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Efficacy of leisure intervention groups in rehabilitation of people with an acquired brain injury

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Bachelor of Physiotherapy

A thesis submitted in fulfilment of the requirements for the Masters App. Science (MAppSc)

January 2014
Faculty of Health Sciences
The University of Sydney
Declaration of originality

I certify that this thesis and the research reported in it are original. It contains no material that has been submitted for the award of any degree in any other university, and that to the best of my knowledge and belief, this thesis contains no copy or paraphrasing of material previously published or written by another person, except where due reference is made in the text of this thesis.

Signed

Elizabeth Jane Mitchell (Physiotherapy)

27 August 2013
Acknowledgements

This research project was supported by the NSW Department of Health Clinical Education and Training Institute (CETI), now known as the Health Education and Training Institute (HETI), as part of the Rural Research Capacity Building Program (RRCBP). The RRCBP provided both academic and financial support without which this project would not have been possible. Sincere thanks must go to Emma Webster and David Schmidt for the dedication, efficiency and passion they have shown to the RRCBP and its participants. Thanks also to the other candidates in the RRCBP for sharing this experience with me.

Sincere thanks to Professor Craig Veitch, Dr Megan Passey and Professor Leanne Togher for their invaluable assistance throughout the project. I feel very privileged to have worked with such experienced and passionate researchers and I thank you all for your availability, practical advice, enthusiasm and commitment. I would also like to acknowledge Dr Rob Heard for the practical advice and support he gave me in regard to the statistical analysis and Jenny Price the Librarian at Wagga Wagga Base Hospital for her assistance in sourcing the relevant literature.

This research would not have been possible without the support of my manager, team leader and colleagues of the South West Brain Injury Rehabilitation Service (SWBIRS) and I thank them all very much for their continued support over the past two years. Thank you to the participants of this research project, the amazing people I work with every day. Thank you for being willing subjects in this research and assisting us to further our understanding into what is effective rehabilitation following a brain injury.
Last but not least I would like to thank my family who have been a constant source of encouragement and inspiration. I thank them for giving me the determination to achieve my goals in life. Thank you in particular to my husband Erik who put up with me (and an untidy house) while I was on this mission.
Abstract

As individuals become less vocationally active such as after a brain injury, engagement in leisure and social activity increases in importance to the person’s well-being. However it is often the case that following a brain injury, for a variety of reasons some people have difficulty accessing what is available in their local area. The adult team at the South West Brain Injury Rehabilitation Service (SWBIRS) in Albury, NSW recognised an ongoing need within the population they service for direct leisure intervention as part of the rehabilitation and adjustment to injury process. A program called *Pushing the Boundaries* was developed in an attempt to trial leisure intervention through groups rather than on an individual basis which had been the current practice.

This study aimed to determine whether participation in a *Pushing the Boundaries* program targeting individuals with an acquired brain injury (ABI) living in rural, regional and remote NSW, improved the leisure satisfaction, self-esteem and quality of life of participants.

Using a pre and post intervention design, participants completed the Leisure Satisfaction Scale, World Health Organisation Quality of Life Scale –Bref and the Rosenberg Self-Esteem Scale prior to each program, immediately following and at three months post program. Data were analysed using a Wilcoxon signed-rank test. Individual leisure goals generated by participants during the program were also investigated to gain further insight into the personal effects of the program.

Invitations for participation in both the program and the research were sent to 100 past and present clients of SWBIRS. Twelve adults (8 men and 4 women) participated. They had a mean age of 36 years (range 19-49 years). Seven of the
participants had acquired their injury more than two years previously and for 10 of the participants the cause was trauma. Participants completing the week-long program showed a significant improvement in leisure satisfaction ($z = 3.06, p = 0.002$), self-esteem ($z = -2.22, p = 0.03$) and quality of life ($z = -1.96, p = 0.05$) 3 months post program. Of the 27 individual goals specified during the week-long program, 22 of these goals were reported to have been achieved three months post intervention, with 11 of the 12 participants reporting to have achieved at least one of their goals.

The findings indicate that adults with an acquired brain injury participating in a leisure program can experience improvements in leisure satisfaction, self-esteem and quality of life. These findings confirm a growing need for active leisure pursuits to be included in the ongoing rehabilitative care and integration of adults with an ABI.

Key words: Brain injury, leisure satisfaction, leisure participation, quality of life, community rehabilitation
Presentations

Presentations at conferences:


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<td>ABI</td>
<td>Acquired brain injury</td>
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<td>AMI</td>
<td>Acute myocardial infarction</td>
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<td>BIRP</td>
<td>Brain Injury Rehabilitation Program</td>
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<td>CARN</td>
<td>Centre Active Recreation Network</td>
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<td>CETI</td>
<td>Clinical Education and Training Institute</td>
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<td>CGP</td>
<td>Community Group Programs</td>
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<td>CT</td>
<td>Computed Tomography Scan</td>
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<td>CTP</td>
<td>Compulsory third party</td>
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<td>Electrocephalograms</td>
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<td>Glasgow Coma Scale</td>
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<td>HREC</td>
<td>Human Research Ethics Committee</td>
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<td>ICF</td>
<td>International Classification of Functioning Disability and Health</td>
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<td>LEP</td>
<td>Leisure Education Program</td>
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<td>LIVE</td>
<td>Leisure Is a Valuable Experience Program</td>
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<td>LPS</td>
<td>Leisure Participation Survey</td>
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<td>LSS</td>
<td>Leisure Satisfaction Scale</td>
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<td>LTCS</td>
<td>Lifetime Care and Support Authority</td>
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<td>MVA</td>
<td>Motor vehicle accident</td>
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<td>NSW</td>
<td>New South Wales</td>
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<td>QOL</td>
<td>Quality of life</td>
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<td>PTA</td>
<td>Post traumatic amnesia</td>
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<td>PTSD</td>
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<td>PUP</td>
<td>Potential Unlimited Program</td>
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<td>RRCBP</td>
<td>Rural Research Capacity Building Program</td>
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<td>RSES</td>
<td>Rosenberg Self-Esteem Scale</td>
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<td>SCI</td>
<td>Spinal cord injury</td>
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<td>SWBIRS</td>
<td>South West Brain Injury Rehabilitation Service</td>
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<td>TAC</td>
<td>Transport Accident Commission</td>
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<td>TBI</td>
<td>Traumatic brain injury</td>
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<td>TLU</td>
<td>Transitional living unit</td>
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<td>US</td>
<td>United States</td>
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<td>WFNR</td>
<td>World Federation of Neurological Rehabilitation</td>
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Chapter 1

Introduction

1.1 Context of the Problem

Acquired brain injury (ABI) is a traumatic life event for the majority of people who experience this condition. Individuals with an ABI frequently experience changes in their ability to undertake their previous roles in society including work, leisure and social interaction. This thesis presents findings from a group-based leisure intervention trialed in rural residents with ABI.

Research has demonstrated that after an ABI there is persistent disability in the areas of interpersonal relationships and leisure activities (Dikman, Machamer, Powell & Temkin, 2003; Douglas, Dyson, & Foreman, 2006) and many people have difficulty accessing the facilities available in their local area. Social isolation is a frequent problem following an ABI, and lack of friendship a continuing theme (Callaway, Sloan, & Winkler, 2005; Morton & Wehman, 1995).

