven days?'** It was actually the eighth day from when I'd had the frame off and they just went **'NO, policy is seven days so I'm not going to write that down'.***

These actions can be identified as 'denying personhood', identified by Higgins (2001, p117) as these nurses appeared totally detached from the situation and from PC's suffering. Some hospitals have a policy of automatic readmission to the hospital if problems occur after a set amount of time after surgery. At this hospital it was seven days, but PC's surgery occurred eight days prior to his presentation to the Accident and Emergency department so he was not readmitted. PC then attended a private accident and emergency department but was asked to leave as he could not pay for the care he needed. He elaborated further:

> *They put me on all sorts of pain killers and nothing was working!... I was in real bad pain. Then about two hours later the doctor came in looking all funny and goes, **'I really hate saying this but, I have to!... This is hospital policy unless you can come up with $1600 you have to leave now'!...***

The doctor appeared reluctant to request the payment as it was obvious PC needed medical assistance, but he was required to comply with *hospital policy*. There was no negotiation regarding the payment and, as he had insufficient funds, he left the establishment and returned to a public sector Accident and Emergency department. These interactions also caused PC to suffer pain and discomfort. As soon as he was seen by the medical staff he was given intravenous analgesia, antibiotic therapy and was admitted to the hospital for several weeks.

Frank (2001, p358) identifies that once admitted to hospital the individual is reduced to a 'diagnostic category,' as personal suffering is often ignored and the health professional usually only pretends to care. However, when commitment is demonstrated by the health professional the psychological distress and the burden of illness are reduced for the patient (Higgins, 2001; Speedling and Rose, 1985). Lupton (2003) suggests that the rapport between the health professionals and the patient is comparable to a parent/child relationship as the patient tends to rely on the health professionals for physical and emotional support. This unequal power relationship can leave the patient ignorant about their condition or illness and somewhat disempowered as they are relegated to the periphery of the decision making process (Bail, 2008; Fox, 2002; Beck, 1992). However, should the health professional be articulate when expressing their views about what is occurring, then patient's generally feel more empowered and comfortable with their care (Higgins, 2001; Moore, Adler and Robertson, 2000; Speedling and Rose, 1985). The interactions in this study illustrated how some health professionals in both the private and public sectors rigidly adhere to existing policies. Such inflexible adherence to policy is difficult for most healthy people to manage but, for those who are sick and disabled, it served to reinforce their vulnerability.

Another participant, PG, was surprised by the response he received when he revealed his intention to resume riding his motorcycle once he had sufficiently recovered from his injuries:

> PG *When I was in the rehabilitation hospital a social worker, psychologist or some woman came in. I don't know, she must have been trying to help with the loss of my leg. No help at all was she!... All because I'm a bike rider and I will always ride a bike. It's a reality!... And I told her* **'I'm going to get back on a bike and ride'.** *She actually turned around and said to me* **'You have a death wish'!...** *She walked out after that.*

While the therapist obviously considered bike riding to be foolish, her response was perceived as insensitive by the participant. PG believed the therapist should have been more supportive about his intentions and desire to ride again. PN also had problems explaining to his rehabilitation consultant his concerns about explaining to a potential lover about his amputation and prosthesis:

> PN *I tried to explain to the rehab lady. I said,* **'OK you don't know me, we've just met and we take a liking to each other. After a few weeks you come over and decide that you're going to stay the night and I say excuse me while I take my leg off. How are you going to feel?'** *She said,* **'Well'** *she went white and said,* **'OK I understand.'** *She said,* **'Well obviously you have to meet the right person'.** *I said* **'OK well what do you do, everybody you meet you say, Hi I've got a prosthetic leg or what?'** *They just don't understand. I don't know, it's hard to explain to somebody.*

PN eventually wanted to have an intimate relationship with someone. He was requesting advice about how to tell someone about his amputation, but became frustrated when he perceived a lack of understanding and support from his listener. When healthcare staff present as unsupportive, ignore patients and appear reluctant to listen to them then, Widar, Ek and Ahlstrom (2007); Lupton (2003); Fox (2002) and Higgins (2001) indicate that the patients are feeling uncared for, becoming disenfranchised and that problematic power relationships are occurring.

Lack of integration with healthcare professionals, friends, former colleagues, communities and institutions alters one's self image, reduces self-confidence, self-esteem and self-respect, thus enhancing and reinforcing the need to isolate oneself

(Chapman and Volinn, 2005; Hentz, 2002; Charmaz, 1983). Unfortunately, isolating oneself can cause more negative thoughts about the self and society which makes it even harder to socialise. This is because one's self- respect, self-esteem and self confidence are further reduced which, again, supports the need to isolate oneself, thereby creating a downward spiral. Therefore, poor self image and confidence underpins difficulties with social interaction and a lack of positive reinforcement from this social interaction causes a further reduction in self-confidence so the person withdraws further from society (Chapman and Volinn, 2005; Hentz, 2002; Charmaz, 1983).

Summary

In this chapter precursor events were discussed which resulted in the basic social problem, Loss of Self which was experienced by all the participants. Development of Loss of Self occurred in two ways for the participants; either from sudden or gradual loss of limb function from either major or minor trauma. When loss of limb function occurred suddenly, these participants had often experienced major trauma with impairment and loss, usually occurring within hours or days of the critical event. In these cases, injuries were generally life-threatening and serious, requiring, lengthy recuperation and restorative processes to salvage (where possible) some elements of limb function.

When loss of limb function occurred gradually it was usually as a result of the participant experiencing minor trauma, causing a delayed impairment. Frequently their loss of limb function developed sequentially, over weeks and months, as an outcome or consequence of unsuccessful management of their original injury. The participants had looked to the medical profession to repair their damaged limb as they underwent multiple investigations and treatments in order to achieve a cure. However the procedures they endured typically caused more damage to their effected limb. This process resembled the downward spiral of a helter skelter as their limb function never returned to its previous level of movement, activity or function.

Physically, the participants were actively restricted. They were unsure of their body's performance and this caused the participants' physical self to become lost.

Psychologically, they were traumatised, as their future personal narratives underwent considerable changes to reflect their new disabled situation. As the mood of the participants changed the moral self became fractured, as they lacked self-confidence, self-esteem and self-respect. Socially, the participants became isolated as they had lost their ethical aims of working hard and being active. Their social isolation also reinforced a loss in the moral self as their communication with others had altered because of their perception of becoming abnormal.

CHAPTER 4

<u>The Basic Social Process:</u>

<u>Accepting a Reduced Self</u>

Overview

In order to deal with the basic social problem, Loss of Self, the participants were required to engage in the shared core process that was identified as: Accepting a Reduced Self. This chapter explains the stages and identifies the aspects of this process. Acceptance is concerned with being tolerant and acknowledging, or agreeing, to specific circumstances (Oxford English Dictionary, 2003). For the participants in this study, Accepting a Reduced Self influenced their ability to cope and move on with the situation that developed when they lost limb function. They now had to tackle the biopsychosocial disruption produced by their loss of limb function as they were required to constantly manage their resultant disability. Some participants had difficulty believing that their limb function was permanently lost, as the thought of enduring the consequences of their disability was too stressful. Others were in a constant state of biopsychosocial flux, recognising the permanency of their loss while struggling with physical impairment, emotional trauma and social stigma.

Accepting a Reduced Self had three distinct stages: Floundering, Treading Water and Wading to Shore. Floundering was conceptualized as a scene of chaotic activity with minimal productivity. The participants in this stage failed to recognize the permanence of their impairment often reacting to as opposed to acting in the situation so acceptance of their situation was poor. Treading Water was visualised as a stage of confusion, whereby the participants suspected that their disability was permanent and made practical plans to manage it. However internalizing their loss of limb function still could not occur so, it appeared their acceptance of their disability was variable. Wading was conceded as an action which when developed the participants could cease Treading Water and move to the shore. The shore was considered a space of safety and when reached it allowed the participants to minimise the problems, chaos and uncertainty of Floundering and Treading Water. When Wadding to Shore the participant's

acceptance and adaptation to their situation was constant and they appeared to manage the stresses and strains of their impairment with a level of surety and confidence. The three stages were interconnected, not sequential or mutually exclusive and were always relational, as their borders were permeable and intersecting and all influenced each other in relation to the biopsychosocial consequences that the problem Loss of Self created for the participants. This meant that a participant could be Floundering from a psychological perspective but Treading Water or Wading to Shore from a social or physical perspective. Also, the relevant aspects of the stages were linked as participants could, for instance, have the ability to shower independently but have difficulty moving from one destination to another. Therefore, multiple combinations of the three stages could develop, as each stage and aspect influenced the participants' biopsychosocial ability to Accept a Reduced Self. Other mediating factors that influenced the basic social process were the participant's pain experience, the type of trauma experienced, the length of time since their injury and their support crew.

Floundering

When the participants were at the Floundering stage they struggled to manage the biopsychosocial consequences which they experienced following their injury. Their displays of coping abilities appeared poor and sometimes were non-existent. While attempting to Accept a Reduced Self, these participants were unsure of how to start to cope with their current problems. Rebuilding their lives with their impairment appeared impossible to them, as often they were overwhelmed by their physical limitations, psychological turmoil and social isolation.

Biological (Physical)

At a physical level, when the participants were at the Floundering stage, they tended to rely on others to meet their physical needs. For example, PJ relied on her partner to assist her in the shower and meet her personal grooming needs: *I have to get my husband to help shower me.* The physical difficulties associated with moving from one place to another at the Floundering stage was a challenge for the participants, with several using wheelchairs or aids. PC required a wheelchair but, as he was so heavy, pushing him was physically too difficult for his partner, thus he tended to stay home:

> PC We *just don't go out. It's too much of a hassle. Because I'm such a big guy if we go any where it's in a wheel chair, but that's such a struggle for X* (his partner) *to push. It's too much like hard work.*

PN met the challenge of moving around through utilising his prosthesis, even though it made his stump feel numb. To cope with this situation, he would remove his prosthesis at the earliest convenience.

> PN I *can't sit there with it* (his prosthesis) *on. Even at work I take it off. I'm sitting at the desk in the corner so nobody can see me so I take it off and rest my leg on it.*

Research suggests that the wearing of a prosthetic limb aids sensory and motor cerebral reorganisation, although it is common for amputees to not wear their prosthesis (Karl, et al., 2004; Murray and Fox, 2002; Kooijman, et al., 2000).

Managing the home, cooking and cleaning all appeared difficult for the participants who were at the Floundering stage. Both PC and PH had adults to help them prepare meals:

> PC *X* (his partner) *leaves me something for lunch…the freezer is full of frozen meals.*
>
> PH *Mum cooks tea for me! Not that I've asked her to but she can't see the point of me cooking again when she's cooking. She used to cook it back when I lived in the other house too.*

Ricoeur (1992) suggests when one cannot physically perform certain tasks, then the body is compromised and the self becomes lost. PJ explained how her daughter shared the burden of meal preparation.

> PJ Now *X is eight* (years old) *that child has to get up in the morning, make her own breakfast, make her lunch, get herself dressed and does her own hair.*

As the conversation progressed it was obvious that this child's assistance did not cease with self-care, but extended to other family members:

> *She gets the babies out of bed and changes their nappies, she makes their breakfasts.*

After breakfast, she washed and dressed her two sisters in the morning prior to going to school. When the child was at school these two sisters were cared for by their parents though, once she returned home from school, the eight-year-old's tasks recommenced:

> *X comes home from school and we do homework together for about half to one hour and then it's,* **'X, can you be with the kids for a minute? X, can you help mum do this?'**

The local welfare authorities were monitoring this situation regarding the household duties and the responsibilities this child was assuming. Reliance on others reinforced the participant's dependence, reducing their self-confidence and self-esteem, which influenced how they felt about themselves as well as their psychological wellbeing.

Psychological

From a psychological perspective, when the participants were at the Floundering stage of Accepting to a Reduced Self they tended to either:

- deny the consequences of becoming disabled;
- set inappropriate goals;
- blame someone for their injury;
- descend into despair about the consequences of losing limb function.

Denial

Schmitz Saile and Nilges (1996), state that denial is present when people cannot accept the physical limitations caused by chronic pain and keep seeking a cure for their disability. Smith and Sparkes (2005, 2002) also suggest something similar when those with spinal cord injury do not accept their injuries. Payne, Joseph and Tudway (2007) advocate that accepting things as they were before their trauma can be easier to tolerate than challenging the status quo, as developing new or alternative beliefs requires a change in one's practice and further expectations. McCracken, Crombez and Dahl, (2008) agree, indicating that recognising the permanence of one's disability and making one's goals more realistic could be more of a challenge than concentrating and trying to meet one's pre-injured aspirations. Parkes (2002) acknowledges that denial is an ongoing state when the

postponement of painful issues regarding current reality and present trauma are too difficult to accept.

Denial was evident for one participant who had been unable to walk since early childhood. Despite this, she insisted she was not disabled:

> PH *I don't class myself as disabled*

This woman was wheelchair bound, used a car especially adapted for those with a disability, parked in a disabled bay, had ramps around her house and had several facilities fitted throughout her home designed to assist with the management of a disability. She had three goals in life: firstly, she wanted to work for a living; secondly, she wanted to buy a car; and lastly, she wanted to be 'normal'. She seemed to believe that if she attained the former two goals, her third goal of normality would also occur.

> *I said, **'I want to go out and get a job, buy a car and be normal'**. I never had any vision of going on a pension* (financial government assistance). *It wasn't my scene. I didn't want to be dependent on a pension. It wasn't my cup of tea.*

PH exceeded her goals when she took on a mortgage to purchase a house, although maintaining the repayments proved difficult:

> *I mean, if I hadn't a job none of this would have come about* (she would not have been able to buy a house). *I'm trying to keep a mortgage going on one income, it's not exactly easy.*

To cope with the financial stress PH tried to find a second job to help pay her mortgage but this was impractical and unrealistic. She was already experiencing problems meeting her present full-time work commitments because of the negative sedative effects from the medications she was prescribed:

> *I was popping a lot of pills. A bit like I am at the moment, but a lot of the medications I'm taking really make it hard. Like, how do I now get up and go to work?*

PH used allocated leave for any required surgeries so she was not away from work and would still be paid during these absences:

> *I was putting off going into hospital for 3 months but I ended up going in and that was my leave gone.*

She used her rostered days off and sick days to keep clinic appointments, again to allow her financial commitments to be met:

> *As long as he* (the doctor) *does what he does on a Friday I usually manage to get it done on a rostered day off, if it's going to be a day job or something.*

PH appeared to have drive, motivation and a good work ethic, however the physical demands she put on her body were unrealistic. She tried to continue working and maintain her disability as separate entities, as opposed to integrating them. For PH there was no thought of changing jobs, changing work times or consulting with her employers as to how she could still perform her duties as well as ease her physical burden. This behaviour could be construed as working against her disability, not working with it, as identified by Charmaz (1995, 1991, 1983) because she refused to accept her physical limitations. If PH acknowledged her limitations and changed her workload then maybe her physical health would have improved in the long term.

Parkes (1971, p110) suggests that those who deny the permanency of their loss of function often become the 'hero of the ward,' as they react with indignation regarding their disability. This situation occurred for PI who believed he could prove the medical staff wrong and overcome his paraplegia:

> PI   *At the very beginning I was on top of the world. I thought,* **'It's not a problem** (his paraplegia) **'I'm going to prove those buggers** (the doctors) **wrong. I'll do this and that'**.

After several months of personal rehabilitation, PI realised that the advice he received from the doctors was correct and he would remain wheelchair bound for the rest of his life:

> *Which I did a lot of it I got a lot of movement back and that was through sheer effort, pushing myself, you know. But still the doctors kept saying,* **'You're not going to get any better'** *and now I've got to the stage where I'm thinking,*

> *'Am I getting better, am I getting stronger? NO'!... And it's very hard to take.*

After realising that his improvement had ceased, his mood became low and he spent several months in a psychiatric facility. Eliott and Olver (2002) believe that unrealistic expectations are not detrimental. These researchers suggest that they may have some benefit as the individual tends to alter their perspective regarding hope when they have the ability to cope with the situation (Eliott and Olver, 2002). Given this notion, it would seem PI was now ready to move to the next stage of Treading Water accepting that his paraplegia was permanent and lose the expectations of further improvement, as he realised his limb function had not increased in over a year. Conversely, Smith Landsman (2002, p22) suggests that denial is maladaptive as it stops and prevents those affected 'seeing and taking necessary action' for future improvement; being unable to set realistic goals to help them manage their disability.

Inappropriate Goals

In this study there were two participants who coped with the consequences of their disability by initiating new, but somewhat unrealistic, goals when they had lost limb function. PA discussed working as a counselor or becoming a teacher and both goals would have been achievable with her disability but, as the conversation continued, her ultimate goal was revealed:

> PA *I've got a long road to start again. I thought about being a counselor, that was my first option, the second option I thought, maybe I'll go teaching, teach home economics, or some cooking classes at the tech.*

The conversation suddenly changed from what she could realistically accomplish with her current injury, to what she ideally wanted to accomplish in the future.

> *But what I really, really want to do, I want to be a fitness trainer. I'd go to the gym and be a trainer doing an aerobic teacher or something like that, is really what I really, really, really would like to do. So, I hope next year or so I'll be drug free I hope and running.*

PA was experiencing CRPS and had florid motor and trophic symptoms[1] that had responded poorly to all current known treatment. CRPS can be recognised as a persistent/chronic lifelong pain condition, with functional restoration by constant rehabilitation the primary goal (Harden, Swan, King, Costa and Barthel, 2006; Stanton-Hicks, Burton, Bruehl, Carr, Harden, Hassenbusch et al., 2002). The higher the levels of motor and trophic changes, the more difficult it is to regain full function of the limb (Harden and Bruehl, 2006). Re-occurrence of the condition in adults is approximately 2%, though pain and immobility of any limb can develop at anytime, requiring careful monitoring and regular drug therapy (Wilder, 2006). For PA, to be drug-free, running and fulfilling her desire to become a fitness instructor, appeared unlikely at the time of interview. Two years post interview, PA required a stick to walk, had poor leg movement, continued to require medications and remained unemployed.

PJ was another participant who appeared to have set herself unrealistic goals. She had ceased creating her artwork because she could no longer use her right hand and it appeared unlikely that its function would return owing to the established nerve damage. An attempted radial nerve repair had occurred (after it had been accidently severed) but, with such an injury, restoration and resumption of limb function is highly unlikely (Jääskeläinen, 2009). Despite several years of physical and psychological interventions, PJ's symptoms continued to escalate. Nonetheless, even with these symptoms PJ stated she wanted to return to her artwork. A recent goal she had set for herself involved publishing a collection of poetry:

> PJ *I'm an artist and a poet. I've been published in five books and I can't do my artwork. I love painting and making things. I've had to give it up, at least for the foreseeable future, that's one of my goals* (to return to her artwork). *Another one of my new goals I've set is to write a poem every two weeks, to make a book.*

One year post interview, no artwork or poetry had been created. It seemed that both participants had developed and maintained unrealistic goals and expectations about their futures, suggesting that they were denying their ongoing physical

---

[1] Trophic symptoms refer to skin, nail and hair changes

limitations and these behaviours prevented them accepting their situation Not only were these participants denying their physical limitations but they also blamed another person for their injury.

Blame

The notion of blame is to assign responsibility for a situation, or wrongdoing, to something or someone, so fault is acknowledged and allocated (Smith Landsman, 2002). Some people cannot accept the randomness of their trauma as it corrupts their personal belief system, so they decide to reject the happening as an accident and allocate blame (Smith Landsman, 2002). At least five of the participants (including PJ and PA) used the notion of blame when managing their injury, either blaming the health professionals, themselves or someone else associated with their trauma. PJ blamed the medical profession because the surgeon had damaged her radial nerve when he removed a wrist ganglion. She was having her case assessed by the Health Review Board (this board assesses medical complaints) and had employed a lawyer to progress her claim:

> PJ *I made a complaint to the Health Review Board. I blame the doctor, he should have followed through more. In that first twelve months if he had re-explored* (the damaged wrist) *there was more of a chance my nerve would have repaired itself to some degree* (reducing the pain and aiding function) *and I wouldn't be in this situation* (increased pain and reduced function).

After a long wait (approximately seven years) she was awarded a generous settlement. PE also blamed the medical professional for his lack of progress:

> PE *Then, of course, you look to somebody to blame,* (which doctor) *who stuffed up, who did something wrong?*

In contrast, PA blamed herself for letting the same surgeon operate twice on her injured knee even though the first operation had failed:

> PA S*o stupid, me! I should have gone straight down to Perth and got it done!...* (her knee reconstruction) *But I didn't. I thought I'd stay here and give this guy another shot at it.*

Blame is maladaptive as it hinders one's ability to accept life events and reduces one's capacity to cope with such trauma (Startup, Makgekgenene and Webster, 2007; Smith, 2006; Richardson, 2002). Smith Landsman (2002) states that self-blame can be a double-edged sword, having both positive and negative results. On the one hand it aids self-control and helps personal motivation for instance, 'I've done this I must live with it', although this did not appear to be the case in this study for those who were at the Floundering stage. Alternatively, self-blame can enhance the negative outcomes of personal trauma as the person believes their injuries are justification for past deeds such as, 'I deserved this because I'm a bad person' (Startup et al., 2007 p 401; Smith Landsman, 2002).