Participation in leisure activity has been demonstrated to be an important factor in life satisfaction, subjective well-being, perceived quality of life and social integration following an ABI (Malley, Cooper, & Cope, 2008). Engagement in leisure activities is increasingly recognised as an important determinant of quality of life (QOL) (Turner-Strokes, 2003) and is now a recognised health domain in the World Health Organisation International Classification of Functioning Disability and Health (ICF) (Turner-Strokes, 2003). The importance of leisure has been increasingly recognised over the years, and it is now accepted as part of the triad of occupational performance self-care, work and leisure (Daniel & Manigandan, 2005). However, little has been written in rehabilitation literature in terms of the effects of leisure interventions, and several recent studies have
Leisure intervention groups for people with ABI highlighted this gap (Carbonneau, Martineau, Andre & Dawson, 2011; Daniel & Manigandan, 2005; Wise et al., 2010).

Many people who sustain an ABI experience long-term disability and are unable to return to their usual activities in the workplace, in the community and at home. Psychosocial problems such as decreased social contact, loneliness and depression that can remain persistent long-term problems after a brain injury are often the most significant concern for family members. These psychosocial problems may actually be the major challenge for improving community re-entry (Morton & Wehman, 1995).

Research suggests that following a brain injury, quality of life is more strongly related to healthy psychological functioning than is the degree of physical impairment (Corrigan et al., 2001), and therefore “successful” rehabilitation needs to work on restoring both physical and psychological functioning. A comprehensive rehabilitation program must assist clients to manage their discretionary time in order to enhance their expression, self-concept, social interaction skills and community involvement (Paulsen, 1984).

The project that is the focus of this study had two main aims firstly to measure the efficacy of a *Pushing the Boundaries* program in promoting leisure satisfaction among persons with an ABI living in rural, regional and remote NSW. The second aim was to gain an understanding of the personal effects in a range of domains including self-esteem and quality of life in persons with a brain injury who participated in this intervention as part of their rehabilitation.

Rehabilitation services that can successfully increase leisure satisfaction and QOL are likely to reduce the social burden associated with severe ABI and facilitate the restoration of the QOL of survivors—one of the fundamental aims of community-based ABI rehabilitation (Thomas, 2004). When leisure satisfaction is not addressed as part of
a rehabilitation program, individuals with brain injuries may be discharged without the
independence and self-confidence needed to face life’s challenges (Prvu, Nava, Yaffe,
& Hagar, 1999), and without the appropriate skills to lead a healthy and satisfying way
of life.

1.2 Overview of thesis

The remainder of this thesis takes the following form. In Chapter 2 I present a
literature review related to leisure interventions for ABI. Before outlining some of the
interventions that have been developed to improve leisure satisfaction following an
ABI, I discuss the definition, incidence and prevalence of ABI in Australia, variability
in injury and recovery post ABI, and some of the common changes in a person
following an ABI. A brief overview of the impact that an ABI can have on both leisure
participation and social interaction will follow. Relevant literature on the various leisure
interventions that have been developed for people with an ABI or traumatic brain injury
(TBI) has been presented to create an argument for why leisure intervention is an
important part of community rehabilitation. A discussion of approaches to
contextualized (or context-sensitive) rehabilitation and self-identified goal setting has
been included as these approaches were very much a part of the Pushing the Boundaries
Program. Methodology, study design and ethics approval is included in Chapter 3. In
Chapter 4 I present the quantitative results, individual goal attainment and barriers to
participation within the study participants. The key findings are discussed in Chapter 5
along with further discussion of the results and consideration of the limitations and
strengths of the current study. Chapter 6 highlights the conclusions, recommendations
and clinical implications of the findings.
Chapter 2

Literature review

2.1 Definition of acquired brain injury

Acquired brain injury refers to any damage to the brain that occurs after birth. That damage can be caused by trauma, a stroke, brain infection, alcohol or other drugs, or by diseases of the brain (Brain Injury Australia, 2012).

Traumatic brain injury (TBI), a form of ABI, occurs when a sudden trauma causes damage to the brain. TBI can result when the head suddenly and violently hits an object, or when an object pierces the skull and enters brain tissue (National Institute of Neurological Diseases and Stroke, 2013).

Definitions of TBI and ABI tend to differ slightly between countries, studies, legislation and disability groups and this has caused some confusion. According to the Brain Injury Network (2013) all TBIs are ABIs, but not all ABIs are TBIs, and the words are not interchangeable.

There must be a distinction in the two terms, and internationally, there is. ABI is the broad category. TBI is one of its numerous sub-classifications. So, the better way to state the connection of the two terms would be, \textit{TBI, a form of ABI}. (Brain Injury Network, 2013).

The term ABI will be used throughout this paper to cover all acquired damage to the brain, regardless of the cause.
Neuropalliative conditions are usually caused by brain damage and include rare conditions such as Huntington’s disease, vegetative state and locked-in syndrome (Fenech & Baker, 2008).

### 2.1.1 Incidence and prevalence of ABI in Australia

Estimates of the incidence of brain injury vary widely due to differences in operational definitions, study methodologies and hospital admission practices among many other variables. However, the incidence of brain injury in Australia is estimated to range from 57–377 cases per 100,000 per year which is similar to the range for overseas estimates (Fortune & Wen, 1999).

ABI is a common condition, with over half a million people estimated to be living with ABI in Australia. Three out of every four of these people are aged under 65. As many as two out of every three acquired their brain injury before they turned 25, and three out of every four people with ABI are men (Brain Injury Australia, 2012).

The leading cause of ABI in Australia is stroke, with around 60,000 new strokes occurring each year. The vast majority of these occur in people aged 65 and over. The next largest cause of ABI is trauma. Over 22,000 Australians were hospitalised as a result of a TBI in 2004–2005. Many of those TBIs, over two in every five, were caused by a fall, nearly one in three was due to a motor vehicle accident (MVA) and one in six was caused by an assault. Trauma and misadventure account for the majority of brain injuries in people aged under 65 (Brain Injury Australia, 2012).

### 2.1.2 Variability in injury and recovery

Severity of injury can range enormously for people who sustain an ABI, and it often takes some time to determine how serious the brain injury is. Each individual
differs depending on where and how much of the brain is injured and whether any swelling occurs (Toronto ABI Network, 2013).

The nature of the damage, and the parts of the brain affected, can vary considerably depending on the cause. Damage can be focal. For example, in TBI a specific part of the brain may be impacted against the skull and bruised. In some cases, damage may be diffuse and widespread. For example, in acceleration/deceleration injuries such as those sustained in a MVA whereby blood vessels and nerve fibres throughout the brain can be torn by shearing forces (Jennett et al., 1981, cited in Fortune & Wen, 1999).

CAT Scans (CT) and electroencephalograms (EEG) can give some indication about damage to the brain, but tests alone cannot always predict long-term recovery outcomes. Sometimes the severity of the injury is measured by the Glasgow Coma Scale (GCS) together with the length of time a patient experiences post traumatic amnesia (PTA) (Toronto ABI Network, 2013). Individuals coming out of a coma may go through a period of PTA which may last for hours, days or weeks. PTA is considered a stage in the brain’s recovery process during which individuals may be disoriented, highly distractible and confused and may have difficulty with thinking, memory and concentration. They may also be afraid, disinhibited, agitated and emotionally labile (Synapse, 2013). General indication of injury severity as indicated by PTA duration is as follows:

- PTA less than 5 minutes = very mild injury
- PTA between 5 and 60 minutes = mild injury
- PTA 1–24 hours + = moderate injury
- PTA 1–7 days = severe injury
- PTA greater than 7 days = very severe injury (Synapse, 2013).
2.2 Changes following ABI

There is little understanding in the community about ABI and the impact it can have on individuals and families. Long-term effects are different for each individual, although it is common for people with an ABI to get tired more quickly and have difficulty with concentration and short-term memory. People with an ABI may experience long-term changes in their ability to think and learn and in their behaviour and personality. They may also experience communication difficulties and changes in their physical and sensory abilities (Brain Injury Australia, 2012).

As medical science improves the number of people surviving ABI also increases. This growing number of survivors has resulted in an increased need for rehabilitation services (Fines & Nichols, 1994). Survivors of a moderate to severe ABI may have a normal or near-normal life span, but they often have to deal with permanent cognitive, physical, emotional, behavioural and psychological impairments (Brandstarter, Bontke, Cobble & Horn, 1991). The presence of ABI is often associated with symptoms of depression, behavioural problems and substance abuse (Ommaya, Salazar, Dannenburg, Chervinsky & Schwab, 1996), post-traumatic stress disorder (PTSD) and sometimes feelings of loneliness (Ponsford, 1995). Sometimes it is the case that these emotional sequelae are not addressed by conventional rehabilitation which tends to focus on physical and cognitive impairments.

Helping those with severe ABI to maintain social involvement through activity can give these individuals opportunities to develop personal interests and access to social ties. These activities can lead to reduced individual care demands and the support placed on families (Douglas, Dyson, & Foreman, 2006). There is growing consensus that the treatment of individuals with an ABI should not end when they are discharged from hospital but must continue throughout their lives (Stumbo & Bloom, 1990). It has been
suggested that the long-term supports for these people must address their living environment, work life, recreational pursuits and maintenance of social networks (Dryovage & Seidmen, 1992).

2.2.1 Impact of ABI on community integration

There have been many definitions of community integration over the years. Most of them include the resumption of valued social roles and the facilitation of social access. Some describe community integration as more than just a physical presence and the resumption of social roles. They believe it should also ideally include ongoing meaningful relationships of mutuality and reciprocity (Duck, 1994) that are formed through the development of shared phenomena (Lee, McCormick, & Austin, 2001).

Social integration, which includes both the number of persons in an individuals’ social network and satisfaction with the amount of time spent with others, is a vital component of life satisfaction for people in the general population, and there is an increasing body of evidence suggesting this is also true and perhaps even more so, for those who have had a brain injury (Lo Bello et al., 2003). Social integration in the community can be seriously compromised following ABI primarily because of cognitive and emotional/behavioural changes that have been shown to be challenges for the individuals’ social networks (Brown, Gordan, & Spielman, 2003; Zencius & Wesolowski, 1999). The literature suggests that social isolation is a frequent problem following an ABI, and lack of friendship is a continuing theme (Callaway, Sloan & Winkler, 2005; Douglass & Spellacy, 1996). According to Douglass & Spellacy (1996), lack of friendship and lack of involvement were the overriding themes in the needs expressed by 35 adults with severe ABI living in the community more than 3.5 years after their injury (mean time 7 years post injury). Studies also suggest that social isolation and dissatisfaction with social networks tend to increase over time and often
Leisure intervention groups for people with ABI lead to secondary psychological sequelae (Burleigh, Farber & Gillard, 1998; Callaway, Sloan & Winkler, 2005). Given the impact of ABI on friendships and social networks, it is important that interventions are developed to minimise the loss of friends and facilitate the development of new friendships (Burleigh et al., 1998; Callaway et al., 2005).

Quality of Life is a term used to indicate individuals' perception of their position in life in the context of their culture and value systems and in relation to their goals, expectations, standards and concerns. It is a broad-ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, and their connection to salient features of their environment (WHO Collaborating Centre, 2013). Many people who sustain an ABI experience long-term disability and are unable to return to their usual activities in the workplace, in the community and at home. Quite often they have a lot of spare time on their hands but become occupationally deprived because of difficulty accessing the community or engaging in desired or meaningful activities. It has been suggested that satisfaction with leisure rather than satisfaction derived from job, family, health or financial resources, is the chief determinant of psychological well-being in this population (Beard & Ragheb, 1980) and rehabilitation services that can successfully increase leisure satisfaction, self-esteem and QOL are likely to reduce the social burden associated with severe ABI (Douglas, Dyson & Foreman, 2006).

A search of the literature by Morton and Wehman (1995) revealed four primary themes around the psychosocial and emotional sequelae of individuals with traumatic brain injury (TBI). The first theme describes a population group that is at high risk for a significant decrease in their friendships and social support. The second theme is around the lack of opportunity for establishing new social contacts and friends. The third theme
relates to a decrease in leisure participation for people with a TBI, and the fourth theme centers on the high levels of anxiety and depression that people with a severe TBI can experience.

Many people with a brain injury have problems with leisure time, socialization and lack of availability of social activities (Fazio & Fralish, 1988). It has been suggested that leisure activities provide the ideal setting for people with a brain injury to test their social skills (Rosenthal, 1983). According to Bier et al., (2009), involvement in leisure activities can help create a broader social network that could provide some respite for family members and friends who are often still managing the activities of daily living of the person with a TBI many years after the trauma. Other possible strategies for increasing social activity within this population could include addressing the issues of depression and fatigue (Brown et al., 2003).

It has been suggested that a person’s healthy psychological functioning can be restored following a brain injury if rehabilitation teams can increase that person’s repertoire of skills needed for successful social integration. Rehabilitation specialists working to increase an individual’s level of social integration may expect greater post-injury adjustment to be reflected in greater life satisfaction and family satisfaction (Lo Bello et al., 2003).

### 2.2.2 Impact of ABI on leisure participation

Leisure and recreational activities are an important part of rural life, but it is often the case that following a brain injury some people have difficulty accessing what is available to them. More than 90% of people with TBI report a reduction in their leisure participation and many of these people also report dissatisfaction with their leisure (Quintard et al., 2002, cited in Carbonneau et al., 2011).
Leisure pursuits, defined as *occupations for enjoyment* (Canadian Association of Occupational Therapists, 1997), are just one area of role participation often adversely affected by ABI. A significant behavioral deficit experienced by persons with ABI is often the decreased initiation of purposeful activity that may be especially important during leisure time (Davis & Chittum, 1994). There are several studies indicating that people with a brain injury are often unable to return to previous leisure activities and have fewer interests than they did prior to their injury (Brown & Vanderdergoot, 1998; Sloan, Winkler, & Callaway, 2004). People with a brain injury also tend to be involved in less physical and more passive recreation than previously, and it has been suggested that depression and fatigue play a role in this reduced involvement (Brown, Gordon, & Spielman, 2003).

The importance of an active lifestyle following an ABI is increasingly being recognised for its benefits to QOL and the prevention and management of secondary health conditions resulting from a sedentary lifestyle (Blake & Batson, 2008). Reasons why people are less physically active following an ABI or TBI can include physical, cognitive and psychological variables, along with environmental and societal barriers (Hasset & Moseley, 2009).