Lack of personal ownership regarding the consequences of one's trauma results in poor adaptation to their resultant injuries as it promotes the role of the 'victim,' 'this was done to me; I did not do this myself' (Smith Landsman, 2002 p16). Other participants blamed people who were associated with their accidents. For instance PI blamed his co-pilot in the hired aircraft for the crash and his injuries. The co-pilot ignored medical advice from his personal doctor and flew with the participant. During the flight, the co-pilot had a cardiac event, the plane crashed, the co-pilot died and the participant was left an incomplete paraplegic. He attempted to sue the dead pilot's insurers for compensation, but lost his case. This made him more angry and frustrated than he was initially:

> P.I *It wasn't an accident; it was an act of negligence!... I said to them* (the insurers) ***'If the wing had fallen off and we hit the deck, that's an accident. But when a bloke was told not to drive or fly and he went against doctors orders, then that is not an accident'!...***

PN blamed the other driver involved in the crash which caused his traumatic amputation:

> PN *What they* (the police and insurers) *are trying to say and my lawyer disagrees with this, is* ***'That I didn't give way to the right'***. *My lawyers have read the witness statements and read her statement* (the other driver involved in the crash) *and have said,* ***'That it is wrong.'***

The police had closed PN's case and this had angered him because he disagreed with their decision. He had recruited a private investigator and lawyer to continue the investigation into his accident as he believed a conspiracy was occurring; the other driver was from an influential family with government connections.

Startup et al., (2007) suggests that blame can allow a person not to take responsibility for their actions so they have a 'no-blame' clause for all future misdemeanours (Startup et al., 2007 p401). For example, should future personal plans go wrong then they may blame their disability and those who caused it, thereby absolving themselves of personal responsibility for their trauma, their injuries and their future (Startup et al., 2007). Blame was unhelpful for the participants in this study as it focused their thoughts on past events and prevented them from becoming motivated and accepting their loss of limb function. Blame appeared toxic for the participants because it locked them into a negative quest for the truth, or justice, which, it appeared, had already been discovered. Parkes (1993) recognises that viewing a life changing event as a negative process is not good for one's personal mental health. Also, while these participants continued to blame someone for their situation they remained at the Floundering stage regarding the management of their disability and this added to their feelings of hopelessness and despair concerning their impairment, which further influenced how they accepted and coped with their disability.

Despair

Despair is exhibiting feelings of despondency, a lack of justice, misery, low mood, desolation, loss of control, gloom and hopelessness, as one cannot escape the pain, trauma and loss they have experienced (Smith Landsman, 2002; Oxford Dictionary of English, 2003). Several of the participants were despairing about some aspect of their current situation and this hindered their ability to cope with their impairment. For example, PE was despairing about his excessive workload:

> PE *Any little thing stresses me. I get stressed over the silliest thing. And then as soon as I get stressed, the symptoms* (his pain symptoms) *all come back straight away. At work I'm that far behind the eight ball, I just don't know what to do to be quite honest.*

PJ despaired about her pain so much that she would cry on a regular basis. Although she knew this behaviour exacerbated her suffering she could not control her distress:

> PJ *I'm crying a good quarter of the day, every day. You cry with the pain and sometimes it makes it* (the pain) *worse but you can't stop and there's pretty much nothing you can do.*

PN was despairing about his loss of limb function. He cried for his loss and this influenced his mood:

> PN *A lot of the time I cry myself to sleep because of the fact I've become lonely. And I have mood swings as well, you know!... I'm down, I get miserable and then I sort of like get irritable! it's just annoying!...*

He continued to despair about his future:

> *I know later on in life it's* (his amputation) *going to affect me. The fact is, I've seen older people at the rehabilitation hospital go through a lot of trauma and go through a lot of hard times. I think I'm going to have a really hard life when I get a bit older. Physically because if this* (he points to his prosthesis) *is affecting my back now. When I get to 60 or 70 years of age I'm going to have a lot of problems. I'm not going to cope well when I'm old.*

PN's perception of his future was depressing and miserable. He was focused on potential difficulties he may experience and not what he could do here and now, at this present point in time. Similar thoughts occurred for PC who worried about becoming *a cripple* should his leg be amputated. Becoming physically compromised and psychologically challenged with their loss of limb function and, ultimately, Loss of Self, influenced the participant's ability to socially Accept a Reduced Self.

Social

From a social perspective, the participants who were at the Floundering stage tended to manage their disability by reducing their social contacts. Lack of integration with others reduces self-confidence, self-esteem and self-respect, enhancing and reinforcing the need to isolate oneself (Chapman and Volinn, 2005; Hentz, 2002; Charmaz, 1983). However, isolating oneself can cause more

negative thoughts about the self and society which make it harder to socialise. Self- respect, self-esteem and self confidence are all reduced further and a vicious circle develops. PC and PN tended to stay home because their impairment caused them extreme physical difficulties which ultimately lead them to detach themselves from society:

> PC *I don't go anywhere; it's too much of a hassle!*

> PN *I've become a hermit, I have and that's being honest. Yesterday, for example* (Sunday), *I didn't get out of bed all day. I got up at 6am; I had a shower and went back to bed. Because I can't seem to do anything in comfort so if I don't have to do anything, I won't do it.*

Restricting social outings is discussed by Charmaz (1991) and Miles et al. (2005) who describe how the lives and worlds of those with a disability contract. Staying safe in the home is easier than venturing out to face the unknown within a challenging world. PM also coped with his disability by withdrawing himself from social activities and admitted he was now more introverted. One reason for this was because he could no longer ride his motorbike so his association with his friends had reduced:

> PM *Well I've kind of closed down a bit, I don't go out as much as I used to, stuff like that. I suppose with the bike I could ring up my mates and we pulled the bikes out of the shed and go for a ride. Whereas, with the cars, well, they tend to stay in the shed.*

When questioned about riding pillion with another rider, his response illustrated that this would be unlikely: *I haven't been riding on back as a pillion yet.* He acknowledged that there would only be one friend who he could ride with as a passenger because of the style of bikes they rode. He rationalised this situation with the response, *But that's life, you've got to get on with it.* When the environment was not conducive to his disability, PK coped with his loss of limb function by isolating himself:

> P.K *I stay away from places I'm not going to feel comfortable. I shouldn't have to do that!... But I do!... Because a lot of places are not geared up for wheelchairs and it's hard when you make a scene.*

Lack of personal/public validation and interaction diminishes ones self-concept, identity and efficacy, influencing how one socialises with a disability (Bonanno, 2004; Richardson, 2002; Charmaz, 1983; Goffman, 1963). PF acknowledged that since becoming a paraplegic he was unsure about becoming romantically involved with anyone, so he remained living on his own:

> P.F *I'm not sure I want to get involved with anyone, you know, because you don't know, being in a wheelchair you lose a bit of confidence in that side of it* (sex and intimacy)*. And you don't know how genuine people really are.*

It often feels safer for those with disabilities to remain alone rather than risk being ridiculed by others as ridicule causes shame and suffering and, when people suffer, the self is reduced (Taleporos and McCabe, 2002; Asbring and Narvanen, 2002; Goffman, 1963).

Sexual issues continued to be a problem as PE explained how his poor sexual performance was causing tension in his marriage: *So that's weighing on my mind at the moment.* He believed his knee operation had caused damage to his sexual ability and he acknowledged that his *wife had needs too* he explained that he was worried about this situation. PN was still able to perform sexually but coped with his disability by ending his relationship with his current lover:

> PN *I used to have a female friend. I sort of ended that relationship because of the fact that I couldn't cope with it* (physical and psychological intimacy) *any more.*

It is common for people who have an altered body image to perceive that others would have difficulty coping with their altered physical state. Such perceptions influenced their ability when Accepting a Reduced Self. Goffman (1963) and Taleporos and McCabe (2002) support this perspective, suggesting that when an individual perceives changes in their body/self image they expect to be viewed differently by family, friends and society.

Remaining employed for those who were at the Floundering stage was an issue and this further reduced their social circle of contacts. Those who experience limb

trauma can have difficulty returning to the employment sector, especially if persistent pain and reaching one's destination are problems (Mackenzie, et al., 2006). However, their lack of employment impacted on their financial situation. For instance, PB spoke about the effects of being unemployed:

> P.B *I mean I was a miner working underground, now I can't work and that's one thing I do miss. I mean I used to get $1,700 bucks a fortnight* (in 1985).

When the participants were at the Floundering stage of Accepting a Reduced Self they appeared to be more dependent on others, they often denied their disability, blamed others for their injuries, were despairing about their present/future lives and were usually socially isolated. For those who had progressed to the stage of Treading Water, the biopsychosocial consequences of their loss of limb function and the Acceptance of a Reduced Self did not appear to be as overwhelming, as they attempted to be more self-reliant when attempting to manage daily issues.

Treading Water

Participants who were at the stage of Treading Water were the ones who tried to be as independent as possible, either by using strategies or aids. Their routines were fragile and independence was lost if aids were not available or their schedule was changed, causing biopsychosocial difficulties which usually returned them to a more dependent state and reinforced the precariousness of their new found acceptance and adaptation.

<u>Biological (Physical)</u>

Physically, the participants who were at the stage of Treading Water tried to be more independent than those who were at the Floundering stage. An example was they attempted to meet their hygiene needs independently. This was done in one of two ways; either by using a new routine or with the use of aids, as PH and PM described:

> PH *I don't even shower every night because it's too hard. It's not hard, it's strenuous so I have one every second night.*

> PM *In the shower I now have a scrubbing brush so I can scrub underneath my arm and shoulder. Before* (his accident) *I used to stand in the shower but now I sit.*

PM lived alone, his clothing had been *adapted* (by his mother) to accommodate his disability and he had installed aids at home so he could remain independent:

> PM *I've had my clothing adapted. Instead of buttons I've got Velcro. With my work jeans I've got like another belt underneath, so that I can pull it through a hook and pull it across. I then Velcro it, so I can do up my fly and I put a belt for decoration. It's the same thing with my jeans. I've got a hole and I have a lever on my dresser in my bedroom. I hold the button, use the lever and I put the button through in that way.*

These strategies appeared to be working well for him when at home but difficulties would occur if he had to dress elsewhere.

Having the ability to physically reach one's destination when at the Treading Water stage was still an issue for some participants, although they did develop plans to manage this problem so they could get about as much as possible. PD used the facilities on the second storey of her home to make light refreshments and this allowed her to reduce her journeys using the stairs, which she found difficult:

> PD *We're lucky we've got a sitting area there as well so I have coffee, tea and all that sort of stuff, so that's not too bad. But if I had to come downstairs all the time it would be an absolute nightmare.*

PF indicated that provided he looked after himself, using his wheelchair was manageable, so he made a conscious effort to maintain his health and control his weight to aid his mobility and get out and about as he required:

> PF *Because you can get around easy if you keep yourself fit, healthy and strong and diet properly, you can make it easy for yourself. It's the same as if you were walking and you were overweight, you'd struggle getting around. You know if you look after yourself, like I do, I don't find it hard to get around.*

The ability to manage their homes and the practicalities of everyday living required them to accept, plan and adapt to their disability and those at the Treading Water

stage did attempt to take part in these activities and not rely solely on others. For instance, PD had a problem pushing a shopping trolley around the supermarket so she now took her teenage children with her to do the weekly shopping:

> PD W*e still go shopping. I used to go and do that by myself but now the kids come with me to take the load of the trolley, because I can't push the trolley.*

PL had changed his culinary technique when preparing his meals and, though it made the task longer, this allowed him to remain independent:

> PL *If I make a chicken and vegetable casserole stew something or other, I can't stand at the table to cut it all up. So I bring it in here and chop it up on the table but, because I'm seated, it'll take me 20 minutes to chop it all up.*

PM had a brachial plexus injury and discussed how he now needed more time, as he had altered his practice to complete tasks autonomously around the home.

> PM *As I said, a four hour job takes me eight hours to do. I would cut a bit of wood with my saw and I'd hold it in my hand. Now I just clamp it to the bench and cut it with a saw.*

Achieving success with these tasks improved the participant's self-confidence and self-esteem which assisted in improving their psychological wellbeing when Accepting a Reduced Self.

Psychological

The use of medical technology to aid the return of their limb function was a major psychological focus for those who were at the stage of Treading Water. These beliefs and behaviours are reinforced by the biomedical approach used by the medical profession, who often promise the hope of curing disease and the repairing of broken bodies to justify the treatments and procedures they advise, so that lives can return *to normal* (Williams, Dunning and Manias, 2006; Eliott and Olver, 2002; Morse, 1998). PP described how the multi-disciplinary medical team used the notion of *false hope* to encourage their patients to maintain their bodies at an optimum physical level:

> PP *But now we've actually got quite a powerful tool because we can say,* ***''Look, you know, they're making some gains in research; don't know if it's going to be in your lifetime'.***

PP and the team used the notion of favourable outcomes and future research as an enticement for those affected by spinal cord injury to manage their disability and to prevent complications occurring such as pressure sores, bladder problems and weight gain.

> *And, well, I think we're really lucky to be able to say that now, whether it eventuates in the next 10-15-20 years? Actually I think it might be a false hope but it is a hope!...*

Using hope as an incentive for future medical discoveries so that patients are encouraged to maintain a particular level of fitness could be classed as being deceptive in the current medical climate, even though it is done without malice and with the best of intentions. Furthermore, this hope was somewhat paradoxical, as it gave them incentives to care for their bodies post-injury with the expectation that it would work normally for them should their limb function return. However, these incentives encouraged the participants to remain focused on their past life and hindered reconciliation and acceptance to a future without limb function and its associated issues. Janoff-Bulman and Timko (1987, p155) also identify this paradoxical situation as a 'false hope' (as PP had stated) as the person continually denies their situation and defends unrealistic and opposing information.

Frank (1995) states how sick individuals create a storyline of initially being healthy, they then acknowledge their current illness, but expect to return to their healthy status at some stage, thereby restoring the body (and the self) to their pre-injury/sickness status. Similar perspectives occurred in this study when the participants had lost limb function. Some of the participants discussed how they hoped their limb function returned so they could resume their normal pre-injured lifestyle. Participants, PG, PK and PM hoped that this would occur, either through nerve regeneration or by growing a new limb.

> PM *All I say is, the way that technology is going today you never know they might be able to fix it* (his brachial plexus

> injury) *in another five to ten years. The way the stem cell[1] research is going and stuff like that? Technology has sky rocketed in the last five years. Imagine what it can do in another five years?*

PM was hopeful that this research would repair the damaged nerves in his arm so that movement and sensation would return. PK was unsure what technology could help him but, again, was hopeful his injured spinal cord could be repaired:

> PK *There's technology and there's things happening everyday out there. And I do hope someday they'll* (the doctors) *have a trial and they say to me,* **'We need a 100 people'** *or they'd ring up and say,* **'X we want to see you for a minute and have a talk',** *or maybe someone has seen my X-rays and they want to fix it* (his spinal cord).

Lupton (2003, p7) acknowledges that should the ill and infirmed become content in their sick role, then they are often deemed as 'malingering.' Therefore, it is essential that those who are ill demonstrate to society that they want to get well. PG seemed frustrated, as he wished stem cell research would advance quicker that it was currently doing and grow him a new limb as soon as possible:

> PG *Some days it's that* (his leg) *bloody sore I wish they'd plough down the road of stem cell technology. You know, re-growing limbs and organs and give me another leg!...*

The notion of hoping for a techno *fix* was useful because it helped the participants manage their disability and maximize their abilities. PK believed that if it took twenty years for technology to advance to a level in which it could *fix* his body, that would be acceptable as he continued to manage his body as best he could in its disabled state:

> PK *Look, even if it takes twenty years I still maybe alright and that's why I keep things going as they are* (being physically fit).

PM exercised his limb and used his sling (as advised by medical staff) to prevent the muscles wasting and stretching:

> PM *I was told,* **'Keep my arm in a sling so it doesn't stretch the tendons in the shoulder'.** *The reason they said to*

---

[1] Stem cell research is concerned with using cells from embryos to regenerate new tissue.

> *exercise it* **'is just in case they do find a cure down the road, they said all the joints would still be moveable instead of square. They'd be round and working'.**

Having atrophied and weakened muscles would impede any return of limb function, so by keeping their muscles firm and strong the participants were prepared for their limb function returning. The desire to be fixed and made whole again after loss of limb function is reinforced in research by Smith and Sparkes (2005, 2002) and Morse and O'Brien (1995).

While the participants were waiting for technology to return their lost limb function, those who were at the stage of Treading Water often displayed strength of character and hardiness when Accepting a Reduced Self and this helped them accept and cope with their disability. Hardiness and strength have been recognised as protective factors that can assist an individual manage adversity (Earvolino-Ramirez, 2007; Salick and Auerbach, 2006; Bonanno, 2004; Richardson, 2002; Schmitz et al., 1996). For example, PF talked about being strong and how it had assisted him coping with his paraplegia:

> P.F *I think it's built in me* (his strength and ability to cope). *You find out what qualities and gifts that you don't realise you have got. I think your health and your personality comes out stronger. You've always got it there, but sometimes you don't have to use it. But, when you are in a corner and in a tough situation, you've just got try to be as strong as you can and try and stay on top of everything!...*

These ideas are congruent with the inherent qualities that are required when one wants to be in control of one's life after an unexpected life changing event (Bonanno, 2004). PG demonstrated hardiness as he helped his friend repair his car shortly after being discharged from hospital:

> P.G *When I first got out of hospital, one of my mates came around on his bike with his side car and says,* '***Oh I've got to get a gear box for my car come and give me a hand.'*** *Like I'm a day and a half out of hospital and here I am laying underneath a car putting in a gearbox!...*

His friend had confidence and trust in PG's abilities and these actions enhanced his self-esteem and self-respect. In contrast PH's colleagues complained about her

because she had a volatile temper and, according to PH, one person in particular contributed to her stress level suggesting that PH had a mental health issue: *Because I've got a bad temper, I need a psychiatrist!* She described how she was unpopular with her work colleagues when defending herself against what she perceived as discrimination. She acknowledged that she was *not the nicest person in the world, but who is? No one's perfect! I've got a short fuse!... So, my dad's got a short fuse.* She rationalised that her 'short fuse' and strength of character were characteristics that have helped her to better manage her disability:

> P.H *That's probably where I've got it from. I can't stop that I've got his genes. I can't take them out and change. If I'd have been more like mum, I probably wouldn't be here today. I'd be sitting at home on a pension twiddling my thumbs. I don't know? It might be only those genes of dads that has given me the get up and go to do what I'm doing!...*

PH likened her behaviour to that of her father's and intimated that her fighting spirit had assisted her with her accomplishments to date.

Social

Socially, when the participants were in the stage of Treading Water, they did attempt to socialise with others. To encourage their socialisation and reduce the potential stigma associated with having a disability, several of the participants chose not to inform others about their loss of limb function as a way of preventing the formation of a negative social image. For example, PG tended not to divulge to others that he used a prosthetic limb as he wanted to be seen as 'him' as opposed to being perceived as an *amputee:*

> PG *I found in most cases I tended not to tell people straight up* (about his amputation). *If they find out, they find out, I'm me first and an amputee second. It's easy to just let people know you. If they see you've got a limp, you've got a limp, I mean there're plenty of people with two legs that limp.*

PG preferred social interactions to be unbiased, impartial and equitable, so they could get to know him as a person with *a limp*, not as *an amputee*. PJ was also disinclined to tell anyone about her poor limb function, as she believed they would not understand and judge her disparagingly:

> PJ *In one aspect, I don't want everybody to know* (about her loss of function). *As people can't understand how bad it is and they sort of look at you and think **'Come on'*** (do better).

Social distress and stigma caused by personal and community actions, reactions and interactions can activate sensory regions in the pain matrix of the brain, as it shares the same neuro-cognitive substrates (Eisenberger, Jarcho, Lieberman and Naliboff, 2006). In other words, personal and social rejection causes neuro-stimulation in the same area of the brain that is responsible for pain pathways (Eisenberger et al., 2006). Altered relationships with others reinforced the participant's impaired self-identity, self-esteem and confidence as their altered image was met with disapproval and disdain. Lack of societal and personal approval reduces one's self-concept, identity, confidence, efficacy and self-esteem, shaping how one lives with impairment (Bonanno, 2004; Richardson, 2002; Charmaz, 1983; Goffman, 1963). Personal validation was also influenced by the participants' sexual partners as those who were at the stage of Treading Water attempted to maintain some sort of intimate relationship with their partner. Unfortunately this was not always possible. PI, a paraplegic, was willing to try different techniques to manage his sexual relationship with his wife. He commented, *I'm willing to try anything for her,* but since his accident she had refused to take part in any form of sexual contact with him.