Several studies were found that discussed some of the barriers to participation in leisure activities for people with disabilities. Transport, in terms of both cost and distance to venues, was commonly identified as a barrier (Bier, Dutil & Couture, 2009; Douglas, Dyson, & Foreman, 2006). Activities being held at locations that were not disability-friendly, and a lack of congruence between an individual’s interests and the activities offered in their region were also found to be a major influence on participation (Douglas, Dyson, & Foreman, 2006). The scheduling of activities and the composition of the activity groups was also found to play a role in determining participation levels.
People with an ABI may have more time to engage in leisure activities. However, a lack of finances can deprive them of the enjoyment of a number of leisure activities that would be available to the general population (Brown, Gordon, & Spielman, 2003). Physical, cognitive and emotional changes can create further barriers to their participation in leisure activities (Bier et al., 2009; Fines & Nichols 1994). Not having the opportunity to choose from a variety of leisure pursuits and physically and psychologically experience the benefits and characteristics of leisure participation were also identified as barriers to participation (Fines & Nichols, 1994). Three studies were of particular relevance to this current study and are investigated in more detail below.

The impact of a moderate to severe TBI on participation in leisure activities at one year post injury was studied by Wise et al., (2010). Participants (n=160) were taking part in an inpatient rehabilitation program at a Level 1 trauma centre, and results suggested that they experienced a substantial decrease in the number of leisure activities performed after injury. It was reported that many participated in leisure less frequently, participated for less time or required assistance. Most participants were moderately to severely bothered by these changes, regardless of age. While it is difficult to make comparisons with other studies because of the differences in study design and other parameters, this study supports previous evidence that survivors of TBI experience a substantial decrease in participation in leisure activities after injury, with a negative impact on life satisfaction. Results of this study also indicated a shift to more home-based, sedentary and isolating leisure activities after injury, which is of particular concern. Similarly, Bier et al. (2009) who also explored leisure participation of individuals with TBI who were recruited from a rehabilitation program (in and out patients), found significant changes in leisure participation pre- and post-trauma.
Fatigue and lack of transportation were the most common barriers to participation in this sample.

In a recent Queensland study, outpatient participants (n=20) receiving brain injury rehabilitation reported discontinued participation in a number of leisure activities including sporting activities, going to pubs, listening to music/radio and visiting family and friends (Fleming et al., 2011). The predominant reason for discontinuing or decreasing participation identified in this group was disability, followed by restrictions due to medical advice and personal choice. Additional reasons included driving cessation and financial limitations. The outpatient participants (n=18) of this study were 251.6 mean days post injury (range 42–898) and were still involved with a rehabilitation program. The studies examined in this section clearly demonstrate that following a brain injury people report a reduction in their leisure participation which is often accompanied by a decrease in leisure satisfaction. Reasons why this occurs are varied but can include physical, cognitive and psychological problems along with environmental and societal barriers.

2.3 Literature search method

A review of the existing literature relating to brain injury rehabilitation, leisure programs, leisure satisfaction and QOL was conducted. The literature databases searched included CINAHL Plus, Ovid MEDLINE, Ovid PsycINFO, EBSCOhost (Health and Psychology) and Google Scholar. Additional papers were identified from the bibliographies of relevant studies retrieved by the search strategy and these were also included in the review. Key search terms employed were brain injury, leisure satisfaction, leisure participation, therapeutic recreation, quality of life, community integration, leisure neuropalliative and community rehabilitation. International literature was considered, but only those papers written in English were included. Searched
## Table 1: Methodological Characteristics of Included Studies

<table>
<thead>
<tr>
<th>Authors and year of publication</th>
<th>Country</th>
<th>Client group</th>
<th>Study type</th>
<th>Variables</th>
</tr>
</thead>
<tbody>
<tr>
<td>5. Davis &amp; Chittum, 1994.</td>
<td>United States</td>
<td>TBI adults (n=6)</td>
<td>Momentary time-sampling procedures</td>
<td>Active leisure engagement</td>
</tr>
<tr>
<td>6. Thomas, 2004</td>
<td>Australia</td>
<td>ABI adults (n=14)</td>
<td>Mixed method longitudinal study</td>
<td>QOL and adjustment to ABI</td>
</tr>
<tr>
<td>7. Walker et al., 2005</td>
<td>NSW Australia</td>
<td>TBI adults (n=11)</td>
<td>Prospective repeated-measures design</td>
<td>Goal planning ability and goal attainment</td>
</tr>
<tr>
<td>8. Lemmon et al., 1996.</td>
<td>United States</td>
<td>Mild TBI professional women (n=12)</td>
<td>Pre and post</td>
<td>Ability to rely on others, self-esteem, problem solving ability and understanding strengths and limitations</td>
</tr>
<tr>
<td>10. Gemmell &amp; Leatham, 2006.</td>
<td>New Zealand</td>
<td>TBI adults (n=18)</td>
<td>Within group design and between group design</td>
<td>Medical outcome scale, self-esteem and mood.</td>
</tr>
</tbody>
</table>
literature covered the period of 1980-2012. The most relevant literature was found from 2003 onwards, indicating that leisure programs as a part of ABI rehabilitation is a relatively recent area of interest.

Ten publications were most relevant to the current study’s focus and purpose. For convenience, those studies are summarised in Table 1. Briefly:

a) Three studies evaluated the outcomes of leisure education programs (LEPs) for individuals with an ABI (1, 2, 3) two studies investigated the outcomes of interventions to increase leisure activity post TBI (4, 5).

b) Three studies explored the outcomes of Outward Bound type programs for adults with an ABI (6, 7, 8).

c) One study evaluated a 12-week recreational kayak program on adults with a TBI concerning outcomes for self-concept, leisure satisfaction and leisure attitudes (9).

d) One study explored the outcomes of a six-week course in tai chi for individuals with TBI (10).

There is a range of therapies traditionally used to stimulate the engagement of people into leisure activities following a brain injury. Many of the studies focus on the early transition phase and therefore do not capture how people’s experiences may change over an extended period of time. The majority of efficacy studies reviewed shared the common limitations of such projects. Differences in project design, outcome measures and statistical methods used in the studies reviewed limited comparison of the various studies and prevented either a meta-analysis or formal systematic review. Key findings from the review are outlined in the following sections. Each section has varying direct applicability to this project but all provide perspectives relevant to leisure
interventions for people with brain injury. No studies were identified that specifically evaluated leisure programs for rural people with ABI. However several research papers were found that have some similarities to this study. With different project designs, parameters and demographic groups it is difficult to compare the various studies.

Studies 1, 2 and 3, which evaluated the effects of leisure education programs (LEPs) for individuals with traumatic brain injuries, are considered the most relevant to this study as the younger age of the groups tend to be similar to the age of participants in this study and the approach to rehabilitation is similar. These studies explored whether the LEPs had affected leisure satisfaction as well as a range of other outcome variables included leisure participation, perceived self-confidence, perceived freedom of leisure, leisure attitudes, leisure self-efficacy, community integration and general well-being. Of the two studies (4 and 5) that examined the effects of increasing leisure activity for people with ABI, study 4 evaluated the effects in terms of social integration, social support, mental health and QOL. Study 5 explored a group-oriented contingency to increase leisure activity among adults with TBI. However, it dealt with only the increased occurrence of activities and not the impact that the increased leisure activities had on participants.