On a less intimate level several of the participants did socialise with others and would ask for help in one way or another, although sometimes these requests were declined or ignored. Pragmatically, they all agreed they had learned *patience* since their injuries and were more accepting of negative behaviours directed towards them. PL was in hospital for a long period of time and believed he was ignored by the hospital staff. This experience of not being listened to, led to the development of greater tolerance, *You soon learn patience.* PF similarly expressed that his difference (as a paraplegic) was influential to him developing patience:

> PF *And you've got to learn patience and when you need help, sometimes you can't expect people to be there all the time and do things for you straight away. Some people knock*

> *you back. You've just got to say **'Well, fair enough.'** You can't force people to help you!'*

PI acknowledged that when his requests for help had been forgotten or ignored, he had to make a further request for help:

> PI *Because, at first, you have to sum up the courage to ask someone to give you a hand to do something. And they say, **'I'll be over on'** whatever day and they don't turn up. Then you've got to try and ask them again.*

PI recognised that asking a second time for help was more difficult.

The participants in the Treading Water stage did attempt to meet and mix with others. For example, PL acknowledged that he had always been a bit of a loner, tending to socialise with *a couple of friends*. Since his accident, his circle of friends had reduced even further, so much so that his communication skills were beginning to deteriorate: *I'm not going out and doing things, I'm not interacting with people.* Nevertheless, he was trying to rectify the situation, as he had made a social commitment to some people to go sailing:

> PL *I mean I've made a commitment to a couple of guys that I'll be at these places at these times so, you know, you have to be there no matter what. And that's good from the point of view of forcing me into that.*

Also, during this stage, several of the participants tried to maintain their work routines. For example, PD had retained her fulltime job as a nurse manager, though she struggled with some of the duties, *I can't even run to a MET call*[1] and nursing personnel and, though clearly struggling, she was attempting to meet her nursing obligations. Two other participants, PE and PM, gradually returned to work after months of rehabilitation and their work hours were slowly increased over days and weeks. Therefore, when at the Treading Water stage the participants:

- attempted to be more independent, though they did request help when needed;
- tried to return to work when possible;

---

[1] A Medical Emergency call (MET call) at this hospital is an emergency that warrants the attention of all senior medical and nursing personnel.

- displayed strength of character, as they managed their loss of limb function.

During this stage there was the expectation by the participants that limb function would return and life would return to normal and this belief encouraged them to actively manage and preserve their disabled bodies. These management approaches included maintaining their weight at an optimum level and caring for their skin, muscles and joints. Sometimes the participants transcended the Treading Water mind-set and flowed into the latter stage of Accepting a Reduced Self, which was identified as Wading to Shore.

Wading to Shore

When the participants were in the stage of Wading to Shore they were able to manage independently and incorporated their disability into their future. In the stage of Wading to Shore, the participants showed personal determination, developed a positive attitude to their situation, displayed empathy for others with similar conditions and became involved in community activities. All these behaviours appeared to aid them when Accepting a Reduced Self.

Biological (Physical)

The participants who were at the stage of Wading to Shore appeared to be physically independent. For example, PB described how adept he was at managing most things single-handed. As he expressed this attitude: *I just get in and have a go.* He often refused help, as he liked to attempt to perform the task:

> PB *Somebody will say, **'I'll do that for you. No, I want to have a go myself. If I need help I'll ask for it, it doesn't bother me'.***

Other participants became so proficient at managing their personal activities regarding their self-care that they developed a new 'disability identity' recognized by Yoshida (1993, p223) which focused on their impairment. For instance, PF explained how he tried to manage his physical restrictions independently. This required that he focus on himself and his body as he concentrated all his time and energy on managing his disability.

> PF *You're doing things because of the paraplegia. That's what I find, anyway. It seems a 24 hour day job, just about. You seem to be spending a lot of time looking after yourself. The hours seem to go!... You are just permanently trying to look after yourself the best way you can!...*

PF detailed how he spent his time:

> *That's with keeping fit and trying to make the best out of what you've got left. You've got to watch for pressure sores, using your common sense. Rub cream on your bum two to three times a day* (to prevent pressure sores).

PF continually managed his illness to prevent any potential, negative complications associated with his paraplegia arising which would warrant him being hospitalised and, ultimately, contribute to the loss of his independence:

> *I think because I rub cream on my bum everyday and look after my skin the best way I can, well, I don't seem to get as many,* (pressure sores) *like some other guys do. I mean, some other people don't lift themselves and look after themselves properly.*

He rationalised about why he concentrated his time on his care and how he performed it:

> *After a while it's just an everyday thing. You know, it's something you've got to do to survive. If you don't do it you're buggered!...*

By surviving, PF meant living independently:

> *It's something I got to do everyday and that's what I was saying before. It includes the amount of intake of fluid because you have to catheterise. What you eat, so you don't get over weight, just about everything. And that seems to be, like, just about a fulltime job doing that.*

Performing such activities focused his actions on managing his disability. Likewise PI developed his own personal rehabilitation routine. He devised exercises to strengthen his lower limb muscles in the hope that their strength and function would return:

> PI *If you come in to my lounge it's like a brothel because all my exercise equipment is in the lounge. That's where I sleep now. On the floor, it's easier. I had it* (exercise equipment)

> *in the main bedroom but I couldn't do the same sort of stuff as I can on the floor. So, at the back of the coffee table I've got the clock radio and, underneath it, I've got some of my equipment, elastic bands, elastic swings and weights.*

Again, this participant was focused on improving his condition which did occur over time. He was also practised at managing bladder and bowel issues:

> *I've got this stress incontinence so I'm sort of living off the clock. I've got to watch what time it is. I've now got to watch what I've drank, what foods I've eaten and what fluids they've got in them so I know how much is roughly in my bladder! Then I've got to work out from there where I can empty out* (his bladder).

PI explained the strategies he had in place if it was not convenient to catheterise himself:

> *If I cannot do it* (catheterize himself) *then I have to leave early. I put on pads, at least I've got protection on both sides and you don't feel so bad* (if he is incontinent). *I've got a change of clothes, a change of everything! If anything should happen I go to the car and get cleaned up. If somebody says something about being whatever I say,* **'I was a baby once, I'm a baby again, it's as simple as that,'** *you've got to laugh with it!...*

PI's day was cleverly framed by monitoring his daily intake of food and drink. He continually assessed the volume of urine in his bladder so he could avoid being incontinent in a public place. Should this situation occur, however, he had developed strategies to cope with the situation which included having a change of clothes, pads in his car and self-deprecating humour to disguise his embarrassment. Experiencing a chronic illness and disability forces individual actions to change, as managing the consequences of their impairments leaves little time for other activities (Miles et al., 2005; Bury, 1991; Charmaz, 1991).

Getting out and reaching one's destination for those who were Wading to Shore was possible. Several participants drove cars that had been altered to compensate for their disability. If a wheelchair was used, then they were skilful at managing these wheels and often surprised themselves at the level of their dexterity and skill. For example, PK decided to wheel himself to work while his wife was on holiday:

> PK *X* (his wife) *was away last week. I wheeled my self to work. Well, I don't drive. Bloody hell, it only took me 20 minutes. One of the workers said,* **'What you saying?'** *I said* **'I've come from home to here'.** *He said,* **'You never did, mate somebody picked you up!'... 'No they didn't!...'** *I said,* **'I wheeled here and I'll wheel home tonight if you watch me!...'** *It took me 20 minutes to get from home to work with no dramas what- so- ever.*

Having the ability to complete the journey to and from work increased PK's self-confidence and self-esteem to the extent that when a colleague did not believe his achievement, he challenged them to watch when he wheeled himself home after work, although this challenge was ignored. These qualities are typical when someone feels positive about themselves (Salick and Auerbach, 2006; Smith and Sparkes, 2005; Schimtz et al., 1996). Schmitz et al. (1996) describes these positive behaviours as accommodating one's disability, as people modify their goals to meet life changes and manage problems created by their impairment. This is achieved by revising their aims and aspirations, altering their personal standards, adapting a new routine, incorporating their disability and giving up unrealistic expectations as they accept their limited capacities (Schimtz et al., 1996). This mastering of personal assessment skills concentrates on having an openness to change, being flexible with goals and expectations and acknowledging that life is now different with a disability (Smith and Sparkes, 2005; Richardson, 2002; Schimtz et al., 1996). There were also incidents which gave the participants who were Wading to Shore a positive psychological boost.

Psychological

The participants who were Wading to Shore psychologically looked for positive aspects to their situation. As the participants accepted and adapted to their situation, they displayed a positive attitude, performed positive self-appraisal, showed empathy for others and demonstrated determination in managing their disability. The data indicated that a couple of the participants accepted that riding motorcycles was dangerous:

> PB *But I knew the risks! It was an accident. I knew it could happen and I accepted those risks when I decided to ride motor cycles. Because I love them! I still love them, today! I was like everybody else, I thought it would never*

> *happen to me. So when I woke up and came to, the realisation that it had happened, there was nobody to blame.*

> PG *He* (his brother) *rides bikes as well and we both have friends who are all bike riders. We've seen it, we sort of know the consequences of what we're doing anyway. There's a very real possibility that every time we get on the bike we may die. Nothing is certain in life, so if there's something you enjoy doing you've just got to go and do it.*

Both of these participants recognised that their choices put them in jeopardy of major injury every time they used this type of vehicle. Their acceptance of this risk appeared to help them adapt to their loss of limb function and move on with their lives:

> PB *It happened to me, well that's it. I can't do what I used to do but let's get on and do what I can do! I just did what I was asked to get myself better in the hospital. I just did whatever I could. You know, it's hard to say how did you do it? Because you don't know, you just get on with it.*

PB showed acceptance of his injury and PG showed a similar attitude acknowledging that his loss of limb function was as a result of someone else's *mistake.*

> PG *It's the classic, a little old man behind the steering wheel hits a bike rider. It happened! I had friends who said **'We'll get him for you!'** (they would assault him). I said to them **'It's not worth it it's just a little old man who made a mistake.'** He lost his license and after the accident he probably never got it back again, because he probably lost his bloody nerve to drive.*

These participants acknowledged responsibility for their actions and displayed resignation and reconciliation with their situation which seemed to assist with the consequences of losing limb function. Another quality that helped some participants accept and cope with their loss of limb function was a positive attitude as it created a dynamic progressive psychological perspective. For instance PG applied for a position working on a seismic vessel that would operate in rough seas. He failed to mention to his future potential employer he was an amputee:

> *At the initial interview I never said anything about being and amputee. I found out a week later that I got this job working*

> *at sea. I went to the offices and said **'Look I thought you'd better know I'm an amputee'.***

He was subsequently told he couldn't have the job, however, he argued his case and *ultimately I got the job.* Once on board the vessel he then had to prove himself to his boss and colleagues.

> *The boss of the geophysical company goes **'You're on trial for six weeks and in light of your circumstances** (his amputation) **if you live you get the job''** At one stage we got swamped by a 20 metre wave. Of the whole crew that was out there at the time, I was the only one left standing. After that night we'd only been at sea for two weeks. The boss actually came up to me and said, **'Don't worry you've got the job'.***

After surviving in rough seas and not asking for special favours as an amputee, PG proved himself to the ship's hierarchy and crew. He kept his job and this enhanced his self-esteem and confidence.

PB displayed a positive attitude and became a role model for others who had suffered trauma. As he explained:

> PB *The nursing sister would send me down to other wards to talk to guys who had less wrong with them than I did. Because they'd given up! They'd quit. They blamed the world, were angry with the world. They had less wrong with them than I did. I'd talk with them a while, joked around and cheered them up. That's why she sent me down there.*

He explained how when he was he enrolled in a local community college from the hospital and met someone there on crutches:

> *He asked, **'How I got there?'** I said, **'I drove.'** He stated he'd **'Never be able to drive'** and I asked him, **'Why?'** His mother hugged me because he never used to go out unless his mum took him. Now he's got his own car and is out all the time.*

PB's positive attitude helped others to cope with their trauma by assisting with their motivation, offering social support and demonstrating that life can progress and be positive after trauma. This behaviour resembles the recognition and motivational social support that is gained when people join groups or associate with others that are exhibiting similar behaviours or have similar problems (Grizzell, 2007;

Kritsonis, 2004). Parkes (1971) indicates that those who positively come through a major transition are the ones who will help others in similar situations, either physically, psychologically or socially.

Performing a positive self-appraisal focusing on what the individual can do as opposed to what they cannot aids their ability to accept and accommodate their trauma (Schimtz et al., 1996). Several of the participants completed a positive self-appraisal. PO experienced severe trauma resulting in several amputations yet, despite these injuries, he concentrated on what he could do as opposed to his lack of abilities:

> PO   *It's been a bit of an eye opener in my life* (his accident*)!... The whole system, the health system the whole lot!... I'm still pretty young. I can still do a lot of things. I can still drive, ride and do everything!... There's always someone worse off than myself? Oh yes, at times, when you see other people…*

Participant, PB embraced his new life with his housemate, her daughter and his new grandchild:

> PB   *That life ended* (his pre-injury life) *and now I've got this one, but I've got to make the best of this one and I'm doing that with X. I treat X's daughter as my own, she's got a little daughter, so I've got a grand-daughter. I'm as proud as punch and I'm having a good life.*

This example corresponds to Salick and Auerbach's (2006, p1025) phase of 'choosing to go on' and Parkes (1988, p58) calls this a time of 'taking stock' of what has occurred and assessing the transitions that are required to move on with life. Several of the participants compared themselves to others who were less fortunate than themselves empathising with them:

> PO   *At times, when you see other people* (who are less fortunate)*, I just think* **'Shit!'***... What really cracked me up once, was a mate took me to Brisbane Hospital children's ward to see little babies and kids. I might be mad, long-haired and tattooed, but I mean those tears rolled down the cheeks, I can tell you. And to see little babies with cancer!... That just blew me away! I can still do a lot of things. I can still drive, ride and do everything!...*

PO performed a positive self-reappraisal and developed a more positive self-esteem, while PM acquired acceptance and compassion for others who relied on medication. In addition, PL expressed sympathy and empathy for those who have had a *hard deal* in life:

> PM *I used to look at a bloke I worked with, he'd had a heart attack and he'd bring his little card then and I'd think, **'Ah you bloody idiot'** and now I'm the same, you know.*
>
> PL *I suppose you have a bit more appreciation of other people. I mean, not that I had a harsh opinion of other people who had problems, but you certainly develop a bigger sympathy or empathy, you develop more empathy for people who have got problems. I mean before you go, **'Oh a bit rough, you got a hard deal out of that,'** whereas now, **'Mmm, yes I understand what you're going through.'***

This type of appraisal aids those affected to develop empathy for others with similar or worse conditions, as they begin to view their own physical state from a more positive perspective (Salick and Auerbach, 2006; Bonnano, 2004; Schmitz et al., 1996; Parkes, 1971). In his autobiography, Sam Bailey explained how seeing other spinal cord injured patients who required more help than himself made him see his own injuries in a more accepting, optimistic light and gave him the motivation to be as independent as possible (Bailey and Bailey, 2006).

Determination also aided the participant's psychological perspective and several of the participants displayed this behaviour as they tried to make the best of their physical abilities. For instance, PF was initially given assistance by the hospital to help him remain as independent as possible after becoming a paraplegic:

> PF *Oh yes, well they* (the rehabilitative staff) *showed me and taught me, guided me. Then it's up to you to do a lot yourself.*

He was determined to not rely on others, trying to be as self-supporting as possible:

> *I mean, I just got into it and trained as hard as I could to get as good as I could so I didn't have to be a burden on anyone. And trying to make the best of what you've got left.*

PF did not want to be a liability or an inconvenience to society as rejection was possible, so he strived to be as independent as possible. Clarification of how patients were educated was sought from PP. According to this expert practitioner:

> PP *We actually employ a patient educator, a patient and family educator. The patient goes through a series of lectures, sitting down talking to this person. What we do now is we ask the patient, '**Who they would like to be involved in their rehabilitation program?**' And they make that choice. It could be on their own, or it could be with a significant other.*

PG had his crash in the month of February and six months later he was back wearing his prosthesis and working. This showed great determination, to combat the severity of his injuries in such a short space of time:

> PG *After I lost my leg, they said, '**It was going to take 18 months for me to be rehabilitated because of the skin grafts at the back of my knee.**'*

PG was resolute as he challenged time-frame he was given:

> It was, '**I'm damn well determined to do the other.**' *So they fitted me with a prosthesis in July/early August* (approximately six months post injury) *and, at the same time, they did that* (he received his prosthesis) *I got a job. I went back to work in a bike shop. So I went to work at RG (a shop) and stayed there for a year or so.*

Another participant showed determination by insisting he return to the workforce as a paraplegic (though he could have comfortably retired):

> PK *You know, that wasn't even an option* (retiring from work). *The option was '**No**' and it wasn't even an option. It was, '**Get off your arse and get on with life**'. What other option is there?* (regarding work). *I've always, well I've never been unemployed in my life, never had to rely on other people in my life for what we've got.*

PK's determination persisted as he continued to work on a fulltime basis.

PR recalled how one wheelchair bound student showed determination when she tried to change her lecture times and venue. The student had lectures allocated in a high-rise building which had no wheelchair access. It took the administration of the

university half of the semester (approximately seven weeks) to change the allocated room, so that the student could access her class:

> PR *But she had to fight so much just to get them to enforce that policy. It was incredible!...*

The student demonstrated impressive perseverance and determination to change her lecture to an appropriate venue and time acceptable to her, so she could meet her other para-Olympian commitments.

<u>Social</u>

At a social level, the participants who were Wading to Shore tended to mix with others as they always had. PO would mix with his *mates*, as usual and PG continued to actively play with his children, despite being an amputee. He was required to modify his behaviour some years later after his amputation, because of an unrelated acquired back injury:

> PG *No, I still wrestle with the kids or do hand stands, up until I hurt my back in 2000. I mean, I could walk on my hands and do handsprings and summersaults, jump of the roof, climb trees.*

PK had decided to arrange a holiday with his wife and father-in-law:

> PK   *I mean we go away, on the Indian Pacific* (a train). *We're going to South Australia get off there and get on the Ghan* (a train) *to Darwin.*

PK and his wife's plans appeared well-organised and they had already considered taking an extra driver (his father-in-law) to travel with them. They had the route mapped out and his wife was already viewing the carriages of the train to insure it would meet their needs:

> *We'll take one of our cars on the train and then we're going to drive from Darwin back home* (to Perth WA)*. We've got grandkids in Darwin, in Kununurra and in Derby, so we'll come back down.*

From a working standpoint, those who were at the Wading to Shore stage managed to work as they choose. A further example was PK, who owned his own business which appeared to be prosperous:

> *My mate came down and asked **'If I would be interested going into business?** And we started off, I had all the infrastructure. I was still a supplier and then K (his partner) come on board and we just started ticking. We lived out of this house for 8 months, I suppose. There were trucks parked on my lawn, now we've bought a bigger block and we'll probably spend up to 300 grand to do it all up; offices, sheds.*

At the last count, his firm employed twenty people and continued to grow. Another participant, PO, chose not to work as he explained:

> *PO I could do some work if I really wanted to but I don't want to push it, I could do a bit of work on the computer.*

He explained that though he did not work he was prepared to do something with his time:

> *You've just got to do it, mate you know. Why sit around you know, I'm not going to sit and vegetate and lay in bed all the time.*

As he did not have paid employment, PO became a loyal, active local resident, assisting his community by educating adolescents about the consequences of dangerous behaviours:

> *Also, there's a quadriplegic in the X centre (a state run home for those with spinal cord injuries) at the moment. He and I are trying to get a thing going, to go and talk to the schools. I'm letting him do it all and I'll just back him up. But yes, he's going through with it. I'll go and talk about being lunatics when you're young and that sort of thing.*

There was also a problem in the housing complex where PO lived. The residents were being intimidated with aggressive behaviour from intoxicated members of the public. Subsequently, he decided to tackle this problem personally.

> *I joined everybody up to Neighbourhood watch[1] around here. Everyone I see they say, **'Why is it someone with one arm and one leg doing this?'** I said, **'No-one else wants to do it.'** I went to a meeting, I've done everything right. I went to the Innaloo[2] meeting then I had a phone call from the*

---

[1] Neighbourhood Watch involves the local residential and business communities observing and reporting to the police any antisocial behaviour.
[2] Innaloo is a suburb of the Perth metropolitan area.

> *coppers* (policemen) *from the Morley[1] branch.   I said,* **'I want to tidy the place up mate get rid of these glue sniffers'**. *And nothing will stop me.   I'm just a straight shooter straight, down the line. And that was how it started.*

PO worked for the state branch of Amputees-in-Action[2] and recently had started a surf lifesaving club for those with a physical impairment. He enlisted the help of volunteers and surf club members in assisting those with disabilities to gain safe water experiences. There was also another participant who spoke about spending time aiding the community. PI was a voluntary driver for the physiotherapy department at the local hospital.

> PI *I do volunteer work and I'm still doing it now. I drive them there, I've got one tomorrow that I've got to pick up and take to physiotherapy.*

He also regularly returned to the spinal unit where he had been a patient to chat with newly diagnosed spinal cord injured patients.

> *Yes, I was in there the other day. I went to see them* (other patients). *I'd say the doctors said* **'I could never do that'** *and then I'd wiggle my feet and their eyes would light up.*

Giving something back to society and experiencing individual growth from personal trauma can occur (Salick and Auerbach, 2006; Smith and Sparkes, 2005). Mark Zupan in the movie 'Murderball' (a movie portraying the lives of the 2004 American Olympic wheelchair rugby team) discusses his visits to spinal cord rehabilitation centres to show other paraplegics that there is a life after injury (Rubin and Shapiro, 2005). He explains that contributing in this way makes him feel good about himself and his life and also helps the new wheelchair bound person feel better because of the motivation and positive feelings he instils in them.

It would seem, that those who were at the stage of Wading to Shore coped much better biospsychosocially than those at the stages of Floundering or Treading Water. This was because these individuals appeared to be physically independent,

---

[1] Morley is a suburb in the Perth metropolitan area.
[2] Amputees in Action is a local and national run support group for new and established amputees to meet and discuss issues which affect them as a group with a disability.

psychologically accepting and accommodating with regards to their impairment and socially interactive in their reduced self role. However there were several modifying conditions which influenced the participant's ability when Accepting a Reduced Self. These were identified as, the level of pain experienced by the participants, the amount of social support they received, the type of trauma they had experienced and the length of time they had lived with their loss of limb function. These together with the biopsychosocial factors are depicted in figure 2.
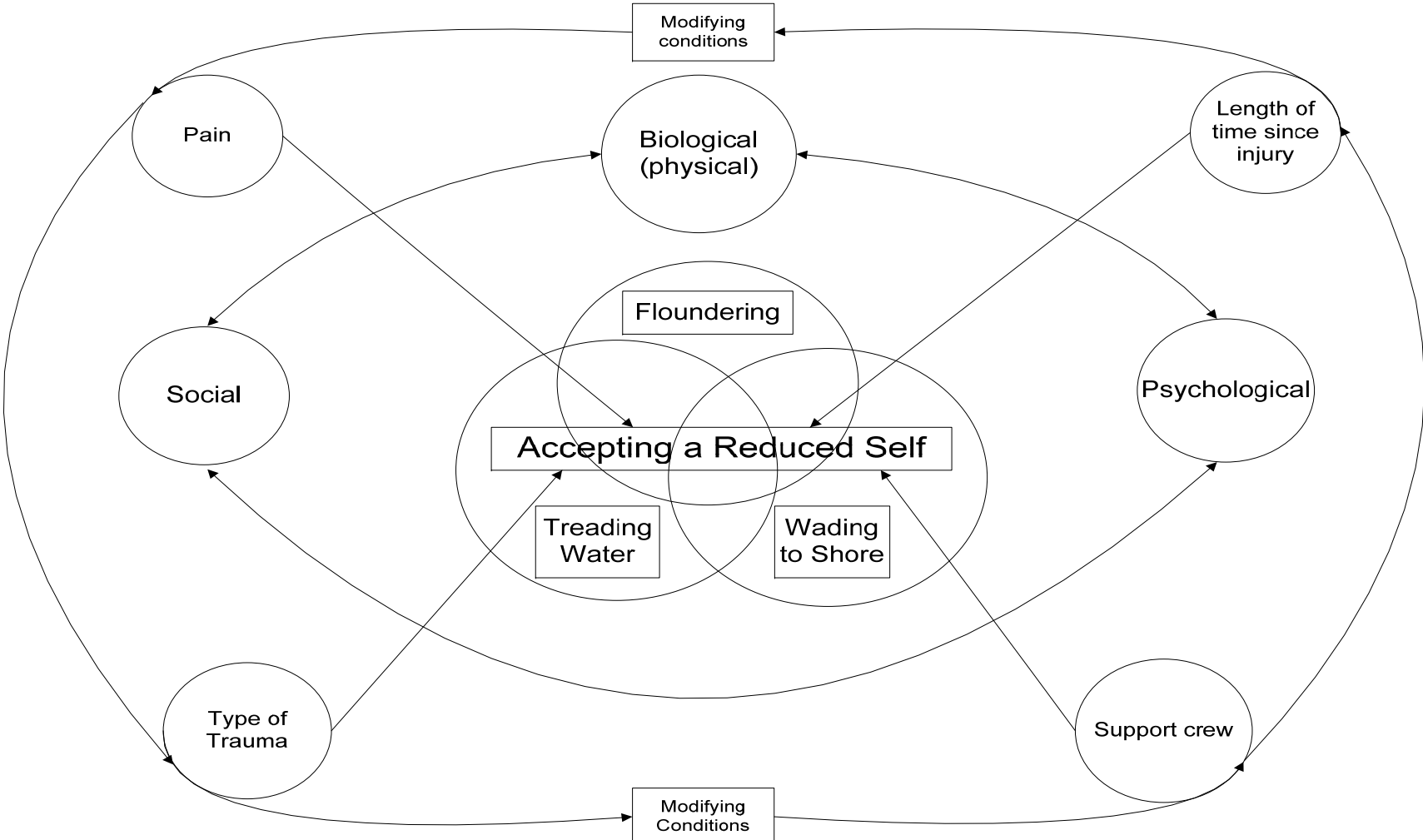
Figure 2 Basic Social Process: Accepting a Reduced Self

Modifying Conditions

The modifying conditions in the data which influenced the stage the participants reached when Accepting a Reduced Self were identified as:

- the successful management of their persistent pain;

- the availability of their support crew;

- the type of trauma these participants received (major or minor);

- the length of time since their loss of limb function.

These conditions appeared to impact whether the participants were Floundering, Treading Water or Wading to Shore.

Pain

During the Floundering stage pain was a prominent issue for the participants who often became engrossed in this problem. Charmaz (1991) discusses how, when in pain, some sufferers react by becoming immersed in their illness. She suggests that persistent pain stretches beyond the physical self, draining one's energy and consuming the mind, as future plans are put on hold to accommodate one's pain. Several of the participants described how their pain not only caused them discomfort but also strange sensations. For instance, PF explained that he had *phantom pain* as well as *other types of pain:*

> PF *My biggest problem now, I'd say, is fighting consistent pain. . Well, it's always been pretty bad from day one, it's always been there.*

PF also acknowledged how his pain had been ongoing since his original injury and it appeared that there was no end in sight to his pain problem. Another participant, PJ, described how the pain in her finger caused strange sensations in her neck and seemed to extend the length of her finger tips:

> PJ *I've got a tingling pain and a shooting pain up my neck. Every time I lift absolutely anything with my right arm it sends shooting pains out my fingers, which I can't understand. I know there is phantom pain with people who have lost limbs but I didn't have fingers that long* (she raises both her hands, one horizontal, one vertical and blocks the vertical hand with the horizontal one several centimetres away from the tip of her longest finger).

Being consumed by pain was apparent at the Floundering stage and several participants managed this situation by isolating themselves and withdrawing from activities, as PC and PK expressed:

> PC *You go to do something, or you plan to do it tomorrow, but you're in that much pain you don't want to do anything!... And then the pain is there. Once it's there, I can't stand anyone being around me.*
>
> PK *If it* (the pain) *happens here* (at home) *on the weekends. I just go straight to my room. Because I've got somewhere to lie and I'll just lay there. I prefer to go and lie down and take it* (endure the pain).

Inactivity and isolation are regarded as passive pain management strategies as are injections or the use of medications (Blyth et al., 2005). All these passive pain management strategies were used by the participants in this stage, furthermore, these passive techniques were often unsuccessful, as PA, PJ and PK explained:

> PA *They* (the doctors) *tried a nerve block in my back. Then I had an infusion. And that didn't work either.*
>
> PJ *I was referred over to the pain clinic. We tried injections and nerve blocks but nothing has worked.*
>
> PK *I mean, out of all the things X* (pain specialist) *has done, all the needles, whatever he's done, they've never ever done really anything at all. I said to X, 'Look, it* (his procedure) ***didn't do any good at all. You were right in one sense, you told me the pain would get worse and that did happen.'***

The pain actually increased for PK the last time he underwent injections for pain relief and it was not only the injections that caused the participants' problems. Regarding the use of medications several participants seemed to have ongoing issues with the side effects of their prescriptions. For instance for PE and PJ, analgesics appeared to be more of a problem than their pain:

> PE *The side effects* (from the medication)*, I couldn't pee. So you'd be on the toilet 25 minutes most times just to have a pee. And constipation, every time I went to the toilet it was like passing a tennis ball or something. I had piles* (haemorrhoids)*. I haven't bled so much!... So you don't want to go to the toilet but nature says you've got to and I needed cream for the haemorrhoids.*

PE had difficulties with voiding and constipation, while PJ stated that she became pregnant after her pain medications interacted with the effectiveness of the contraceptive pill she was prescribed:

> PJ *I was on the pill and another medication* (used for pain control) *I was on wiped it out. I fell pregnant!... Because of the medication, I have short-term memory loss, weight gain, dizziness, loss of appetite, a huge appetite. I wake up every morning feeling hung over because of the anti-depressants. I'm on oxycontin[1] Initially that gives my energy a boost. Then my eyes are drooping and I'm tired. The ketamine[2] puts me all over the place. I don't know what the hell I'm doing half the time, I'm running around in circles at home.*

PJ also had problems with feeling unwell, had a varying appetite, mood swings and lacked control over her thoughts and behaviour which she attributed to the medications. Williams, et al. (2006) acknowledges that analgesics can cause side effects and was an issue for some of their 20 interviewed participants. Some of these side effects included drowsiness, nausea, agitation and inadequate pain relief. These problems were recognised several weeks after receiving a joint replacement. In this study, the participants continued to experience similar side effects months and even years, after their trauma.

Using multiple medications (regardless of the side effects) or undergoing repeated procedures did not aid the participants to develop a personal, independent pain management plan. These passive techniques were self limiting and McCracken et al. (2008) suggest that when people utilise medical interventions for analgesia they force themselves to try harder to maintain their current health status and/or return to their old way of living and they do not learn to integrate the pain into their lives. This perception of wanting their pre-injured life to be returned influenced the psychological perspective of the participants when coping with their pain and the potential for it to become a permanent fixture in their lives.

When at the stage of Treading Water the participants were more active with their pain management strategies.   Blyth et al. (2005, p290) identifies the pain

---

[1] Oxycontin is a schedule eight (an opioid) medication given for pain relief.
[2] Ketamine is a drug used for anaesthesia however, in low doses, it helps with analgesia.

management strategies of distraction, relaxation and positioning as 'active' methods of controlling pain. The data indicated that there was one participant who tried to distract himself:

> PB *The only way I can cope with the pain is to sit in there* (his bedroom) *grit my teeth and to distract myself playing games or watching something on television.*

When in pain, PB distracted himself by watching television or playing computer games. Two participants used positioning to help reduce their pain. PI put himself on the floor and raised his feet off the ground:

> PI (When his pain is bad) *I just chuck myself on the ground and lift my feet up a bit. I try and push a cushion under here* (in the arch of his back) *where it'll take a bit of the pain away.*

PM would take his arm out of its sling and rest it by his side to ease the pain:

> PM *The main reason I take my arm out of the sling is so I can lay comfortable.*

Position and relaxation have been identified as non-pharmacological pain relief strategies, however research regarding their efficacy is scant (ANZCA, 2010; Macintyre and Schug, 2007; Therapeutic Guidelines 2007; Nicholas, Molloy, Tonkin and Beeston, 2000). The above participants all tried active strategies, as suggested by Blyth et al. (2005) to relieve their pain which appeared to have some analgesic effect, as opposed to using the passive strategies of isolation, immobility, consuming medications or undergoing further surgery. Although, when these active techniques failed, they then returned to the passive strategy of consuming medication, as PB and PM described:

> PB *Well when it starts to get bad* (his pain) *I'll take some ordine* (morphine liquid) *and that'll fix it. Most times it does, sometimes it doesn't so I'll take a couple of tablets to see if they work. If that doesn't work, I generally go see my GP and she gives me an injection.*

> PM *You do get your good and bad days, 99.9% they're really good, you know, it really doesn't bother me, but then I might have one day when is gives you a bit so I just take medication and that helps it out.*

When at the stage of Treading Water the participants did attempt to maintain some control over their pain.

At the Wading to Shore stage the participants tended to tolerate their pain and usually ceased taking their medications as they either ignored their pain or controlled it in other ways, such as socialising with friends. As PO described:

> PO *Shit happens!... But I've learnt to live with it now. OK, I've got pain and that but I'll live with it. I'll live with it for the rest of my life!... Like at the clinic the other day* (where he collects prescriptions)*, I just thought* **'What am I doing taking all this crap'?** (his medications). *Like I said I get pain but I get over it!...*

PO elaborated further:

> *I was on methadone and all that crap, you know, because of the pain. But I went cold turkey I've just got to!... It's better for my body, I think. I've just got to do it!... It's sort of stuffs me up, you can't live like that!... I still suffer with a lot of pain but I put up with it now. I sort of think getting out with my mates and having a bit of a reality check and a few beers is better.*

Socialising is an 'active' positive strategy according to Blyth et al. (2001, p290) and using such a support system helps to boost self-esteem and confidence. It appeared throughout the process of Accepting a Reduced Self the issue of pain was interwoven, as the majority of those who suffered from this phenomenon acknowledged the impact it had on their physical being, the influence it had on their mood and how it contributed to them becoming socially isolated and Madjar (1997) acknowledges the invisibility of pain makes it difficult for those around a sufferer to be aware of their suffering.

Support Crew

In this study, Support Crew is synonymous with social support. Current literature indicates that having a support network in the form of physical or psychological assistance usually helps individuals accept and manage their disability (Earvolino-Ramirez, 2007; King, Willoughby, Specht and Brown, 2006; Halcomb et al., 2005; ABS, 2004a,b; Bonanno, 2004; Williams, Barclay and Schmied, 2004; Richardson, 2002). This can occur because a support network offers indirect influences such as

emotional support, caring, respect, believing in; or environmental behaviour such as problem solving assistance, sharing information and active physical help (Williams, et al., 2004). The concept of social support is diverse and complex and some of the features associated with the term are love, caring, reliability, willingness, self-esteem, extended care and security (Williams et al., 2004). In this study the majority of the participants (12 of the 15) received some sort of help and assistance, either as practical hands on help and/or as emotional support. The ABS (2004a,b) reports that approximately 75% of people with a disability receive help from a family member. Boughton and Halliday (2009) acknowledge that with the pressures on the hospital environment many people are discharged home from hospital who still require practical help, support and sometimes nursing assistance and such help is usually given by a family member or partner. Having a Support Crew or caring network to offer such assistance tended to encourage and motivate the participants in the challenging times of Accepting a Reduced Self. A Support Crew offered practical assistance and this was especially true for those who were at the Floundering stage, as these participants seemed to rely on others to meet their most basic needs. For instance PA need her husband's help in the shower and PM needed his mother to alter his clothes. The data indicated that thirteen of the fifteen participants relied on their social networks to help them in some way with household chores, for example meal preparation:

> PC *I can make a cup of tea but only now!...* (a year after his injury) *The freezer is full of frozen meals, or she* (his partner) *makes me sandwiches. I couldn't do it!...*

Sometimes participants had problems paying for goods and accommodation and relied on family and partners for financial assistance. For instance PA's ex-partner and parents assisted her financially:

> PA *I had to move, that was hard, I went and slept on his* (ex-partner) *couch. He's been looking after me. Now he's always making sure I've got $50, saying* **'Here go and buy something for yourself'.**

Others had problems managing housework and child care duties, as PJ explained:

> PJ *I can't make beds, vacuum, do the dishes, cook. I can't dress my own child!*

PE could not help his wife perform the housework.

> PE *My wife works and we try and share the workload as much*
> *as we can and around the house, I can't do!...*

The participants Support Crew also offered help and assistance by giving them psychological and emotional support. This type of support occurs in the form of positive reinforcement, tolerance and understanding which increases self-esteem and self-confidence (Bonanno, 2004; Williams, et al., 2004; Richardson, 2002).   For example, PB received psychological support and tolerance from his housemate:

> PB *The only person I've had really support me since my*
> *accident is X* (his housemate). *She's been the only one that's*
> *really supported me since the accident and that's only been for*
> *ten years. Yes, we've been best buds* (friends) *for a long time.*
> *There's never been anything else, we're just best mates.*
> *There's nothing that interferes with the relationship of mate-*
> *ship. It's great, we're best mates, we get on well.*

PG identified the tolerance and support, his wife displayed:

> PG *As you saw out the front, I've got bits of crap, cars sitting*
> *out there. I've had them for too long, pulling bits and pieces of*
> *them to fix up other cars. I can only work for an hour at a time*
> *so what would only take me a week now takes me three months.*
> *So I mean that way my missus* (his partner) *has to be very*
> *understanding.*

The front of the house was cluttered with old car parts because PG was now very slow at repairing them with his disability. Other ways emotional support was given to the participants was through the acceptance of them as people, regardless of their injury, their altered appearance or their physical limitations. PG's close friend 'X' visited him within a day or two of his discharge from hospital, asking for his help with his car:

> *That was X's way of helping me get back on with life. It*
> *worked, because none of them let me sit down and think about*
> *it* (his amputation). *Everyone was around me, it was like* **'Yes**
> **this has happened but so what? Let's get on with it!...'**

Such behaviour indicated that, though the participant had lost his leg, he was still considered a friend and a trusted mechanic. These beliefs significantly enhanced his self-confidence and self-esteem.   PK acknowledged that the care and support he

received from his support team helped him manage his life with his disability on a daily basis:

> PK *The best thing on my side is who's in my support team. They're the best!... My father in law, my wife, my sons and my friends. A few of my friends couldn't give two rats* (about his paraplegia) *they're no different since I had my accident as to how I am now* (in his wheelchair).

PO recognised how his friends had supported him with his injuries. When asked about how he managed his injuries he replied:

> PO *A good routine and getting back with my mates probably!... Getting back into the biker lifestyle, where your brothers are your brothers and they stick with you 110%!...*

PO had severe physical injuries but he continued to be affiliated with several bikie gangs. The members also helped him psychologically:

> *Just once you're down, once you've had an accident, you've got mates there all the time!... They come and see you all the time. I know all the clubs here in X and they look after me 100%. Just by their support. They* (the gang members) *look after us you know, the ones that are down* (who are disabled).

It has been reported that having psychological and emotional support helps people accept and manage their disability better than those who are unsupported (Widar et al., 2007; King, et al., 2006; Halcomb, et al., 2005; Horgan and MacLachlan, 2004; Richardson, 2002; Charmaz, 1991). Such support assists the individual to develop coping skills, to better manage their trauma and increase self-esteem and confidence (Earvolino-Ramirez, 2007; King et al., 2006; Halcomb, et al., 2005; Bonanno, 2004; Richardson, 2002). The majority of participants in this study had a Support Crew that assisted them either physically, financially or psychologically although, despite this help, most continued to be at the Floundering stage of Accepting a Reduced Self as they struggled with their disability and their situation. However, there were three participants (PF, PL and PN) who did not have a Support Crew. These participants were all male, often socially isolated (except for medical or health related visits), suffered with persistent pain and all had experienced major trauma.

Type of Trauma

Major Trauma

In this study ten of the participant's experienced major trauma as classified by RPH (2008) and their injuries consisted of spinal cord injury, limb amputations and severe traumatic limb damage. Limb function with these conditions can be lost immediately as the consequences of such trauma are often catastrophic, with victims requiring extensive acute care and long-term rehabilitation (Halcomb and Davidson, 2005; Morse, 1997; Morse and O'Brien, 1995). Those who experienced major trauma in this study suffered biopsychosocially. From a physical perspective three of the participants, (PB, PG and PO), were at the Wading to Shore stage, as they were totally independent when managing their physical needs. Other participants seemed to drift between the stages of Treading Water and Floundering. There was only one of the ten participants who had experienced major trauma who appeared cemented in the Floundering stage: PC. He remained very dependent on his partner in many areas of his life, so much so that he had moved in to live with her when discharged from the hospital, as opposed to returning to his own home. Regarding pain management, the majority (nine of the 10) of the participants who experienced major trauma used medications to manage their pain. Sometimes a few participants (PB, PI and PM) would use active techniques but, when these failed, they would resort to consuming analgesics. PO was the only one to cease taking any analgesics.