Three Wilderness Adventure Therapy programs (6, 7, 8) were run in conjunction with Outward Bound Australia (OBA) with different focusses for each of the programs. One program’s (6) focus was on adjustment to injury, another (7) was on the development of goal planning ability, and the third (8) was about improving self-esteem and better understanding the participants’ own strengths and limitations.

Several other publications were identified that investigated the effectiveness of leisure education programs for other neurological conditions and these publications will be discussed briefly in Section 2.6.4. Although not directly relevant in terms of the
population group under study, these publications do provide further evidence of the potential of leisure education programs.

2.4 Benefits of leisure participation following ABI

Research indicates that involvement in leisure activities has several positive effects on physical health, mental health, life satisfaction and psychological growth for adults without disabilities (Tinsley et al., 1993) and the literature suggests that leisure has similar benefits for people with acquired disabilities (Fines & Nichols, 1994; Thomas, 2004). Some propose that leisure assists people in overcoming difficulties, possibly by buffering the effects of stress (Iwasaki, Zuzanek, & Mannell, 2001), and in adults with brain injury leisure activity has been shown to increase self-confidence and promote feelings of well-being (Prvu, Navar, Yaffe, & Hagar, 1999). It is well documented that leisure is an important component in the lives of people with disabilities and it is often associated with community involvement, life satisfaction, self-esteem and a reduced incidence of depression (Danial & Manigandan, 2005; Douglas, Dyson, & Foreman, 2006; Gemmell & Leathem, 2006).

Leisure is an important focus of study for several reasons. Leisure is an important component in the lives of people with disabilities and is correlated positively with life satisfaction and self-esteem and negatively with depression (Kinney & Coyle, 1992). However, leisure specialists have all but ignored the leisure patterns and needs of people with disabilities (Daniel & Manigandan, 2005) and, according to Prost (1992), there is little understanding about the meaning of leisure among people with a disability. There is much literature focused on leisure-skill acquisition for people with developmental disabilities rather than the independent initiation of these skills when they already exist, as may be the case with people who have an ABI (Davis & Chittum, 2004). Thus, active leisure programs for individuals with an ABI are a relatively new
and unexplored territory. However, there are many who believe that active leisure programs are not only valuable for their therapeutic value, but more specifically that they are an important tool in facilitating redefinition of one’s “self” following a brain injury (Berryman, James, & Trader, 1991). Leisure programs in the past have been used as tools to aid in adjustment to injury (Thomas, 2004). Prigatano (1989) believes that leisure, or rather play as he calls it, reveals an aspect of the self that is important to the rehabilitation process because it can enable people with ABI to be in contact with the experiences that maintain a sense of the old identity while at the same time helping them to make the necessary adjustments following their brain injury.

The focus of QOL enhancements can come through meaningful occupations such as leisure occupations that are enjoyable and satisfying. For a leisure occupation to be truly meaningful it should include a “sense of importance, purpose or meaning for the individual and opportunities for accomplishment or achievement as well as exploring self-identity” (Fenech & Baker, 2008, p. 370). Leisure occupation can give the person with an ABI an opportunity to be fully human, to experience a sense of belonging, health and capability while preventing the boredom and occupational deprivation that may arise if one has too much free time (Fenech & Baker, 2008, p.370). It is important that the leisure occupation embarked on has meaning and is engaging to the individual (Miller, Polgar, & Landry, 2004). Furthermore, it has been suggested that experimentation, personal growth (Miller, Polgar & Landry, 2004) and giving the individual control over the choice of the activity (Ryan & Deci, 2000) are important ways of investing meaning to an activity.

Facilitating the restoration of the QOL of survivors is one of the fundamental aims of community-based ABI rehabilitation (Thomas, 2004) and leisure programs are increasingly being seen as a supportive and enabling medium for enhancing QOL for
Leisure intervention groups for people with ABI

persons with disabilities (Ross, 1983). Leisure intervention groups can provide an opportunity for participants to explore recreational opportunities and discuss potential barriers along with supporting social integration of the individual.

2.5 Interventions developed to improve leisure satisfaction post ABI

Leisure intervention can take many forms. Direct leisure intervention, for example, may take the form of adaptation of a leisure activity or the environment in which it is being performed. It can also include assisting a person to learn a new leisure activity or supporting a person in the initiation and planning process associated with starting a new leisure activity. Alternatively, indirect leisure intervention could be in the form of value clarification by changing the attitudes of the person towards leisure and assisting them to choose a leisure activity that interests them (Daniel & Manigandah, 2006). Leisure interventions developed for individuals with ABI range from a wide variety of leisure education programs (LEPs) through to kayaking programs, tai chi groups, wilderness and outdoor adventure programs, facilitated and organised community leisure activities and many more. This section examines just a few of these interventions and the effects they have had on the individuals who participated in them.

A number of studies were found that demonstrated the positive impact of leisure interventions for people with acquired disability (e.g., TBI, spinal cord injury and neurological diseases). Some studies focussed on people with a particular disability. Other studies focused on the particular leisure activity. Only a few included rigorous evaluation designs with pre/post testing.

2.5.1 Leisure education programs post ABI

Three studies explored the effects of leisure education programs on adults with ABI. One study examined the effects of a Leisure is a Valuable Experience (LIVE)
Leisure intervention groups for people with ABI

program run in an outpatient rehabilitation program in the north-west region of the United States on the participants (n=9) who completed the program (Prvu et al., 1999). Sessions were developed to meet the goals and objectives of the population and classified under the four components of Peterson and Gunn’s (1984) leisure education content model, i.e., leisure awareness, leisure resources, social interaction skills, and leisure activity skills. The program aimed to target leisure awareness while building social interaction skills and knowledge of leisure resources. Participants reported that participation in the program gave them increased confidence, encouraged them to try new skills, allowed them to reveal thoughts, feelings or physical skills and made a difference in their attitude toward recovery. Results indicated that by increasing the leisure skills and knowledge of community resources among those with a brain injury, there was an increase in self-confidence and leisure participation which, in turn, increased leisure satisfaction. It has been suggested that self-efficacy may play an important role in this process (Wise et al., 2010). As patient demographics were not included in the article, participants’ age, injury type and time since injury are unknown.

More recently in a Canadian study, Carbonneau et al. (2011) assessed a leisure education program based on Bandura’s (1982) theory of self-efficacy that successful performance is rooted in competency of efficacy beliefs or an awareness of one’s own ability to complete a task. The program was designed to raise awareness of and participation in meaningful, new and/or alternative ways to pursue leisure activities, build skills in individually selected leisure pursuits and overall increase leisure satisfaction (Carbonneau et al., 2011). This was a small mixed methods study with pre, post and follow-up assessment. A convenience sample of participants with TBI (n = 3), all men who had sustained moderate to severe brain injuries more than 2 years prior to the study, were invited to participate in the leisure intervention. The program, initially
designated to assist people in engaging in meaningful leisure activities following a stroke, was also found to improve leisure satisfaction and self-efficacy for the three participants. This extended to improvements in general well-being and health-related quality of life for two of the three participants. The study was limited in terms of its convenience sampling procedure and sample size. However, the results suggest that engaging in leisure education at the level of understanding the meaning of leisure has a greater benefit than simply doing exercises, and these promising results warrant further investigation (Carbonneau et al., 2011).