Psychologically, the majority of those who experienced major trauma struggled to accept their injuries and see a positive bright future. There were two participants (PB and PO) who acknowledged that life with their injury was good and they had to actively make the best of it. Several participants (PG, PK and PM) hoped that their limb function would be returned so that life could return to how it used to be. While this belief encouraged them to manage their physical wellbeing, it also prevented them accepting their long-term future as a person with a disability; hence, they remained, at times, Treading Water with their impairment. There were two participants (PC and PN) who were highly despairing about their disability and could see no positive future prospects or hope regarding their injuries. PN also was fixed on allocating blame for his accident as was PI and with such negative thought these participants appeared to be psychologically at the Floundering stage in relation to Accepting a Reduced Self.

Again, those who had developed independent living skills after major traumatic injuries tended to be comfortable socialising as they had done previously. For the other seven participants who experienced major trauma their social calendar was influenced by numerous decisions such as their physical independence, the current pain experience at the time of the pending social event, who would be at the event, where they were to socialise and the state of their finances. Only three of the participants were in paid employment (PN, PK and PM) at the time of the interviews, though budget restrictions appeared to be needed in the household. Several participants had attempted to work after their accidents but had subsequently left, for one reason or another.

Minor Trauma

The consequences of relatively minor operations, which are usually performed as day cases, often go largely unmonitored. This is because patients are now being discharged earlier in today's health care system, though discharge planning, follow-up care and assessment all generally poorly provided (Boughton and Halliday, 2009). Despite these operations/procedures, often being classed as routine, limb function can still be lost if nerve damage occurs or if a syndrome like CRPS develops (Stanton-Hicks, et al., 2002). The five participants in this study who suffered minor trauma (including the participant experiencing a childhood infection) tended to struggle with their subsequent injury, so much so that most resided in the Floundering or Treading Water stages of Accepting a Reduced Self. For instance P.J remained totally dependent on her partner for her physical needs, whereas the other four required partial help or aids to promote their independence.

Four of the five participants (PA, PD, PE and PJ) appeared to be confused and unsure as to how such a benign injury had created such havoc in their lives and thoughts of this injury (and their pain) becoming permanent was usually unacceptable and rejected. PH (who experienced the childhood infection) on the other hand denied that she was *disabled* though she required a wheelchair to reach any destination. It had been suggested by her consultant that she commence using an electronic wheelchair to ease the physical strain on her shoulders, (these joints were in constant use as she pushed herself in her wheelchair). The participants who experience minor trauma were generally despairing about their injuries, their futures

and most (PA, PE and PJ) allocated blame to someone for their disability. Psychologically these participants were Floundering in Accepting a Reduced Self.

All the participants who experienced minor trauma struggled with their pain, its persistence and intensity appeared to influence every aspect of their lives. These participants managed their pain passively, either by resting or with the use of medications. However the majority of the participants with minor trauma continued to work (PE, PD and PH) despite experiencing pain and discomfort. Usually this type of socialisation was the only kind of social activity this group performed; rarely did they mix with others outside of work because of their pain, mood or physical limitations. Therefore from a social perspective the participants who experienced minor trauma appeared to be Floundering when Accepting a Reduced Self.

Length of Time

Previous studies suggest that individuals begin to adapt, reconcile and accept their trauma and injuries over a period of time as they become used to their situation and their altered life trajectory (Salick and Auerbach, 2006; Halcomb and Davidson, 2005; Morse, 1997; Morse and O'Brien, 1995). However, for these study participants this did not appear to be the case as their adaptation to their injuries and acceptance of reconciliation was not as clear cut in relation to how long they had been injured. Harrison, Umberson, Lin and Cheng (2010) state that skill development improves with the length of time living with a disability and this was apparent in this study. The longer the participants lived with their disability, the more adept they became at physically managing their injury. For instance PB and PO had been injured between 15 and 30 years ago and managed their injuries independently, including their homes, shopping and preparation of food. Also, the earlier in life people experience their impairment, the more likely they are to manage it (Harrison et al., 2010). Participants PB and PO did receive their injuries at fairly young ages which supports this research. Although, in contrast, PH had received her injuries as a child and was now in her forties, so she had many years managing her disability but still relied on her parents for assistance regarding the housework, meals and other physical support. Also PJ had received her injuries eight years ago (when she was 18) but her physical disability remained with no new strategies to try and gain more independence.

Again, those who had been injured decades earlier appeared more accepting and at ease with their disabled state. For example, PB and PO had reconciled their injuries, as they rationalised that it was important to make the best of what time they had left. They saw some positives in their futures, living with their disability. PG, however, remained reluctant to inform people of his prosthesis and continued to be hopeful that science would grow him a new leg. Similarly, although injured over 15 years ago, PF readily acknowledged that he had physically modified and adapted his behaviours to manage his disabled state but psychologically he had not *accepted* his situation as he expressed he had *never accepted nor will he accept becoming a paraplegic*. The participants who had been injured between one and 10 years ago continued to be challenged psychologically as many were despairing about their impairment, continued to blame others for its occurrence and were ever hopeful that they could be renovated and fixed by some technological breakthrough.

Length of time since injury influenced how PG and PO socialised. As mentioned, these participants were injured several decades ago and socialised as they always used to, though both were unemployed. The majority of participants (PD, PE, PK and PN) who were in paid employment had all received their injuries within the past five years. However, three of the study participants (PB, PF and PG) had originally commenced regular employment after their injury, only to resign because of their physical limitations and pain issues. This could suggest that ongoing employment may become more difficult with long-term disability because of the stresses it puts on the body. In this study there was one exception to this notion and this was PH. She continued to work (despite losing limb function decades ago), although she did seem to be struggling to manage her current employed status because of her ongoing physical issues.

Summary

This chapter has described the stages, processes and adaptations which developed by the participants towards Accepting a Reduced Self. These stages were identified as Floundering, Treading Water and Wading to Shore. All three stages had various biopsychosocial influences for the participants and all were interlinked, creating a boundless process as the participants attempted to achieve Accepting a Reduced Self with their loss of limb function. There were several modifying conditions that

influenced the participants ability in Accepting a Reduced Self and these were recognised as how well they managed their persistent pain, having a support crew, the type of trauma the participants experienced (major or minor) and the length of time they had lived with their injury. Despite these modifying conditions, most participants appeared to have difficulty coping with their loss of limb function and Accepting a Reduced Self.

CHAPTER 5

<u>Discussion and Conclusion</u>

Introduction

This chapter gives an overview of the substantive theory which emerged from this study which included the basic social problem of Loss of Self and the basic social process of Accepting a Reduced Self, together with their associated biopsychosocial categories, properties and modifying conditions. Comparisons are made with relevant theories, models and frameworks, such as the Trauma Trajectory, Loss, Stress/Coping and Accommodation/Assimilation literature, which were found to have relevance for some aspects of this newly developed substantive theory. Implications for the research findings are explained in terms of their application for clinical practice, management and research. The aims and research questions are then answered followed by the limitations of the study concluding with suggestions for future research.

Components of the Proposed Substantive Theory

In order to develop the substantive theory, 15 participants were asked to describe their experience of losing limb function and four expert nurses were ask to explain and clarify the care and treatment that had been given to the participants. In retrospect, it appeared that theoretical saturation occurred after interviewing 10 of the participants however, a further five interviews were performed to confidently ensure that saturation had occurred. The interviews with the expert nurses also aided saturation as they recounted similar incidents from their experiences with others who had lost limb function. The substantive theory developed described the basic social problem experienced by all participants and the process of how the participants managed to live day to day with their loss of limb function.

<u>The Basic Social Problem: Loss of Self</u>

The basic social problem was identified as Loss of Self and described what happened when the participants met with their trauma and the abrupt, profound dislocation that occurred to their taken for granted lives. The participant's lives were projected into an un-anticipated, complex world of hospitals and social service systems as their

personal boundaries and territories were altered to incorporate the biopsychosocial changes required to cope with their loss of limb function - which could develop suddenly or gradually. The impact of these changes reverberated across the entire spectrum of family and social life.

Sudden loss of limb function occurred for the majority of the participants when they suffered acute, major traumatic loss of limb function, often developing at the injury site. Many of the participants spent time in high dependency care units and, once they had overcome the acute phase of their trauma, they were moved to a rehabilitation area in order to recover as much limb function as possible. Gradual loss of limb function occurred when several of the participants experienced some sort of minor trauma (including infection) and, in order to promote the return of their limb function, the participants underwent multiple, unsuccessful minor surgical/investigative procedures to correct their limb damage. Usually the results of these procedures caused more loss of function and further deterioration and disability.

The Basic Social Process: Accepting a Reduced Self

Accepting a Reduced Self was recognised as the basic social process and was composed of three stages: Floundering, Treading Water and Wading to Shore. Each stage had progressive biopsychosocial consequences for the participant, with those at the Floundering stage being biopsychosocially more dependent than those Wading to Shore, although the participants did appear to drift between all the stages. This was because the stages were interrelated, though not sequential or dependent on each other as their borders were porous and intersecting. Therefore, socially a participant could be at the Floundering stage, although biologically (physically) they demonstrated that they were coping well with their loss of function and, in this respect, were residing at the Wading to Shore stage. There were also several modifying conditions that influenced at which stage the participants would reside and these were identified as: how effective they managed their pain, the social support they received, the type of trauma they had experienced and the length of time since injury.

Floundering Stage

The participants who were at the Floundering stage displayed no inherent personal coping qualities and struggled daily with the consequences of their disability. Physical restrictions were an issue as they struggled daily with the mundane tasks of everyday living, such as personal hygiene needs. Denial was evident at this stage and initially, for some individuals, it is an appropriate coping mechanism until they are able to gather their thoughts and think about the future (Parkes, 2002). However, in this study, their denial persisted for several years, inhibiting the participant's reconciliation that their loss of limb function would be a permanent fixture in their lives. At the Floundering stage it appeared that rebuilding their lives to incorporate their disability was too much of a challenge, so they often reflected on their life prior to their injury as suggested by McCracken et al. (2008) and Payne et al. (2007). When at the Floundering stage, the participants were often despairing about their situation and some diverted their energies into blaming something or someone for their injury which again kept them focused on their past life and injury. Socially, the participants tended to isolate themselves, usually because of persistent pain, physical differences, creating poor self-esteem, confidence and these beliefs were exacerbated by society's reaction towards them.

Treading Water Stage

The participants who were at the Treading Water stage displayed some biological (physical) coping qualities as they tried to manage their loss of limb function. Most of the participants at this stage hoped that their limb function would return sometime in the future and this hope was supported by media reports of new medical knowledge relating to a range of conditions. With this expectation in mind, some participants maintained their fitness level (keeping the joints of paralysed limbs round and supple) so their bodies would perform as required when limb function returned. Participants at the Treading Water stage displayed hardiness and a strength of character which helped them cope with the adversity of losing limb function. Socially, the participants tried to mix with others as they attempted to continue relationships with friends, colleagues and communities, though they acknowledged this took patience, time and effort to maintain.

Wading to Shore Stage

At the stage of Wading to Shore, the participants appeared more positive about their loss of limb function as they focused on what they could do, as opposed to their biopsychosocial restrictions, showing a determination that allowed them to exceed their expectations. They managed the physical consequences of their disability independently and psychologically, they had a positive attitude regarding their loss of limb function as they accepted their disability into their lives. Socially, they interacted as they had always done and, in some cases, they also contributed to their communities as volunteers in one form or another.

Modifying Conditions

All of the participants in this study experienced persistent pain and how well they managed this condition influenced at what stage (Floundering, Treading Water or Wading to Shore) they would reach when Accepting a Reduced Self. Often it would appear that their pain was as much a problem and impairment on their lives as their disability. The persistence of pain mediated all aspects of their lives physically, socially, sexually, emotionally and psychologically, sometimes affecting their ability to cope with what were once simple facets of their lives. The more control the participants had when managing their pain, the less its potential to influence their biopsychosocial condition.

The use of a support crew had some bearing on how the participants managed their disability. It could be presumed that the more support they had, the more likely they would progress through the stages. However, this was not always the case as some participants had positive, caring and supporting relationships with family and friends but were still at the Floundering stage, biopsychosocially

It is generally expected that those who experienced minor trauma would recover from their injuries quicker and its consequences would not be as severe as those receiving major trauma, but in this study this did not always occur. Those who suffered minor, somewhat benign, trauma appeared to have as much difficulty, if not more, (as many remained at the Floundering stage, biospsychosocially), than those who had experienced major injuries. Though what was noticeable was that two of the four participants (PD and PE) who experienced minor trauma at the time of interview had returned to work.

The length of time since injury could also be indicative as to how one accepts and reconciles their injury, such as the longer the time since their trauma, the more readily their injuries are accepted. Some of the participants in this study had lost limb function over twenty years ago; however, they continued to have issues accepting that their injuries and disability were permanent fixture in their lives.

Comparisons with Related Theories and Frameworks

Trauma Trajectory

The Illness Trajectory Framework of Corbin and Strauss (1991, 1992) (who initially described the experiences of the chronically ill and dying) is the basis of the trauma trajectory. The trauma trajectory has five phases:

1. Pre-trajectory phase which includes what lifestyle factors can predispose the individual to receiving an injury;
2. Acute phase when medical intervention is at its upmost to save life and prevent secondary injuries;
3. Stable phase when medical intervention is stabilised to maintain their current health situation;
4. Unstable phase which includes the challenge of rehabilitation and recovery;
5. Dying phase when the injury is permanent and no further improvement is gained (Halcomb and Davidson, 2005).

This trajectory suggests that, after a period of time, though no specific timeframe is given those who experience trauma move to another level of reconciliation and acceptance of their trauma and its outcomes (Salick and Auerbach, 2006; Halcomb and Davidson, 2005; Morse, 1997; Morse and O'Brien, 1995).

The findings of this study are similar to that proposed by the above authors: that people who experience trauma move through a series of stages to the ultimate stage of acceptance regarding their life changes and limitations. However, most of the participants in this study did not appear to move sequentially to reach the next stage. Many participants seemed to be at multiple stages. For instance, psychosocially they were at the Floundering stage with little hope of reaching acceptance or reconciliation despite being injured years ago (and sometimes decades ago) although, biologically they were at the stage of Wading to Shore, as they had achieved independence with their personal care.

Halcomb and Davidson (2005, p237) suggest that it is a 'misconception' that those who experience trauma become focused on their injury and its consequences, yet they acknowledge that 'few studies have comprehensively investigated holistic recovery from traumatic injury beyond quantitative evaluation of health status'. This research addresses this gap as it investigated how both major and minor trauma impacted on the whole person. It suggests that for the majority of participants in this study their loss and disability was devastating and remained the primary focus in their lives, overriding all other issues as they suffered daily with its consequences but were unable to place the trauma within the context of their larger life story.

Loss

Grief, loss and the theory of its adaptation are well-known and accepted as a common psychological response, by health workers in society today (Maciejewski, Bauhui, Block and Prigerson, 2007). The most familiar grief theory is that of Elizabeth Kubler-Ross, who devised five stages that allow the individual to cope with the stressful situation of death/dying (Maciejewski et al., 2007). These stages are:

1. Denial-   where the individual cannot accept what is occurring to them;
2. Anger-   at the situation that has developed;
3. Bargaining-   with some entity (usually god) for extra time on the earth;
4. Depression-   develops often after repeated hospital admissions and procedures;
5. Acceptance-   when denial, anger, bargaining and depression have all ceased, then this stage is reached (Kubler-Ross, 1985).

Kubler-Ross (1985) suggests that individuals pass through these stages, though they do not have to be in consecutive order and an individual can reside in more than one stage at a time.

For the participants in this study, Kubler-Ross's (1985) theory is useful, as comparisons can be made throughout this theory. For example, two participants (PA and PJ) were in denial about their loss of limb function and developed unrealistic goals regarding their current and future limb function. Anger and frustration were common for the participants, as some blamed, criticised and condemned others (or themselves) for their injuries. The use of bargaining could be occurring with the

medical profession, as some of the participants (PG, PK and PM) tried to maintain their bodies at a peak fitness level in the hope that technology would fix their loss of function and make them whole once again. Depression, mood changes and social isolation were regular themes which appeared to run throughout the basic social problem and process, with three participants (PA, PB and PE), contemplating suicide after their loss of limb function. Acceptance of their loss of limb function and disability was difficult to measure and assess for the participants in this study. There were two participants (PB and PG) who accepted that riding motorbikes probably contributed to the severity of their injuries. Also, some participants (PB and PO) displayed a positive attitude about life and their future (which could aid acceptance) but, for most, it never consistently became established and hence their loss appeared to envelop them.

Loss of Self

This study supported the notion of Loss of Self. Charmaz (1983) identified loss of self as a response to the problems that chronic illness creates for its sufferers. Such physical and emotional distress creates pain and suffering as it causes and maintains a loss of self-esteem, reduced self-confidence, altered self/body-image which ultimately results in a loss of self (Charmaz, 1983). Similar developments occurred in this study for the participant's, although loss of self was a direct result of an acute traumatic injury, not an ongoing chronic illness. For instance in Charmaz's (1983, p170) work, the categories 'living a restricted life', recognises how the chronically ill lose their freedom and access to the world because of their physical restrictions and the unpredictability of their illness. 'Existing in social isolation' acknowledges how the loss of social networks and relationships enhances a loss of self and 'experiencing discredited definitions of self' identifies how personal and public identities change with the onset of chronic illness and disability (Charmaz, 1983 p170).

In this study the biological (physical) consequences of their loss of limb function reinforced the practical difficulties that the participants experienced with basic human needs, such as reaching one's physical destination, bathing and using the bathroom. Their biopsychosocial abilities were variable and, depending on how adept they were at managing these issues, influenced at what stage in this process of

Accepting a Reduced Self they would reach. The social consequences in this study illustrated how the participant's personal and public identities had changed. They now believed themselves and were acknowledged by others to be, abnormal. Often the participants were isolated by friends and communities as their physical and mental capacities had altered since losing limb function. The social difficulties identified throughout the theory in this study are similar to the categories, 'living a restricted life, existing in social isolation' and 'experiencing discredited definitions of self', as discussed in Charmaz's (1983) work. The major difference regarding Charmaz's (1983, p171) participants and the participants in this study were the causes that led to the individual's 'loss of self'. In Charmaz's (1983) case, 'loss of self' was developed by ongoing chronic illness that slowly whittled away at the self, whereas the participants in this study experienced an acute traumatic injury which created their Loss of Self, although the consequence of this injury was chronic disability.

Stress and Coping

Stress and coping were prominent themes running throughout this theory and can be compared with the work of Lazarus (1993) who discusses these phenomena. Lazarus (1993, p4) identifies four concepts to describe the stress process:

- personal environment - this can be a biopsychosocial stress causing a change in homeostasis;
- an evaluation of the situation to assess whether the stress is either 'noxious' or 'benign';
- the coping process used to deal with the stressful situation;
- stress reaction - the influence the coping process has on the individual, biopsychosocially.

Lazarus (1993) acknowledges that 'eustress' can occur, which is recognised as good stress, making individuals feel positive and able to express pride, happiness, love, hope and compassion. In contrast 'distress' can develop, whereby the individual has an infirmed body state which is associated with negative feelings such as anger, anxiety, guilt, shame, sadness, envy, jealousy, fear and disgust (Lazarus, 1993 p5 and 13).

In this study, the participant's loss of limb function was the initial stressor. All the participants classified this event as a noxious experience and most proceeded to cope with their stress in a negative way becoming distressed by their inability to perform. For example, several of the participants experienced anger, anxiety, shame and sadness regarding their trauma, injury and disability. This resulted in them remaining at the stage of Floundering as they blamed others for the incident, were despairing about their situation and generally isolated themselves. To mix with others socially was too physically hard and mentally challenging for these participants. It must also be noted that when the patients were anxious, their pain was exacerbated.

In contrast, there were some participants who tried to be more positive about their experiences regarding their loss of limb function and where at the stages of either Treading Water or Wading to Shore. These participants exhibited hope (though this was somewhat unrealistic, as they expected to be 'fixed' by the medical technology) which encouraged the participants to maintain the joints, muscles and tendons *just in case* their limb function was restored. Also, several participants (PL, PM and PO) who were at the Wading to Shore stage displayed compassion for others in similar situations and this resulted in them acknowledging their own abilities, which is a key concept of the Assimilation and Accommodation model of adaptation and coping.

Assimilation and Accommodation

Assimilation and Accommodation, described by Schmitz et al. (1996), is based on Brandtsädter and Rothermund's (1994) model of how a sense of coping, control and improved self-efficacy can be managed more positively in late adulthood by accepting one's limitations and reassessing goals. Coping with stress and trauma can be influenced by having a positive locus of control, adaptation and a positive self-esteem (which will influence self-efficacy) (Agaibi and Wilson, 2005; Cast and Burke, 2002). Schmitz et al. (1996) postulates that pain causes a threat to personal goals and these goals can either be assimilated or accommodated by the person. Assimilation occurs when the person is focused on unattainable, pre-injured goals causing anger, frustration and features of depression. The person attempts to change their situation by self-corrective actions, using compensatory measures and instrumental activities in the attempt to achieve these past, ongoing goals (Schmitz et

al., 1996). However, those who accommodate their situation downgrade their goal importance and shift their goals to what is achievable (Schmitz et al., 1996; Brandtsädter and Rothermund, 1994). These people review their aims and aspirations, reduce their personal standards, perform a positive self-appraisal of what they can do (as oppose to what they cannot), and adapt new routines that incorporate their disability, as they accept their restrictions and give up unrealistic expectations (Schmitz et al., 1996). These views are supported by Agaibi and Wilson (2005) who suggest that when the person is able to master what they can do, this increases their self-esteem, self-efficacy and self-confidence and they are better able to cope with the stress of their trauma. Schmitz et al. (1996) indicates that those with chronic pain can buffer the consequences of their pain by having flexible goal adjustment and, therefore, become less depressed, have the ability to cope more positively and reduce the potential for disability.