The third study investigated the effects of an LEP using values clarification strategies versus informal discussion on adults with TBI (Zoerink & Lauener, 1991). Values clarification is a technique used to encourage a person in knowing what is important to them and choosing those things that they value and care about the most (Hart, 1978). In this pretest-posttest experimental design study, patients ($n = 12$) at a rehabilitation centre in the US, were randomly assigned to either a leisure education group or an informal discussion group. The values clarification intervention activities were divided into eight, 90 minute sessions conducted weekly. Each educational session was followed by a guided experiential activity. The techniques were implemented using Hart’s (1978) recommendations. The topics included 1) identifying personally enjoyable recreation experiences, 2) choosing from alternatives and examining the choices made, 3) examining and publicly affirming the range of alternatives associated with different activities, 4) exploring past events and making judgments, 5) building a pattern of consistent action, 6) examining benefits and alternatives, 7) removing barriers to action, and 8) planning for the future. Following each session a community re-entry outing planned in accordance with the content of the educational session was implemented. The subjects of the informal discussion group participated in reality-
orientation based activities with goals and objectives corresponding to their cognitive needs. The group met for one hour each week and the goals were addressed through recreational experiences such as card playing and billiards. This group did not receive any formalised leisure education or community based services. Multivariate analysis of variance revealed no significant differences between the groups’ attitudes, satisfaction or perceptions of freedom. There were, however, significant pretest and posttest differences for both groups on the psychological, educational, relaxation and aesthetic dimensions of leisure satisfaction. Results suggested that both interventions, when applied in a day hospital program for adults with TBI, were correlated with improvement in the patients’ psychological, educational, relaxation and aesthetic satisfaction (Zoerink & Lauener, 1991).

2.5.2 Interventions to increase leisure activity post ABI

One Australian study measured the personal effects of a program developed to promote involvement in leisure activity for people who had sustained a brain injury (Douglas, Dyson, & Foreman, 2006). A simple pre and post intervention design was used in this mixed method study to track changes in individual cases and to evaluate group data. Adults with severe TBI, living in metropolitan Melbourne, who participated regularly (i.e., at least weekly) in facilitated and organised community leisure activities over a six-month period reported significant changes in social integration and mental health as measured by the Social Integration subscale of the Community Integration Questionnaire: and the Depression subscale of the Neurobehavioral Functioning Inventory respectively. Participants (n = 25; 21 men and four women) were volunteers who had been referred by the Transport Accident Commission (TAC) to a Melbourne metropolitan community or disability service that was a lead agency through Community Group Programs (CGPs). Participants were aged between 25 and 45 years.
and had sustained severe head injuries with posttraumatic amnesia (PTA) greater than 1 month. On average, 10 years had elapsed since the time of injury (SD = 4.75 years). This program provided funding for transport to and from activities and this was seen as an important facilitator for the program. A sub-group of six participants who were engaged regularly in community leisure activities also reported improved QOL, but these changes were not statistically significant. Participants reported that social involvement made an important positive difference to their lives and how they felt. The difference was also evident on quantitative measures of social integration and mental health (Douglas, Dyson, & Foreman, 2006).

Finally, a small study carried out in a group home in the US examined the effects of a group-oriented contingency reward to increase leisure activities of adults with TBI living in the house. The group members were all rewarded equally by a weekend activity of the group’s choice if they engaged in active leisure activities during 25% of their free time. A poster showing the group’s performance, along with a list of activities to do more often and a list to do less often to help the group meet their goal, was displayed on the kitchen bulletin board. After two weeks at the first criterion level, the criterion was raised for three weeks and then removed. The program was associated with increases in active leisure for four of the six participants. Two of the participants’ behaviour returned to baseline levels during the withdrawal, suggesting that although the treatment was responsible for change in behaviour, the leisure behaviours themselves were not reinforcing. Two remaining subjects did not respond to the group contingencies at all. The program had a positive effect for one of the participants whose behavior change was maintained even after the reward was removed (Davies & Chittum, 1994).
2.5.3 Outward bound, kayaking & tai chi post ABI

In attempting to address the complex issues associated with adjustment to injury and restoration of quality of life following ABI, a number of more creative interventions have been developed and are showing some promising results. These include activities such as Outward Bound programs, Wilderness Adventure Therapy and recreational kayaking. The Outward Bound movement, which is recognised as a leader in the outdoor experiential education field, is gradually becoming known for its benefits for disabled populations. Outward Bound activities have been shown to assist the individual in the development of goal setting abilities and adjustment to a range of injuries including ABI (Thomas, 2004).

Three articles were identified that discussed the use of programs involving Outward Bound activities for adults with TBI. One mixed method longitudinal study examined the outcomes of two Potential Unlimited Programs (PUPs) to determine participant outcomes related to adjustment to ABI (Thomas, 2004). The programs targeted people with an ABI living in rural NSW and consisted of a nine day Outward Bound Discovery course with extensive follow-up group work. Participants ($n = 14$) were on average 6 years post injury. The results indicated that those who participated in the program showed significant and sustained improvement in subjective QOL as measured by the Quality of Life Inventory following the program. Analysis of interview data provided insights into how the program provided opportunities for participants to engage in key tasks of adjustment to injury. Thomas (2004) concluded that the combination of outdoor experiential education with extensive group work in the PUP likely represented a unique and powerful approach for addressing many of the issues associated with the process of psychosocial adjustment to injury and restoring quality of life following ABI.
A prospective repeated–measures design with a single convenience sample was used by Walker et al. (2005) to describe and evaluate a NSW community-based rehabilitation program similar to that used in the research by Thomas (2004). However, the focus of this study was the development of goal planning ability and goal-attainment rather than improving QOL and adjustment to injury. Walker et al. (2005) demonstrated a high level of achievement on specific goals following the goal planning program and a nine-day outdoor adventure course, suggesting great promise for this program as a form of community rehabilitation. Participants (n = 11), 19 – 47 years of age, with a mean time since injury of 6 years were involved in the program. There were three distinct stages of the program which included:

1) 9 monthly meetings in which the group generated fund-raising ideas and conducted fund-raising activities to contribute towards the cost of the outdoor course.

2) A 9-day outdoor adventure course provided by Outward Bound Australia and

3) A final stage which encouraged individuals to work actively on their identified short and medium-term goals.

Twenty-one (80.8%) of the 26 identified goals were achieved. All but one participant achieved at least one goal. Walker et al. (2005) reported that the strength of the program appeared to lie a) partly in the motivation provided by participation in the outdoor course, which appeared to b) encourage participants to work towards broader goals. It was thought that the focus of fundraising for the outdoor course also provided a tangible goal and a real-life context in which to work on developing social skills, problem-solving and organisational and time management skills (Walker et al., 2005).
Lemmon et al. (1996) evaluated outcomes of an Outward Bound experience on a group of 12 professional women who had sustained a mild TBI. The aim of the 3-day program was to increase the self-esteem and self-confidence of the participants by them becoming more aware of their own personal strengths and weaknesses. Participants continued to demonstrate positive changes in self-esteem, ability to solve problems and understanding of strengths and limitations which persisted one year after completion of the program. According to Lemmon et al. (1996) it was the experience of taking risks, facing fears and rediscovering a sense of self that many had not had since sustaining their injury, that was responsible for participants being able to regain trust in their own bodies’ and minds’ abilities. There was a subsequent increase in confidence and self-esteem for these women.

A US study by Fines and Nichols (1994) explored the effects of a 12-week recreational kayak program on the self-concept, leisure satisfaction and leisure attitude of eight adults who had sustained a TBI. Participants were aged between 19 and 55 years and all had been discharged from rehabilitation for more than one year. The kayak program was offered once per week (60–90 minutes) for 12 weeks. The findings of this study indicated that adults with a TBI participating in a kayak program can experience improvements in psychological well-being, leisure satisfaction and leisure attitude. Statistically significant increases were noted on all seven of the psychological measures of the Tennessee Self Concept Scale as well as all six components of the Leisure Satisfaction Scale one week post program. Significant changes were also noted in the affective and behavioural scores of the Leisure Attitude Scale.

Most of the benefits reported for tai chi have involved studies within elderly populations. One New Zealand study used a within-group design to explore the benefits of a six-week course in tai chi for individuals in a younger population with a TBI.
Participants (n = 18) were randomly assigned to an experimental group who received training in tai chi and a control group who were placed on a waiting list for tai chi. The average time since injury for participants was 8.7 years. Results suggest there was significant improvement in the Visual Analogue Mood Scale (except fatigue) with decreases in sadness, confusion, anger, tension and, fear, and increases in energy and happiness for participants. There were no significant differences between groups for health status and QOL as measured by the Medical Outcome Scale Short Form 36 (SF-36) and self-esteem as measured by the Rosenberg Self-Esteem Scale (Gemmell & Leathem, 2006).

2.6 Leisure for individuals with other acquired disabilities

The focus of this section is on leisure programs and their utility in different settings with different groups. A variety of leisure pursuits have been demonstrated to work across a wide range of conditions. Some of these will be discussed in this section. Neuropalliative conditions, stroke, spinal cord injury and brain injury are all acquired conditions that often eliminate the opportunity for people to do what they previously did. Finding other things to occupy them or giving them new skills to be able to participate in a different way have been found to be advantageous for many individuals with acquired disabilities. Leisure programs can teach people leisure skills and guide them through the early steps when they are struggling with a lack of confidence. Similarly, letting individuals “taste test” a couple of options may be all that is required for someone to make a decision about whether or not they would like to pursue a new leisure activity.

Tailoring leisure to suit a wider audience through creative event planning with a multi-sensory approach has been trialed with good results in the UK for adults with complex and profound neurological disabilities (Stonier, 2008). These casual leisure
experiences, which put particular importance on interaction with others and did not require any special skills for participation, were designed to be instantly and fundamentally rewarding, and relatively short-lived with inclusion as a key element. The use of coloured laser lighting, interactive projections, music and an interactive drama event proved to be a successful combination, with participants reporting feeling valued (Stonier, 2008).

Individuals with severe neuropalliative conditions are similar to those with an ABI in that they often tend to take on a passive/spectator role and have fewer opportunities to engage in leisure activities due to a range of contextual factors (Fenech, 2012). Aquability for individuals with severe neuropalliative conditions was trialed in the UK with participants reported as “being in control, learning about themselves and others and feeling healthier” (Fenech, 2012, p.519) following a session of aquability. Participants reported experiencing a sense of achievement and novelty, which was both interesting and enjoyable. Fenech concluded that aquability appeared to be a satisfying use of leisure time for these people.

Another study reported the experiences of two individuals with severe neuropalliative conditions whose leisure occupations were based around sensory stimulation to the proprioceptive and vestibular system and each of the five senses (visual, olfactory, gustatory, tactile and auditory). Both people experienced individualised casual leisure experience and both reported feeling satisfied with their leisure choices and use of leisure time (Fenech & Baker, 2008). The risk for these individuals, as is the case with many people who have ABI, is that their leisure activities can often focus on only one or two of the senses with television and/or music being predominant, and this program attempted to address this imbalance (Fenech & Baker, 2008).
Leisure education programs (LEP) have been demonstrated to be helpful for individuals following stroke. It is important to note the different demographics in these groups, especially in terms of age, when compared with participants of the TBI studies who tend to be much younger. Two randomised controlled trials in the UK evaluated the effectiveness of a leisure rehabilitation group versus conventional occupational therapy group after stroke. Participants in the leisure rehabilitation program had higher leisure scores as assessed on the Nottingham Leisure Questionnaire, than did subjects in the control group who received no intervention and subjects in the group receiving conventional occupational therapy. The authors concluded that leisure rehabilitation is an effective way of maintaining and increasing leisure participation after stroke (Drummond & Walker, 1995).

A home LEP was trialed in Canada for older adults who had retired and had had a stroke. The program supported participants to self-manage their leisure activities. It began with a leisure questionnaire that generated a broad picture of the leisure activities done before the stroke, those still pursued, and activities the clients wanted to begin. Interest, attitudes, frequency and motivation regarding leisure and perceived barriers were also evaluated. Results confirmed that the intervention was successful and had the desired effects of enhancing total and physical QOL (Nour et al., 2002). The researchers recommended that for this program to be maximally effective it should start during the active rehabilitation period in a day hospital.

A more recent Canadian randomised controlled trial set in the home and community, emphasised the effects of a LEP on participation in and satisfaction with leisure activities, as well as well-being and QOL after stroke. The program was divided into three components: leisure awareness, self-awareness and competency development, each of which was covered over 12 sessions. Results indicated the effectiveness of the
LEP for improving participation in leisure activities, improving satisfaction with leisure and reducing depression in people with stroke (Desrosiers et al., 2007).

Many people with spinal cord injury (SCI) experience similar personal and environmental problems as do those with ABI. These include unemployment and subsequent lack of finances, lack of motivation, and attitudinal and architectural barriers (Costilow et al., 1982) that deprive them of participation in a number of leisure activities. A study by Daniel and Manigandan (2005) attempted to improve QOL by improving leisure satisfaction in people with a SCI. In a clinical trial they assessed the effects of a leisure intervention program conducted in a rehabilitation department in India among people with a SCI. It was evident from the results that leisure intervention groups facilitated leisure satisfaction and improved QOL among people following an SCI. The researchers attributed the success of this program to group therapy, which in their opinion provided a supportive environment, facilitated interaction among peers, reduced feelings of isolation, alienation and helplessness, enhanced active coping and improved mood. According to the researchers, the group therapy was easy to implement, could easily be replicated and was cost effective.

Exploring leisure interventions that have been trialled for people with other acquired disabilities is helpful in determining what facilitates both leisure satisfaction and QOL in these groups. It demonstrates that LEPs do work across a variety of conditions. It also demonstrates that successful leisure pursuits can cover a wide variety of activities including LEPs, aquability and the more creative casual leisure experiences involving the use of coloured laser lighting, interactive projections, music and interactive drama.
2.7 Factors to consider with existing leisure rehabilitation approaches

This section describes some important factors which affect existing leisure rehabilitation approaches and are relevant to this study. These factors include rurality as a contextual issue, the disparity of leisure rehabilitation services which currently exists for people with an ABI and the concept of contextualized rehabilitation and goal setting as a marker for successful rehabilitation.