This research focused on those who lost limb function as a result of acute minor and major trauma and supports the theory of accommodation/ assimilation and goal pursuit. For example, the participants in this study who were at the Floundering stage appeared to be assimilating. This was because they struggled to manage their impairment, as they were often despairing about their situation which influenced their self-esteem, confidence and efficacy. The participants who were Wading to Shore had accommodated some aspects of their disability. They tried to set realistic goals within their limits, used their support network as required and looked for positives in their body and their current situation. These behaviours appeared to help when Accepting a Reduced Self.

This research also offers another perspective to that of Payne et al.'s (2007, p80) theory of Assimilation and Accommodation following traumatic experiences. Payne et al.'s (2007) study sought to explain the psychological processes of assimilation and accommodation after a traumatic event. It depicted a trauma trajectory whereby 'adversarial trauma' is the central component (trauma is usually adversarial as one never expects to be a victim). On one side of the trajectory are 'attempts to assimilate' which focuses on how the participants try to maintain their pre-trauma beliefs. On the opposite side of the trajectory is the 'drive to accommodate' as the

participants acknowledge unresolved issues and the need for change which is required to move forward with their life, this trajectory is depicted in Figure 3.
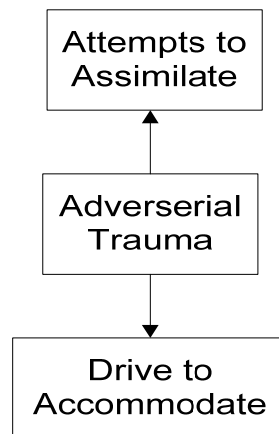

Figure 3 Summary of Assimilation/Accommodation to Adversarial Trauma
Source Payne et al (2007p.80)

These constructs can be compared to the three stages found in this study: the Floundering, Treading Water and Wading to Shore stages. For example, those who were at the Floundering stage were in despair and denial regarding their loss of limb function as they focused on their old life before their injury and, therefore, they were attempting to assimilate. While those who were Treading Water and Wading to Shore recognised that they should move on, they tried to accommodate their loss of limb function even though problems were holding them back.

Contribution to New Knowledge

This study included participants who had lost limb function as a result of acute minor or major trauma. There were four participants who developed CRPS (three from knee surgery and one from removal of a wrist ganglion), four participants had received amputations (all were motorbike riders), four participants were paraplegic (one was from a childhood infection, two from work-related falls and one was a pilot who had a plane crash), another participant had a brachial plexus injury and two had multiple leg fractures and trauma (all acquired from motorbike crashes). The findings indicated that when trauma caused loss of limb function and recovery to their previous physical state, (given the current state of knowledge) was not possible, then accepting and coping with such a loss was extremely difficult for some to manage.

It is well-documented that major trauma causes suffering and a permanent loss of limb function (Holtslag, Post, van der Werken and Lindeman, 2007; Castillo, et al., 2006; Holtslag et al., 2006; Mackenzie et al., 2006; Urquhart et al., 2006; Halcomb et al., 2005; Mackenzie, Bosse, Pollak, Webb, Swiontkowski, Kellam, et al., 2005; Mackenzie, Bosse, Castillo, Smith, Webb, Kellam, et al., 2004; McCarthy et al., 2003; Michaels, Michaels, Smith, Moon, Peterson, C. and Long, 2000; Holbrook, Anderson, Sieber, Browner and Hoyt, 1999). All of these studies, except one, (Halcomb et al., (2005) reviewed literature) used quantitative methodology, with the primary source of data collected from self-completed questionnaires and surveys. In some instances interviews were performed but set tools such as the Sickness Injury Profile were used to measure the level of disability. While the findings make a valuable contribution to knowledge in the field of trauma, by nature of their research design, the individual lived experiences of the participants are not addressed. There are two Australian studies identified in the named group. Urquhart et al. (2006) was a study based in Victoria, but because the health care system is coordinated by each individual Australian state, specific experiences, treatments, practices and nursing management would vary and may not have been implemented in Western Australia. This research was also quantitative, using statistical testing to analyse results so that personal nuances, beliefs and actions would be ignored. Halcomb et al. (2005, p18) reviewed the trauma literature for keywords such as 'traumatic injury', 'wounds', 'injuries', 'outcome', 'quality of life' and 'recovery'. It identified several themes such as support, loss of productivity and the psychological impact of trauma and these themes can be compared to similar personal experiences found in this research from the 15 participants interviewed.

Research investigating injuries of both upper and lower limbs, from either acute major or minor trauma with varied time spans from interview to injury (i.e. from one to over 20 years) is sparse. When entering the keywords *loss of limb function major/minor trauma* into the MEDLINE and CINAHL databases full text, no results were found. When entering the same words into PROQUEST database, ten research papers were found. Two of these papers focused on rat studies, three papers explored upper limb trauma (shoulder pain after a stroke, the others discussed elbow or hand reconstruction), two papers examined biochemistry (one in joints and the second in action potentials in paraplegics) one paper studied blood flow in the CRPS

limb, one researched necrotising fasciitis in children and the last paper investigated back pain and x-rays.

This study has addressed a deficit in the literature and the findings add to the body of knowledge as it encompasses a comprehensive range of traumas, from a variety of causes, with diverse timescales since the occurrence of their injury, giving a longitudinal lens on the phenomenon of loss of limb function. This study also investigated the participant's experience both in the hospital setting and post discharge into the community. The care the participants received in hospital was focused on treating their acute injuries, moving them to rehabilitation and, eventually, getting the participants home, which is the goal of the tertiary hospital system. However, once returned to the community, the difficulties that they encountered had not been fully anticipated by healthcare staff, or the participants themselves and readmission to hospital was common. Readmission occurred for a variety of reasons, such as wound infections, pain issues and their inability to function or cope with their loss of limb function in their current community setting.

The literature regarding loss of limb function and the consequences of minor acute trauma is sparse. Consequently, this study adds to the body of knowledge as it described how minor trauma can cause a permanent loss of limb function, causing biopsychosocial sufferings similar to that of major trauma. All of the participants who experienced minor trauma appeared to be at the Floundering stage with the effects of their injuries. It seemed that they experienced a 'cognitive dissonance' similar to that described by Payne et al. (2007, p82) as they questioned 'how has a minor injury created such havoc in my life?'

Three stages of Accepting a Reduced Self were identified in this study: Floundering, Treading Water and Wading to Shore. Each stage was a result of how the individual reacted to the stress of losing their loss of limb function differently. For example, those who were at the Floundering stage were dejected and despondent with their life and injury. Their pain management was passive and they depended on their support crew when available. Crafting a new life with their impairment appeared too much of a challenge for them so they continued to concentrate on what they had lost and how life used to be, prior to their trauma. These thoughts often made them

angry, despairing and frustrated at their current situation. When the participants were at the Treading Water stage, they seemed highly sensitive towards their situation and disability, though they did try to maintain their independence where possible. These participants were more active at managing their pain, though they hoped that limb function would return with the aid of medical technology. At the Wading to Shore stage the participants were confident at managing their disability, they were aware that their disability would not change so they did not waste energy trying to alter their physical state. It seemed that these participants used a more constructive life path, identifying the beneficial attributes they had in their lives and giving assistance to their community in some form.

It was evident in the research that even though the majority of participants received social support from family members, either physically, emotionally or psychologically, it was not enough to help them manage and cope positively when Accepting a Reduced Self. This was apparent as most participants continued to be at the Floundering or Treading Water stages with their disability.

This research also identified that the time span from injury to Wading to Shore and living a positive, productive life when Accepting a Reduced Self, can take years and, sometimes, decades. This is much longer than other researchers suggest. There were also some participants for whom it seemed that they would never be able to be reconciled, accept and lead a positive, productive life with their impairment. For example, PH's injury occurred as a toddler. She was in her forties when interviewed, but appeared to be still at the Floundering stage when coping with her disability and its ongoing problems. She insisted she was not disabled and refused to alter her behaviours to accommodate her loss of limb function and change her working hours. PH worked, owned a car and had a mortgage, but these achievements had taken a toll on her body and her physical problems appeared to be increasing. She had financial stress and hoped to look for a second job to support her income. In addition, her physical problems were causing her to spend more time away from her original workplace which increased her financial woes and did not help her physical wellbeing.

It became clear through this research that losing limb function suddenly, without notice or warning, left the participants lives in chaos. Those who received minor trauma were all at the Floundering stage, psychologically and seemed to have more of a problem accepting the consequences of their loss of limb function, as their injury was initially classed as benign. Despite this classification, permanent impairment, disability and loss of function ensued because of the nerve damage that had occurred or the syndrome (CRPS) that had developed, making comprehension difficult. It is noted that 'minor trauma' hospital admissions are on the increase and continue to contribute significantly to the total hospitalisations as a result of trauma (RPH, 2009 p5). Yet, despite this increase, these injuries are not recognised as altering quality of life or independence (Department of Health and Ageing, 2005). This study has indicated that, in certain situations, this is not always the case.

Those participants who were victims of major trauma and were at the Floundering stage psychologically, continued to fight against their disability as opposed to learning to live with it and accommodate it in their lives. They recalled how they used to be and what they used to do before the event that resulted in loss of limb function. These memories often created anger, frustration and despair as they struggled to accept their body and their disabled identity.

Practical Implications of the Study
The findings of this study identified that there were gaps and variations in the care and management that the participants received. For example, not all participants had access to adequate pain management, psychological counseling, physiotherapy, social work and rehabilitative care. This research also illustrated that the treatment and management the participants received in the acute and rehabilitative phases of their care was not individualised, though it did tend to focus on the functional aspects needed to assist them to return to their communities. Discharge from hospital appeared a primary concern for the health professionals. Despite this focus however, it often became clear that once home the consequences of their disability were more severe than first suspected by the participants and their carers, more practical strategies had to be introduced to manage basic tasks such as reaching a physical destination and managing hygiene needs.

Following the participant's discharge into the community from hospital, the findings of this research indicated that, in the state of WA community care and management for those who had lost limb function as a result of major trauma was limited. Follow-up management by specific specialists and General Practitioners (GP) tended to be the primary way that the participants kept in touch with their health professionals. There appeared to be no home visits by any hospital or community personnel to assess their progress and troubleshoot any potential issues regarding their trauma. This lack of contact with health professionals created problems for the participants as the physical and psychological struggles of accepting the consequences of their injuries became more dominant when they were discharged home and where help was limited.

When minor trauma was experienced, the participant's follow-up management in WA tended to be with their local GP. Again, the relevant specialists who managed the participant's care in hospital had some input but this was inconsistent, despite the consequences of minor trauma causing severe long-term impairment. Some patients were given follow up appointments, with the surgical team responsible for their admission usually weeks/months post-injury, but this was dependent on the type and level of trauma. For example, those with burns or wounds requiring plastic surgery tended to be seen within days of their discharge because wound dressings were often performed initially at the appointment. However, for the majority there was no telephone call, hospital outreach or community service to monitor their progress. The participants also had to arrange their own follow-up with their GP, who may have received information and instructions from the hospital regarding their care and management. Receiving this information in a timely manner was dependent on whoever wrote the discharge plan for the participant (at RPH this was often the most junior person of the medical/surgical team), although some participants waited for their GP to receive this information before they made their appointment. Should the participants need to visit their GP before the discharge letter arrived at the GP's surgery, their GP was unaware of what had occurred in the hospital setting and their ability to manage the participant's care was somewhat limited.

This study acknowledged that minor trauma created a level of disability and physical impairment for the participants that, for some of them, reduced their ability to return

to work. This supports the arguments identified in the literature review by Halcomb et al. (2005) suggesting there is a no clear link between the Injury Severity Score (ISS) and the completion of productive rehabilitation, or the returning to work. The ISS is a method used to describe patients with multiple injuries and is allocated when diagnosis is complete. It is presumed that the higher the score, the higher the risk of mortality and morbidity the individual experiences and the longer their stay in hospital. Nonetheless, the ISS cannot be used to predict employment potential after injury because of the many variables that are required to return to employment such as workplace support, the educational status of the traumatised patient, their mood and motivational state. In this study, the data indicated that following both minor and major trauma all of the participants experienced a significant disability which caused physical restrictions and persistent pain, rendering the ability to be re-employed poor. For those who received minor trauma, their ISS would be low; however, only 50% of these participants returned to work. Therefore, this study supports research by Halcomb et al. (2005) regarding the ambiguity of a high ISS score and one's capacity to return to work.

The findings of this study emphasised the difficulties that can develop from minor trauma and the need for prompt referrals to the relevant specialists to prevent mis-diagnoses and inappropriate treatment. Problems such as nerve damage or unusual pain syndromes were often not diagnosed by the GP or the surgical specialist. It was only when pain became a dominant feature in the participant's lives, their recovery had become stagnated and their anticipated recovery path had lapsed, that a pain specialist was consulted. Ideally, the participants should have been referred to the pain specialist when they initially complained of pain as delays at this point have the potential to result in irrevocable limb damage, with future, long-term biopsychosocial consequences.

It is important that health care professionals understand that surviving trauma is not a linear process. Rather, it is cyclical, with both positive and negative fluctuations and potentially no sense of closure. Trauma survivors remain vulnerable to a range of physical limitations and contextual influences as well as psycho-social mediating factors including depression, anxiety, isolation and poverty.

Summary of Research Aims and Questions

This thesis addressed the issue of loss of limb function as a result of acute trauma. In particular the biopsychosocial consequences have been described and explained taking in to account personal experiences, social processes and interactions that developed at the time of and after injury. The analysis of factors that impacted on experiences illuminated pain, social support, type of trauma (major/minor) and length of time since injury as important influences on the ability to accept and cope with acute traumatic loss of limb function. Furthermore, it emerged that the relationships between the hospital and community settings influenced the biopsychosocial abilities to accept, adapt and live a full productive life after injury. These factors combine to create a situation in which an individual who suffers loss of limb function as a result of acute trauma experiences a basic social problem named Loss of Self. This problem subsequently requires them to put in place a basic social process identified Accepting a Reduced Self. The problem and process has been conceptualised within a substantive theory that explains the biopsychosocial consequences created from the experience of loss of limb function as a result of acute trauma.

Limitations of the Study

The limitations of this study are fourfold. Firstly, participants were recruited from a Pain Medicine Centre in WA that liaised with the Trauma Service in the state. There are other Pain Medicine Centres and Trauma Services in other states that offer different care, management and treatments, both in hospital and the community, because of the availability of their resources. This Pain Medicine Centre sees the most severe pain cases at RPH and it would seem that patients are referred to this centre as a last resort. Secondly, all the participants were of white, European extraction; there were no Indigenous people or individuals with multicultural ancestries involved in this study. These different groups could have offered alternative perspectives to the substantive theory. Thirdly, there are obviously people who have lost limb function, both from major and minor trauma, who were not referred to the clinic and their experiences regarding the phenomenon may differ from those of the participants. Indeed, other people affected by loss of limb function who were not interviewed for this research may follow a trauma trajectory and accommodate their loss of limb function, as suggested by previously cited authors.

Fourthly, all the participant's, except one (PA), lived in the metropolitan area. There were several participants who initially resided in rural Australia but, since developing their injuries, had moved to live in Perth permanently because of the difficulties managing their disability caused them, with restricted access to medical services. However, it must be recognised that there will be country and rural people who have lost limb function and continue to live with their impairment in their country areas. It is possible that these people could describe different issues and needs compared to their city counterparts.

Future Research

Research regarding minor trauma is sparse and an obvious next step would be to follow-up and assess the effects of relatively minor injuries as they can have serious ongoing consequences for some individuals. Often problems are found when the person is sent to a specialist (usually a pain specialist) at the end of their trauma journey and, by this time, limb damage has occurred and return of function can be limited. Common areas that could be investigated are those that are known to potentially result in nerve damage because of their anatomical areas, such as knee arthroscopy/surgery, or unusual syndromes developing such as CRPS from superficial burns and lacerations, or fractures to limbs. If commonalities are found regarding specific procedures and injuries, then potential strategies could be put into place to reduce the risk of their possible long-term effects.

Another area of research could concentrate on the effectiveness of social support for those who experience trauma. Most of the participants received some sort of social support in this study, yet this did not always assist in them reaching the stage of Wading to Shore in Accepting a Reduced Self. Research conducted to identify those who potentially require more assistance than others would aid healthcare professionals and more social support services could be designed and allocated to those who need supplementary assistance when Accepting a Reduced Self.

With the ever growing need to make the most of the healthcare dollar, patients are currently being discharged earlier from hospital and are being cared for in the home. The majority of care and social support given to those in need are often delivered by families, friends and significant others. These informal carers are under immense

pressure, not only to perform practical duties, such as offer general care and treatment, but they are also under the added burden to give emotional support in order to maintain the ex-patient in their home and community. Research into the concerns and consequences of carer stress would be useful so that strategies can be put in place to support and care for those who are caring for the ex-patient who lose limb function as a result of acute trauma. This would aid them to better meet their patients' and their own needs, safely and in a healthy manner.

Conclusion

Most individuals live within a set of predictable, routine normal behaviours. Over time, these behaviours allow them to blend their past experiences and current activities so their futures can follow an assumed trajectory, meeting expected plans and goals (Barton, 2007; Attig, 2002; Liechty, 2002; Janoff-Bullman and Timko 1987; Bury, 1982; Parkes, 1971). When life changing events occur, causing an alteration in behaviour, having advanced warning about them (such as planning for marriage or retirement) can influence their outcomes; so much so, that a major transformation becomes more of a 'minor transition' (Parkes, 1971 p113, 1993). However, when an individual is required to modify and initiate new behaviours because of un-assumed or unanticipated life transforming event, they usually need to accept, adapt and reconstruct their assumptive world and adjust their life trajectory (Parkes, 1971, 1993; Janoff-Bullman and Timko, 1987). As their assumptive world is interrupted and major alterations are required to manage this change, a mismatch occurs between future presumptions and goals and possible current realities, causing a reduction in personal safety, security, confidence and a change to self-identity (Attig, 2002; Bury, 1982; Parkes 1971, 1988). When this mismatch is caused by acute trauma, this can result in reduced self-esteem, self-efficacy and self-confidence which have the potential to create a loss of self, as the adaptation process is marred by insecurity and denial (Agaibi and Wilson, 2005; Cast and Burke, 2002; Smith Landsman, 2002; Charmaz, 1995, 1983; Ricoeur, 1992; Parkes, 1988; Bury, 1982).

This study focused on the acute major/ minor trauma of loss of limb function and collectively examined this type of injury from various personal perspectives. It explored the participant's experiences, social processes and interactions which occurred when a person experienced such trauma. Past and present worlds and

selves were explored, with many participants having difficulties reconciling their past, current and potential future worlds and selves when living with their disability. This research recognised and analysed the factors that impacted on the participants' experiences and investigated the relationships between those factors, both in the hospital and the community setting.

The burden of major and minor trauma is an issue for all concerned, including those who become disabled, their families, their communities and the healthcare system. This burden needs to be reduced to improve the quality of life for those who find themselves in this vulnerable population. This researcher suggests that this can be done by acknowledging that some minor injuries/surgeries/procedures can result in loss of limb function and through the creation of follow-up strategies, these people can be seen by relevant specialists much earlier on their recovery path.

The trauma burden can also be reduced by identifying the personal attributes that allow some people to cope with loss of limb function, while others struggle to manage their impairment and the limitations it creates. If it can be distinguished who can/cannot cope with their loss of limb function, then the scarce, limited resources currently available could be allocated more appropriately and efficiently to individualise patient care. Hopefully, by better meeting the needs of those most vulnerable, re-admission to hospital would be reduced and their lives in the community enhanced to optimal levels, congruent with their disabilities.

References

Adler, P. A., & Adler, P. (1998). Observational Techniques. In N. Denzin & Y. Lincoln (Eds.), *Collecting and Interpreting Qualitative Materials* (pp. 79-109). London: Sage.

Agaibi, C., & Wilson, J. (2005). Trauma, PTSD and resilience: A review of the literature. *Trauma, Violence, & Abuse 6*(3 July), 195-216.

Ahmad, M., & Alsad, J. (2004). Predictors of patients' experiences of nursing care in medical-surgical wards *International Journal of Nursing Practice, 10*, 235-241.

Annells, M. (1996). Grounded theory method: Philosophical perspectives, paradigm of inquiry, and postmmodernism. *Qualitative Health Research, 6*(3), 379-393.

Annells, M. (2004). Grounded theory. In Z. Schneider, D. Elliott, C. Beanland, G. LoBindo-Wood & J. Haber (Eds.), *Nursing Research* (2nd ed., pp. Chapter 11, 163-178). Sydney: Mosby.

Arnstein, P. (2000). The mediation of disability by self efficacy in different samples of chronic pain patients. *Disability and Rehabilitation, 22*(17), 794-801.

Aronoff, G., & Feldman, J. (2000). Preventing disability for chronic pain: A review and reappraisal. *International Review of Psychiatry, 12*(2), 157-169.

Asbring, P., & Narvanen, A. (2002). Women's experiences of stigma in relation to chronic fatigue syndrome and fibromyalgia. *Qualitative Health Research, 12*(2), 148-160.

Attig, T. (2002). Questionable assumptions about assumptive worlds. In J. Kauffman (Ed.), *Loss of the assumptive world*. New York: Brunner-Routledge.

Australian and New Zealand College of Anaesthetists and Faculty of Pain Medicine (ANZCA). (2010). *Acute pain management: scientific evidence* (3rd ed.). Melbourne: Australian and New Zealand College of Anaesthetists.

Australian Bureau of Statistics. (2003a, 24/01/2003). 1301.0 - Year Book Australia, 2003.   Retrieved 27/12/2006, 2003

Australian Bureau of Statistics. (2003b). 4384.0 - National Health Survey: Injuries, Australia, 2001.   Retrieved 10/12/2006

Australian Bureau of Statistics. (2004a). 4430.0 - Disability, ageing and carers: summary of findings 2003. Retrieved from http://www.abs.gov.au/ausstats/abs@.nsf/0/c258c88a7aa5a87eca2568a9001393e8?OpenDocument

Australian Bureau of Statistics. (2004b). *Year Book Australia* (No. ABS Catalogue No.1301.1). Canberra: Australian Bureau of Statistics.

Australian Bureau of Statistics. (2006a). *4825.0.55.001 -Injury in Australia: A snapshot, 2004-05*. Canberra: Australian Bureau of Statistics.

Australian Bureau of Statistics. (2006b). *4935.0.55.001 - Physical activity in Australia: A snapshot, 2004-05*. Canberra: Australian Bureau of Statistics.

Australian Bureau of Statistics. (2006c). *6324.0 Work Related Injuries 2005-06* (No. 6324.0). Canberra: Australian Bureau of Statistics,.

Australian Bureau of Statistics. (2007). *Year Book Australia* (No. ABS Catalogue No 1301.0). Canberra: Australian Bureau of Statistics.

Australian Bureau of Statistics. (2008). *Year Book Australia* (No. 1301.1). Canberra: Australian Bureau of Statistics.

Australian Transport Safety Bureau. (2004). *Serious injury due to road crashes*. Canberra.

Backman, K., & Kyngas, H. (1999). Challenges of the grounded theory approach to a novice researcher. *Nursing and Health Sciences, 1*, 147-153.

Bail, K. (2008). Patient and professional dissatisfaction: A literature review of prognosis communication related to hospital settings. *Contemporary Nurse, 29*(2 June), 135-146.

Bailey, S., & Bailey, J. (2006). *Head over heels* (1st ed.). Sydney: Australian Broadcasting Corporation.

Barrett, J. (2001). The Oxford companion to medicine. Oxford Reference OnLine. Retrieved 9 December, 2007, from http://www.oxfordreference.com.dbgw.lis.curtin.edu.au/views/ENTRY.html? subview=Main&entry=t185.e489

Barton, T. (2007). Student nurse practitioners - a rite of passage? The universality of Van Gennep's model of social transition. *Nurse Education in Practice, 7*, 338-347.

Beck, U. (1992). *Risk Society*. London: Sage Publications.

Birklein, F., Kunzel, W., & Sieweke, N. (2001). Despite clinical similarities there are significant differences between acute limb trauma and complex regional pain syndrome I (CRPS I). *Pain, 93*, 165-171.

Blumer, H. (1969). *Symbolic Interactionism*. New Jersey: Prentice-Hall.

Blyth, F., March, L., Brnabic, A., Jorm, L., Williamson, M., & Cousins, M. (2001). Chronic pain in Australia: A prevalence study. *Pain, 89*, 127-134.

Blyth, F., March, L., Nicholas, M., & Cousins, M. (2005). Self management of chronic pain: A population based study. *Pain, 113*, 285-292.

Bonanno, G. (2004). Loss, trauma and human resilience: Have we underestimated the human capacity to thrive after extremely aversive events? *American Psychologist, 59*(1, January), 20-28.

Bowers, B. (2009). Dialogue: Questions? In J. Morse, P. Stern, J. Corbin, B. Bowers, K. Charmaz & A. Clarke (Eds.), *Developing Grounded Theory* (pp. 125-126). Walnut Creek, California: Left Coast Press.

Bowers, B., Morse, J., Charmaz, K., & Clarke, A. (2009). Dialogue: Doing "Grounded Theory". In J. Morse, P. Stern, J. Corbin, B. Bowers, K. Charmaz & A. Clarke (Eds.), *Developing Grounded Theory* (pp. 21-22). Walnut Creek, California: Left Coast Press Inc.

Brandtstädter, J., & Rothermund, K. (1994). Self-percepts of control in middle and later adulthood: Buffering losses by rescaling goals, *Psychology and Aging, 9*(2), 265-237.

Brooks, J., Fuller, C., & Reddin, D. (2005). A prospective study of injuries and training amongst the England 2003 rugby world cup squad. *British Journal of Sports Medicine, 39*(288-293).

Boughton, M. (1997). Embodied self, human biology and experience. In J. Lawler (Ed.), *The body in nursing* (1st ed., pp. 155-175). Melbourne: Churchill & Livingstone.

Boughton, M., & Halliday, L. (2009). Home alone: Patient and carer uncertainty surrounding discharge with continuing clinical care needs. *Contemporary Nurse, 33*(1, August), 30-40.

Bury, M. (1982). Chronic illness as a biographical disruption. *Sociology of Health and Illness, 4*(2 July), 167-182.

Bury, M. (1991). The sociology of chronic illness: A review of research prospects. *Sociology of Health and Illness, 13*(4), 451-468.

Cameron, C., Kliewer, E., Purdie, D., & McClure, R. (2006). Long term health outcomes after injury in working age adults: A systematic review. *Journal of Epidemiology and Community Health, 60*, 341-344.

Casey, C. Y., Greenberg, M., Nicassio, P., Harpin, R., & Hubbard, D. (2008). Transition from acute to chronic pain and disability: A model including cognitive, affective and trauma factors. *Pain, 134*(1), 69-79.

Cartmill, C., Soklaridis, S., & David Cassidy, J. (2011). Transdisciplinary teamwork: the experience of clinicians as a functional restoration program. *Journal of Occupational Rehabilitation, 21*(1), 1-8.

Cast, A., & Burke, P. (2002). A theory of self esteem. *Social Forces, 80*(3), 1041-1068.

Castillo, R., Mackenzie, E., Wegener, S., & Bosse, M. (2006). Prevalence of chronic pain seven years following limb threatening lower extremity trauma. *Pain, 124*, 321-329.

Chapman, C., & Volinn, E. (2005). Narrative as a window on chronic disabling back pain. In D. Carr, J. Loeser & D. Morris (Eds.), *Narrative, pain and suffering* (Vol. 34, pp. 73-84). Seattle: International Association for the Study of Pain Press.

Charmaz, K. (1983). Loss of self: A fundamental form of suffering in the chronically ill. *Sociology of Health and Illness, 5*(2), 168-195.

Charmaz, K. (1991). *Good days bad days* (2nd ed. 1997). New Brunswick, New Jersey: Rutgers University Press.

Charmaz, K. (1995). The body, identity and self: Adapting to impairment. *The Sociological Quarterly, 36*(4 Autumn), 657-680.

Charmaz, K. (2006). *Constructing grounded theory*. London: Sage Publications.

Charmaz, K., Bowers, B., & Stern, P. (2009). Dialogue: The ethics of interviewing. In J. Morse, P. Stern, J. Corbin, B. Bowers, K. Charmaz & A. Clarke (Eds.), *Developing Grounded Theory*. Walnut Creek, California: Left Coast Press Inc.

Charon, R. (2002). Time and ethics. In R. Charon & M. Montello (Eds.), *Stories matter* (1st ed., pp. 59-76). New York: Routledge.

Chenitz, W. C., & Swanson, J. M. (1986). *From practice to grounded theory*. Menlo Park California: Addison-Wesley Publishing Company.

Connole, H. (1997). The research enterprise. In B. Smith, H. Connole, S. Speedy & R. Wiseman (Eds.), *Issues and methods in research. Study Guide* (pp. Section 1 21- 40). Adelaide: South Australian College of Advanced Education.

Corbin, J. (2009). Taking an Analytical Journey. In J. Morse, P. Stern, J. Corbin, B. Bowers, K. Charmaz & A. Clarke (Eds.), *Developing Grounded Theory* (pp. 35-53). Walnut Creek, California Left Coast Press Inc.

Corbin, J., & Strauss, A. (1991). Response to analysis and evaluation of the trajectory theory of chronic illness management. *Scholarly Inquiry for Nursing Practice, 13*, 155-174.

Corbin, J., & Strauss, A. (1992). A nursing model for chronic illness management based upon the trajectory framework. In P. Woog (Ed.), *The chronic illness trajectory framework* (pp. 9-28). New York: Springer.

Creed, P., & Klisch, J. (2005). Future outlook and financial strain: Testing the personal agency and latent deprivation models of unemployment and well-being. *Journal of Occupational Health Psychology, 10*(3), 251-260.

Cutcliffe, J. (1999). Methodological issues in grounded theory. *Journal of Advanced Nursing, 31*(6), 147-1484.

Denzin, N., & Lincoln, Y. (1998). Introduction: Entering the field of qualitative research. In N. Denzin & Y. Lincoln (Eds.), *Strategies of qualitative inquiry* (pp. 1-34). Thousand Oaks, California: Sage Publications.

Department of Health and Ageing. (2004). *Sports safety of Australia an update July 2003*. Canberra: Department of Health and Ageing, Australian Government

Department Health and Ageing. (2005). *National Public Health Partnership (NPHP 2004) National injury prevention and safety promotion plan 2004-2005* Canberra: Commonwealth of Australia

Department of Mines and Petroleum. (2009). *Safety performance in the Western Australian mineral industry - accident and injury statistics 2007-08: Resources safety*. Perth: Department of Mines and Petroleum.

Dolin, S. (2004). Pain clinic. In S. Dolin & N. Padfield (Eds.), *Pain Medicine Manual* (2nd ed., pp. 1-10). Sydney: Butterworth and Heinemann.

Earviolino-Ramirez, M. (2007). Resilience: A concept analysis. *Nursing Forum, 42(2* April/June), 73-82.

Eisenberg, E., & Melamed, E. (2003). Can complex regional pain syndrome be painless? *Pain, 106*, 263-267.

Eisenberger, N., Jarcho, J., Lieberman, M., & Naliboff, B. (2006). An experimental study of shared sensitivity to physical pain and social rejection. *Pain, 126*, 132-138.

Eliott, J., & Olver, I. (2002). The discursive properties of "hope": A qualitative analysis of cancer patient's speech. *Qualitative Health Research, 12*, 173-193.

Flanagin, B., Cruz, A., & Medvecky, M. (2011). Hoffa fracture in a 14 year old. *Orthopedics, 34,* (2) 138.

Fontana, A., & Frey, J. (1998). Interviewing: The art of science. In N. Denzin & Y. Lincoln (Eds.), *Collecting and interpreting qualitative materials* (pp. 47-78). Thousand Oaks: Sage.

Fox, N. (2002). Refracting 'health': Deleuze, Guattari and body-self. *Health, 3*(3), 347-363.

Frank, A. (1991). For a sociology of the body: An analytical review. In M. Featherstone, M. Hepworth & B. Turner (Eds.), *The body* (pp. 36-102). London: Sage.

Frank, A. (1995). *The wounded storyteller*. Chicago: University of Chicago Press.

Frank, A. (2001). Can we research suffering? *Qualitative Health Research, 11*(3 May), 353-362.

Fraser, L. (2007). Significant developments in occupational health and safety in Australia construction industry. *International Journal of Occupation and Environmental Health, 13*, 12-20.

Fridh, I., Forsberg, A., & Bergbom, I. (2009). Doing one's utmost: Nurses' descriptions of caring for dying patients in an intensive care environment. *Intensive and Critical Care Nursing, 25*, 233-242.

Geertzen, J., van Wilgen, C., Schrier, E., & Dijkstra, P. (2006). Chronic pain in Rehabilitation Medicine. *Disability and Rehabilitation, 28*(6), 363-367.

Gibson, J., Martin, D., & Singer, P. (2005). Priority setting in hospitals: Fairness, inclusiveness, and the problem of institutional power differences. *Social Science and Medicine, 61*, 2355-2362.

Glaser, B. (1978). *Theoretical sensitivity*. Mill Valley California: Sociology Press.

Glaser, B. (2002). Conceptualization: On the theory and theorizing using grounded theory. *International Journal of Qualitative Methods, 1*(2), article 3.

Glaser, B., & Strauss, A. (1967). *The discovery of grounded theory*. Chicago: Aldine.

Goffman, E. (1963). *Stigma* (1986 ed.). New York: Simon & Schuster.

Grizzell, J. (2007). Behavior change theories and models. Retrieved on 14/3/09, from www.csupomona.edu/−jvgrizzell/best_practices/bctheory.html

Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough?: An experiment with data saturation and variability. *Field Methods, 18*(1), 59-82.

Halcomb, E., Daly, J., Davidson, P., Elliott, D., & Griffiths, R. (2005). Life beyond severe traumatic injury: An integrative review of the literature. *Australian Critical Care, 18*(1), 17-24.

Halcomb, E., & Davidson, P. (2005). Using the illness trajectory framework to describe recovery from traumatic injury. *Contemporary Nurse, 19*(1-2, July), 232-241.

Harden. R, & Bruehl. S. (2006). Diagnosis of complex regional pain syndrome *Clinical Journal of Pain, 22*(5), 415-419.

Harden, R., Swan, M., King, A., Costa, B., & Barthel, J. (2006). Treatment of complex regional pain syndrome. *Clinical Journal of Pain, 22*(5), 420-424.

Harrison, T., & Kahn, D. (2004). Disability rites the cultural shift following impairment. *Family Community Health, 27*(1), 86-93.

Harrison, T., Umberson, D., Lin, L., & Cheng, H. (2010). Timing of impairment and health promoting lifestyles in women with disabilities. *Qualitative Health Research, 20*(6), 816-829.

Haylen, P. (2004). Spinal injuries in rugby union, 1970-2003: Lessons and responsibilities. *MJA, 181*(1), 48-50.

Henry, J. (2008). The need for knowledge translation in chronic pain. *Pain Research & Management; The Journal of the Canadian Pain Society, 13*(6 November / December), 465-476.

Hentz, P. (2002). The body remembers: Grieving and a circle of time. *Qualitative Health Research, 12*(2), 161-172.

Higgins, I. (2001). On being cared for by a nurse. *Contemporary Nurse, 11*(2-3, December), 115-124.

Hill, D., Marchant, R., Trafalski, S., & Gant, P. (2007). *Reported road crashes in Western Australia 2004*. Perth, WA: Road Safety Council of Western Australia, Department of the Premier and Cabinet.

Holbrook, T., Anderson, J., Sieber, W., Browner, D., & Hoyt, D. (1999). Outcome after major trauma: 12 month and 18 month follow up from the trauma recovery project. *Journal of Trauma: Injury, Infection and Critical Care, 46*(5), 765-773.

Holtslag, H., Buskens, E., Rommers, C., Prevo, A., & van der Werken, C. (2006). Long-term outcome after lower extremity injuries in severely injured patients. *European Journal of Trauma, 32*(4), 365-373.

Holtslag, H., Post, M., Lindeman, E., & Van der Werken, C. (2007). Long-term functional health status of severely injured patients. *Injury, 38*, 280-289.

Horgan, O., & MacLachlan, M. (2004). Psychosocial adjustment to lower-limb amputation: A review. *Disability and Rehabilitation, 26*(14/15), 837-850.

Hugenberg, K., & Bodenhausen, G. (2004). Category membership moderates the inhibition of social identities. *Journal of Experimental Social Psychology, 40*, 233-238.

Hummel, M., Lu, P., Cummons, T., & Whiteside, G. (2008). The persistence of a long-term negative affective state following the induction of either acute or chronic pain. *Pain, 140*(3), 436-445.

Ide, M. (2004). Sexuality in person with limb amputation; A meaningful discussion of re-integration. *Disability and Rehabilitation, 26*(14/15), 939-943.

International Labour Organisation. (2005). Yearbook of Labour Statistics. *Occupational Injuries.*   Retrieved 8/12/2006, 2006

Irurita, V. (2001). *A pathway to understanding: Application of grounded theory method*. Perth: Curtin University of Technology.

Jääskeläinen, S. (2009). Traumatic nerve injury: Diagnosis, recovery, and risk factors for neuropathic pain. In J. Castro-Lopes (Ed.), *Current topics in pain* (pp. 165-184). Seattle International Association for the Study of Pain.

Janesick, V. (1998). The dance of qualitative research design. In N. Denzin & Y. Lincoln (Eds.), *Strategies of qualitative inquiry* (pp. 35-85). Thousand Oaks: Sage.

Janoff-Bulman, R., & Timko, C. (1987). Coping with traumatic events: The role of denial in light of people's assumptive worlds. In C. Snyder & C. Ford (Eds.), *Coping with negative life events* (pp. 131-155). New York: Plenum Press.

Junge, A., Langevoort, G., Pipe, A., Peytavin, A., Wong, F., Mountjoy, M., et al. (2006). Injuries in team sport tournaments during the 2004 Olympic games. *The American Journal of Sports Medicine, 34*(4).

Karl, A., Munlnickel, W., Kurth, R., & Flor, H. (2004). Neuroleptic source imaging of steady-state movement-related corticla potentials in human upper extremity amputees with and without phantom limb pain. *Pain, 110*(90-102).

Kendall, J. (1999). Axial coding and the grounded theory controversy. *Western Journal of Nursing Research, 21*(6), 743-757.

Ketz, A. K. (2008). Pain management in the traumatic amputee. *Critical Care Nursing Clinics of North America, 20*, 51-51.

King, G., Willoughby, C., Specht, J., & Brown, E. (2006). Social support processes and the adaptation of individuals with chronic disabilities. *Qualitative Health Research, 16*(7, September), 902-925.

Kiser, L., Bennett, L., Heston, J., & Paavola, M. (2005). Family ritual and routine: comparison of clinical and non-clinical families. *Journal of Child and Family Studies, 14*(3, September), 357-372.

Kleinman, A., Brodwin, P., Good, B., & Good, M. (1992). Pain as human experience: An introduction. In M. Good, P. Brodwin, B. Good & A. Kleinman (Eds.), *Pain as human experience* (pp. 1-28). Berkley: University of California Press.

Kooijman, C., Dijkstra, P., Geertzen, J., Elzinga, A., & van der Schans, C. (2000). Phantom pain and phantom sensations in upper limb amputees: An epidemiology study. *Pain, 87*, 33-41.

Kritsonis, A. (2004-2005). Comparison of change theories. *International Journal of Scholarly Academic Intellectual Diversity, 8*(1).

Kubler-Ross, E. (1985). *On death and dying*. London: Tavistock Publications.

Lacoux, P., Crombie, I., & Macrae, W. (2002). Pain in traumatic upper limb amputees in Sierra Leone. *Pain, 99*, 309-312.

Larsson, J., & Sanner, M. (2010). Doing a good job and getting something good out of it: On stress and well-being in anaesthesia. *British Journal of Anaesthesia, 105*(1), 34-37.

Lazarus, R. (1993). From psychological stress to emotions: A history of changing outlooks. *Annual Review in Psychology, 44*, 1-21.

Leder, D. (1990). *The absent body*. Chicargo: University of Chicago Press.

Leigh, J., Macaskill, P., Kuosma, E., & Mandryk, J. (1999). Global burden of disease and injury due to occupational factors. *Epidemiology, 10*(5), 626-631.

Leiechty, D., (2002). The assumptive world in the context of transference relationships. In J. Kauffman (Ed.), *Loss of the assumptive world* (pp. 83-93). New York: Brunner-Routledge.

LoBindo-Wood, G., & Haber, J. (1990). Reliability and Validity. In G. LoBindo-Wood & J. Haber (Eds.), *Nursing Research* (2nd ed., pp. 248-264). St Louis: Mosby Company.

Loeser, J., & Treede, R. (2008). The Kyoto protocol of ISAP basic pain terminology. *Pain, 137*, 473-477.

Lumby, J. (2001). *Who Cares*. Crows Nest: Allen & Unwin.

Lund, D., Caserta, M., & Dimond, M. (1996). The course of spousal bereavement in later life. In M. Stroebe & W. Stroebe (Eds.), *Handbook of bereavement* (pp. 240-254). Cambridge: Cambridge University Press.

Lupton, D. (2003). *Medicine as a culture* (2nd ed.). London: Sage Publications.

Maciejewski, P., Bauhui, Z., Block, S., & Prigerson, H. (2007). An empirical examination of the stage theory of grief. *Journal of American Medical Association, 297*(February 21), 716-723.

Macintyre, P., & Schug, S. (2007). *Acute Pain Management* (3rd ed.). New York: Saunders.

Mackenzie, E., Bosse, M., Castillo, R., Smith, D., Webb, L., Kellam, J., et al. (2004). Functional outcomes following trauma-related lower-extremity amputation. *The Journal of Bone and Joint Surgery, 86-A* (8-August), 1636-1645.

Mackenzie, E., Bosse, M., Kellam, J., Pollak, A., Webb, L., Swiontkowski, M., et al. (2006). Early predictors of long-term work disability after major limb trauma. *The Journal of Trauma, Injury, Infection and Critical Care, 61*(3), 688-694.

Mackenzie, E., Bosse, M., Pollak, A., Webb, L., Swiontkowski, M., Kellam, J., et al. (2005). Long-term persistence of disability following severe lower-limb trauma. *Journal of Bone and Joint Surgery, 87-A* (8-August), 1801-1809.

Madjar, I. (1997). The body in health, illness and pain. In J. Lawler (Ed.), *The body in nursing* (1st ed., pp. 53-73). Melbourne: Churchill Livingstone.

Manias, E. (2002). Pain and anxiety management in the postoperative gastro-surgical setting. *Journal of Advanced Nursing, 41*(6), 585-594.

Manias, E., Bucknall, T., & M., Botti. (2004). Assessment of patient pain in the postoperative context. *Western Journal of Nursing Research, 26*, (7) 751-769.

McCarthy, M., Mackenzie, E., Edwin, D., Bosse, M., Castillo, R., Starr, A., and the Leap Study Group (2003). Psychological distress associated with severe lower- limb injury. *The Journal of Bone and Joint Surgery, 85-A* (9), 1689-1697.

McCracken, L., Crombez, G., & Dahl, J. (2008, 20 August). *Advances in cognitive and behavioural approaches to chronic pain: Developing roles of accommodation, acceptance and psychological flexibility.* Paper presented at the International Association for the Study of Pain 12th World Congress on Pain, Glasgow UK.

Merskey, H., & Bogduk, N. (Eds.). (1994). *Classification of Chronic Pain, Second Edition,* Seattle: IASP Press.

Michaels, A., Michaels, C., Smith, J., Moon, C., Peterson, C., & Long, W. (2000). Outcome from injury: General health, work status and satisfaction 12 months after trauma. *The Journal of Trauma: Injury, Infection and Critical Care, 48*(5), 841-850.

Miles, A., Curran, H., Pearce, S., & Allan, L. (2005). Managing constraint: The experience of people with chronic pain. *Social Science and Medicine, 61*(2), 431-441.

Miller, B., & Keane, C. (1983). *Encyclopaedia and Dictionary of Medicine, Nursing and Allied Health*. Philadelphia: W.B. Saunders Company.

Miller, P., & Rose, N. (2008). *Governing the present*. Cambridge: Polity Press.

Minesafe. (2009). Latest WA mining safety performance figures released. *Minesafe 18*(1), 36-39.

Mock, C., Lormand, J., Goosen, J., Joshipura, M., & Peden, M. (2004). *Guidelines for essential trauma services*. Geneva: World Health Organisation.

Moore, P., Adler, N., & Robertson, P. (2000). Medical malpractice: The effect of doctor-patient relations on medical patient perceptions and malpractice intentions. *Western Journal of Medicine, 173*(October), 244-250.

Morse, J. (1995). The significance of saturation. *Qualitative Health Research, 5*(2), 147-148.

Morse, J. (1997). Responding to threats to integrity of self. *Advances in Nursing Studies, 19*(4), 21-36.

Morse, J. (1998). It takes a lot of donuts to get good data. *Qualitative Health Research, 8*(2), 147-148.

Morse, J. (2006). The scope of qualitatively derived clinical interventions. *Qualitative Health Research, 16*(5), 591-593.

Morse, J. (2009a). "Going beyond your data," and other dilemmas of interpretation. *Qualitative Health Research, 19*(5), 579.

Morse, J. (2009b). Tussles, Tensions, and Resolutions. In J. Morse, P. Stern, J. Corbin, B. Bowers, K. Charmaz & A. Clarke (Eds.), *Developing Grounded Theory* (pp. 13-20). Walnut Creek, California: Left Coast Press Inc.

Morse, J., & O'Brien, B. (1995). Preserving self: From victim, to patient, to disabled person. *Journal of Advanced Nursing, 21*(5), 886-896.

Morse, J., Stern, P., Clarke, A., Bowers, B., & Charmaz, K. (2009). Dialogue: Subjectivity in analysis. In J. Morse, P. Stern, J. Corbin, B. Bowers, K. Charmaz & A. Clarke (Eds.), *Developing Grounded Theory* (pp. 192-193). Walnut Creek, California Left Coast Press Inc.

Muir, B., (2010). Myositis ossificans traumatica of the deltoid ligament in a 34 year old recreational ice hockey player with a 15 year post-trauma follow-up: a case report and review of the literature. *The Journal of the Canadian Chiropractic Association, 54* (4 Dec), 229-242.

Murphy, D., Connolly, D., & Beynnon, B. (2003). Risk factors for lower extremity injury: A review of the literature. *British Journal of Sports Medicine, 37*, 13-29.

Murray, C., & Fox, J. (2002). Body image and prosthesis satisfaction in the lower limb amputee. *Disability and Rehabilitation, 24*(17), 925-931.

Nicholas, M., Molloy, A., Tonkin, L., & Beeston, L. (2000). *Manage your pain*. Sydney: ABC Books.

Oliver, P. (2004). *Writing your thesis* (reprinted, 2006 ed.). London: Sage Publications.

Oxford Dictionary of English. (2003). *Oxford Dictionary of English* (2nd ed.). Oxford: Oxford University Press.

Parkes, C. M. (1971). Psycho-social Transitions: A field for study *Social Science and Medicine, 5*, 101-115.

Parkes, C. M. (1988). Bereavement as a psychosocial transition: Process of adaptation to change. *Journal of Social Issues, 44*(3), 53-65.

Parkes, C. M. (1993). Bereavement as a psychological transition: Process of adaptation to change. In M. Stroebe, W. Stroebe & R. Hansson (Eds.), *Handbook of bereavement* (pp. 91-101). Cambridge: Press Syndicate.

Parkes, C. M. (2002). Postscript. In J. Kauffman (Ed.), *Loss of the assumptive world* (pp. 237-242). New York: Brunner-Routledge.

Parry, K. W. (1997, December 3-6 1997). *How to use grounded theory method to research leadership.* Paper presented at the ANZAM, Melbourne.

Paulson, M., Danielson, E., & Soderberg, S. (2002). Struggling for tolerable existence: The meaning of men's lived experiences of living with pain of fibromyalgia type. *Qualitative Health Research, 12*(2), 238-249.

Payne, A., Joseph, S., & Tudway, J. (2007). Assimilation and accommodation process following traumatic experiences. *Journal of Loss and Trauma, 12*, 73-89.

Phelan, C., Higgins, I., Summons, P., Douglas, J., Dobson, P., & Hodson, F. (2010). An innovative approach to targeting pain in older people in the acute care setting. *Contemporary Nurse, 35*(2), 221-233.

Reeve, C. (2002). *Nothing is impossible*. New York: Random House.

Richardson, F., & Fowers, B. (1998). Interpretive social science. *The American Behavioral Scientist, 41*(4), 465-495.

Richardson, G. (2002). The metatheory of resilience and resiliency. *Journal of Clinical Psychology, 58*(3), 307-321.

Ricoeur, P. (1992). *Oneself as another* (K. Blamery, Trans.). Chicago: University of Chicago Press.

Rose, N. (1999). *Powers of freedom*. Cambridge: Cambridge University Press.

Ross, M. (1989). Relation of implicit theories to the construction of personal histories. *Psychological Review, 96*(2), 341-357.

Royal Perth Hospital. (2005). Pain Medicine Centre New Referrals, *TOPAS*. Perth: Royal Perth Hospital.

Royal Perth Hospital. (2006). *Trauma Registry Report - 2005*. Perth: Royal Perth Hospital.

Royal Perth Hospital. (2007). *Trauma Registry Report - 2006*. Perth: Royal Perth Hospital.

Royal Perth Hospital. (2008). *Trauma Registry Report - 2007*. Perth: Royal Perth Hospital.

Royal Perth Hospital. (2009). *Trauma Registry Report - 2008*. Perth: Royal Perth Hospital.

Rubin, H. A., & Shapiro, D. A. (Writer) (2005). Murderball [DVD]. In J. Mandel & D. A. Shapiro (Producer). USA: Hopscotch.

Salick, E., & Auerbach, C. (2006). From devastation to integration: Adjusting to and growing from medical trauma. *Qualitative Health Research, 16*(8), 1021-1037.

Sandelowski, M. (1995). Focus on Qualitative Methods Sample size in qualitative research. *Research in Nursing & Health, 18*, 179-183.

Sasser, S., Varghese, M., Kellermann, M., & Lormoand, J. (2005). *Prehospital trauma care system*. Geneva: World Health Organisation.

Schmitz, U., Saile, H., & Nilges, P. (1996). Coping with chronic pain: Flexible goal adjustment as an interactive buffer against pain-related distress. *Pain, 67*, 41-51.

Schrag, C. (1997). *The self after postmodernity*. Durham, North Carolina: Yale University.

Siddall, P., McClelland, J., Rutkowski, S., & Cousins, M. (2003). A longitudinal study of the prevalence and characteristics of pain in the first 5 years following spinal cord injury. *Pain, 103*, 249-257.

Silverman, M., & Ricci, E. (1990). Strategies for increasing the rigor of qualitative methods in evaluation of health programs. *Evaluation Review, 14*(1), 57-74.

Smith, B., & Sparkes, A. (2002). Men, sport, spinal cord injury and the construction of coherence: Narrative practice in action *Qualitative Health Research, 2*(2), 143-171.

Smith, B., & Sparkes, A. (2005). Men, sport, spinal cord injury and narratives of hope. *Social Science and Medicine, 61*, 1095-1105.

Smith Landsman, I. (2002). Crises of meaning in trauma and loss. In J. Kauffman (Ed.), *Loss of the assumptive world* (pp. 13-30). New York: Brunner-Routledge.

Smith, T. (2006). Personality as risk and resilience in physical health. *Current Directions in Psychological Science, 15*(5), 227-231.

Spaargaren, G., & Van Vilet, B. (2000). Lifestyles, consumption and the environment: The ecological modernization of domestic consumption. *Environmental Politics, 9*(1), 50-76.

Sparkes, A., & Smith, B. (2003). Men, sport, spinal cord injury and narrative time. *Qualitative Research, 3*(3), 259-320.

Speedling, E., & Rose, D. (1985). Building an effective doctor-patient relationship: From patient satisfaction to patient participation. *Social Science and Medicine, 21*(2), 115-120.

Spradley, J. (1979). *The ethnographic interview*. New York: Holt, Rinehart and Winston.

Stansbury, C., & Warr, J. (2005a). *Claims lodged by workers in the construction industry on the Western Australian workers compensations system 1999-00 to 2002-03 Research Note 1 2005* (No. RN1_2005_CON.doc). Perth: WorkCover WA.

Stansbury, C., & Warr, J. (2005b). *Claims lodged by workers in the mining industry on the Western Australian workers compensations system 1999-00 to 2002-03 Research Note 1 2005* (No. RN2_2005_MIN.doc). Perth: WorkCover WA.

Stanton-Hicks, M., Burton, A., Bruehl, S., Carrr, D., Harden, N., Hassenbusch, S., et al. (2002). An updated interdisciplinary clinical pathway for CRPS: Report of an expert panel. *Pain Practice, 2*(1), 1-16.

Startup, M., Makgetgenene, L., & Webster, R. (2007). The role of self-blame as assessed by the Posttraumatic Cognitions Inventory (PTCI): A self-protective cognition? *Behaviour research and therapy, 45*, 395-403.

Stern, P. (2009). Glaserian Grounded Theory. In J. Morse, P. Stern, J. Corbin, B. Bowers, K. Charmaz & A. Clarke (Eds.), *Developing Grounded Theory* (pp. 55-83). Walnut Creek, California: Left Coast Press Inc

Stevenson, M., Hamer, P., Finch, C., Elliot, B., & Kresnow, M. (2000). Sport, age and sex specific incidence of sports in Western Australia. *British Journal of Sports Medicine, 34*, 188-194.

Strauss, A., & Corbin, J. (1990). *Basics of qualitative research*. Newbury Park California: Sage Publications.

Strauss, A., & Corbin, J. (1998a). *Basics of qualitative research* (2nd ed.). Thousand Oaks, California: Sage.

Strauss, A., & Corbin, J. (1998b). Grounded theory methodology: An overview. In N. Denzin & Y. Lincoln (Eds.), *Strategies of qualitative inquiry*. Thousand Oaks: Sage Publications.

Stroebe, M., & Stroebe, W. (1993). The mortality of bereavement. In M. Stroebe, W. Stroebe & R. Hansson (Eds.), *Handbook of bereavement* (pp. 196-207). Cambridge: Cambridge University Press.

Swanson, J. (1986). Analyzing data for categories and description. In W. Chenitz & J. Swanson (Eds.), *From practice to grounded theory* (pp. 121-132.). Menlo Park, California: Addison, Wesley.

Symreng, I., & Fishman, S. (2004). Anxiety and pain. *Pain Clinical Updates, XII* (7).

Taleporos, G., & McCabe, M. (2002). Body image and physical disability - personal perspectives. *Social Science and Medicine, 54*, 971-980.

Therapeutic Guidelines. (2007). *Therapeutic guidelines analgesic* (5, 2007 ed.). Melbourne: Therapeutic Guidelines Limited.

Thomas, G., & James, D. (2006). Reinventing grounded theory: Some questions about theory and discovery. *British Educational Research Journal, 36*(6), 767-795.

Thomson, S. B. (2004). *Qualitative research: Grounded Theory - sample size and validity.* Paper presented at the Business and Economics 10th Annual Doctoral Conference, Melbourne Victoria Australia. .

Trainor, A., & Ezer, H. (2000). Rebuilding life: The experience of living with AIDS after facing imminent death. *Qualitative Health Research, 10*(5 September), 646-660.

Urquhart, D., Williamson, O., Gabbe, B., Cicuttini, F., Cameron, P., Richardson, M., et al. (2006). Outcomes of patients with orthopaedic trauma admitted to level 1 trauma centres. *Australian and New Zealand Journal of Surgery, 76*, 600-606.

van Manen, M. (1998). Modalities of body experience in illness and health. *Qualitative Health Research, 8*(1), 7-24.

Walden, M., Hagglund, M., & Ekstrand, J. (2005). UEFA champions league study: A prospective study of injuries in professional football during the 2001-2002 season. *British Journal of Sports Medicine, 39*, 542-546.

Walker, D., & Myrick, F. (2006). Grounded theory: An exploration of process and procedure. *Qualitative Health Research, 16*(4), 547-599.

Warr, J. (2005). *Claims lodged by workers in the agriculture industry on the Western Australian workers compensations system 1999/00 to 2002/03 Research Note 4 2005* (No. RN4_2005AGIN.doc). Perth: WorkCover WA.

West, M., Sangani, C., & Toh, E. (2010). Tibialis posterior tendon rupture associated with a closed medial malleolar fracture: a case report and review of the literature. *The Journal of Foot and Ankle Surgery, 49*(6), 565.e9-12.

Wetterhahn, K., Hanson, C., & Levy, C. (2002). Effect of participation in physical activity on body image and amputees. *American Journal of Physical Medicine and Rehabilitation, 81*(3), 194-201.

Widar, M., Ek, A., & Ahlstrom, G. (2007). Caring and uncaring experiences as narrated by persons with long-term pain after stroke. *Scandinavian Journal of Caring Science, 21*, 41-47.

Wilder, T. (2006). Management of paediatric patients with complex regional pain syndrome. *Clinical Journal of Pain, 22*(5), 443-447.

Williams, A., Dunning, T., & Manias, E. (2006). Community care and general wellbeing of patients with comorbidities requiring joint replacement. *Journal of Advanced Nursing, 57*(3), 244-256.

Williams, P., Barclay, L., & Schmied, V. (2004). Defining social support in context: A necessary step in improving research, intervention and practice. *Qualitative Health Research, 14*(7), 942-960.

Wiseman, R. (1997). The interpretive approach. In B. Smith, H. Connole, S. Speedy & R. Wiseman (Eds.), *Issues and methods in research. Study Guide* (pp. Section 3 101-170). Adelaide: South Australian College of Advanced Education.

World Health Organisation (WHO). (2004). *World report on road traffic injury prevention*. Geneva: World Health Organisation.

World Health Organisation (WHO). (2006). *Disability and rehabilitation WHO action plan 2006-2011*. Geneva: World Health Organisation.

Worlock, P. (2001). The Oxford companion to medicine. Oxford Reference OnLine. Retrieved 9 December, 2007, from http://www.oxfordreference.com.dbgw.lis.curtin.edu.au/views/ENTRY.html?subview=Main&entry=t185.e488

Wörz, R. (2003). Pain in depression - Depression in pain. *Pain Clincal Updates, XI* (5).

Yoshida, K. (1993). Reshaping of self: A pendular reconstruction of self and identity among adults with traumatic spinal cord injury. *Sociology of Health & Illness, 15*(2), 217-245.

Appendices

Appendix A   Information Statement

Project Title: Adults' experiences loss of limb(s) function as a result of acute trauma

My name is Mandy Lison-Pick. I am enrolled as a research student at Curtin University of Technology in a PhD course with the School of Nursing and Midwifery. My study focuses on the adults' experience of loss of limb(s) function as a result of acute trauma. The findings of this research have the potential to increase health professionals' knowledge and enhance the care they give to those participants effected by loss of limb(s) function as a result of acute trauma.

I invite you to participate in my research regarding your experiences following your accident. I will ask you to tell me about how this accident effected you, what changes to your life have occurred since your accident and how you coped with such an experience. It is expected the interview will last about 60 minutes, and will take place in a private area convenient to you. With your permission the interview will be audiotaped.

Your care and treatment will continue regardless of your decision about taking part in this project. All information given during the interviews will remain confidential.

Your name will not be used during the research either on the tape recorder or in the final reported research, and the records will be stored in a locked and secure place. You are free to withdraw from the interview at any time without providing an explanation.

If you would like to discuss my proposal or clarify your participation with me my contact number is 9382 7574

Should you have any concerns about the conduct of this research please contact my supervisor Associate Professor Anne Bartu on 9266 2191 at Curtin University of Technology.

Thank you for taking time to read this letter. I will contact you at a later date to ask if you would be willing to take part in the study.

Mandy Lison-Pick

Appendix B   **INFORMED CONSENT FORM**

My name is Mandy Lison-Pick and I am a PhD Student at the School of Nursing and Midwifery at Curtin University of Technology. I am researching the adults' experiences loss of limb(s) function as a result of acute trauma. By participating in this research, you will be assisting in increasing the health professionals understanding of such a condition.

Interviews are being carried out with a number of people who have lost limb(s) function as a result of acute traumatic injuries. You will be asked to share your experiences, regarding how your accident has affected you and the lifestyle changes that have occurred because of the loss of limb(s) function you have experienced.

If there are any questions of concerns you have concerning this project please do not hesitate to contact myself: 9382 7574 or my supervisor Associate Professor Anne Bartu: 9266 2191

I_____ (print full name), hereby agree to participate in the project outlined above.

I acknowledge that:
The aims, methods, anticipated benefits and possible hazards of the research study have been explained to me and the questions I have asked have been answered to my satisfaction.

I voluntarily and freely give my consent to my participation and the recording of the interview required for the research study.

I understand that aggregated results will be used for research purposes and may be reported in scientific journals.

Once transcribed, all tapes will be erased and only de-identified data will be analysed.

I am free to withdraw my consent at any time during the study, in which event my participation in the research study will cease immediately.

I have received a copy of the consent form.

Participant   _____

Researcher   _____

Date   _____

Appendix C   Sample Questions

Could you tell me how you lost your (or the use of your) limb(s)?

How has this impacted on your life?

What are the problems you have experienced?

How have you dealt with them?

Is there anything about your injury that we have not talked about yet?

Has anything positive come from the experience of losing limb function?