2.7.1 Rurality

Health outcomes generally tend to be poorer outside major cities. There are inter-regional differences in risk factors; for example, people from regional and remote areas tend to be more likely than their major cities counterparts to smoke and drink alcohol in harmful or hazardous quantities. Australian Institute of Health and Welfare (http://www.aihw.gov.au/rural-health-impact-of-rurality/) It is also likely that environmental issues such as more physically dangerous occupations and factors associated with driving longer distances at higher speeds play a part in elevating accident rates and related injury in country areas (Veitch, 2009).

Rurality has been associated with both positive and negative factors in the ABI literature. Living in a rural area has been linked to more openness to seeking social support and better quality of life following an ABI (Farmer, Clark, & Sherman, 2003). On the other hand, limited rehabilitation services along with limited work opportunities in rural areas make employment more difficult to achieve following a brain injury which generally leads to increased strain on the injured person and their family.
Leisure intervention groups for people with ABI

(Coetzer, Hayes, & Toit, 2002). No studies were found that specifically evaluated leisure programs for rural people with ABI.

2.7.2 Disparity of leisure rehabilitation services

Another factor to consider in existing leisure rehabilitation approaches is the disparity of services available to people with an ABI in Australia. The considerable variation in services and support offered to people who have sustained a brain injury, their families and carers, often depends on the circumstances surrounding how the brain injury occurred, the state they live in or had the accident in, whether they were working at the time of the accident and which insurer or agency, if any, accepts responsibility for funding the person’s rehabilitation program. Each state has its own services and agencies which vary considerably. Within any one state the services available to public and private patients often differ. An eligibility criterion for a NSW service which is part of the Brain Injury Rehabilitation Program (BIRP) is given in Appendix A as an example.

Each agency also has its own guidelines and procedures for what rehabilitation services will be approved. How each agency deals with rehabilitation in the area of recreation and leisure is often very different and based on different criteria. Some agencies will fund assistant care, membership fees and transport costs for clients to attend particular leisure activities as part of their rehabilitation, and some will not. For example, in NSW the Lifetime Care and Support Authority (LTCS) is considering the funding of leisure and recreation activities for LTCS participants. However at present the Authority will pay only what is deemed as “reasonable and necessary” treatment, rehabilitation and care services that result from the motor vehicle accident injury. This is decided on a “case by case” basis and means a client will get what the agency considers reasonable and necessary according to their criteria (LTCS, 2012).
People with a brain injury who are non-compensable may miss out altogether unless they can finance their own activities. The Productivity Commission’s report released on 10 August 2011 and the subsequent introduction and establishment of a National Disability Insurance Scheme (NDIS) should change the way that disability services are currently provided, but how it will change is yet to be seen.

Studies show the physical, cognitive and social importance of high quality, stimulating leisure activities in preventing degenerative diseases (Fratiglioni, Paillard-Borg, & Winblad, 2004) and the prevention and management of secondary health conditions resulting from a sedentary lifestyle (Blake & Batson, 2008). Post-acute rehabilitation programs for people with an ABI are relatively new and unexplored in terms of availability of recreational services and the therapeutic recreational methods presently employed in those settings (Fazio & Fralish, 1988). In practical terms, many funding bodies are still hesitant to approve leisure interventions as part of a rehabilitation program for people with an ABI despite the growing evidence that it would be beneficial to do so.

### 2.7.3 Contextualized rehabilitation and goal setting

This section sets the scene for this leisure program’s method of delivery. The recent shift towards a more collaborative context-sensitive rehabilitation and goal-directed therapy in a community context was a key feature of the delivery of this program, so warrants considered discussion.

The World Health Organisation (WHO, 2013) has defined rehabilitation of people with disabilities as:

- a process aimed at enabling them to reach and maintain their optimal physical, sensory, intellectual, psychological and social functional levels.
Rehabilitation provides disabled people with the tools they need to attain independence and self-determination.

Within traditional cognitive rehabilitation, the primary treatment goal has included the re-establishment of previously learned patterns of behaviour, the use of compensatory cognitive strategies, or the introduction of external systems or devices to compensate for impairments (Shanahan, McCallister, & Curtin, 2009). During recent years, however, there has been a shift towards a more collaborative context-sensitive approach to rehabilitation that aims to help individuals achieve functional objectives and participate in chosen activities (Ylvisaker et al., 2002). This context-sensitive rehabilitation focuses on helping the individual to achieve practical objectives in the real-world environment in comparison to more traditional cognitive rehabilitation that aimed for improvement or behaviour change by improving knowledge base and skills (Walker et al., 2005). Despite this emerging emphasis on client-centeredness and goal setting in the literature, only one study was found (Doig et al., 2009) that reported and contrasted the perspectives of clients, significant others and therapists on goal-directed therapy in a community context. According to the researchers who conducted this study:

Goals provide structure, which facilitates participation in rehabilitation despite the presence of barriers, including reduced motivation and self-awareness. A therapist-facilitated, structured, goal setting process in which the client, therapist, and significant others work in partnership can enhance the process of goal setting and goal-directed rehabilitation in a community rehabilitation context (Doig et al. 2009).
There is increasing evidence that goal setting can influence client motivation and participation in rehabilitation (Trombly, Radomski, & Davis, 1998). The approach therapists take in assisting clients to establish meaningful yet realistic client-centred goals is likely to have a strong bearing on therapy outcomes (Turner, Ownsworth, Cornwell, & Fleming, 2009). According to Malec (1999) goals can facilitate a client-centred approach to rehabilitation because they can be uniquely tailored to suit each person’s strengths and limitations. Goal-directed therapy requires the implementation of a goal-planning process that identifies client-centred goals (Malec, 1999). The importance of therapists working in community based rehabilitation settings developing goals with clients rather than imposing goals has been emphasised by Kuipers, Foster, Carlson and Moy (2004). According to Pollock (1993) a client-centred approach involving goals that are set by the client enables greater self-determination and control and enhances the person’s potential for active participation. Goals can also provide structure to facilitate participation in rehabilitation despite the presence of barriers that include reduced motivation and impaired self-awareness (Doig et al., 2009).

In their qualitative study, Doig et al. (2009) explored the clinical application of goal-directed therapy in a community-based rehabilitation setting. The intervention consisted of a 12-week goal-directed individualised occupational therapy community rehabilitation program. The perspectives of participants with TBI, their significant others and occupational therapists regarding their experiences of the program were described and studied. All the therapists indicated that goals evolved as circumstances changed or problems became clearer over time. The need to have the flexibility to adapt old goals or form new goals occurred in situations where the goal was too challenging.
when the person lost interest in the goal or when new problems emerged. In this program the use of participants’ goals to direct the content of the therapy programs resulted in overall satisfaction with progress on goals. Although factors such as poor motivation, impaired self-awareness and cognitive impairment were recognised as barriers to client-centred goal setting in this population it was concluded that goals can be a valuable tool in rehabilitation by providing structure to overcome some of those difficulties.

Presently there is much emphasis on return to work as a marker for successful rehabilitation, yet the numbers of those with moderate to severe TBI who return to stable employment remains low (Wise et al., 2010). The approach taken in the rehabilitation of individuals with an ABI may need reconsideration, with more emphasis being placed on leisure activities being included in a therapy program designed to promote reintegration into society and work (Bier et al., 2009; Wise et al., 2010). Using participation in purposeful goal-oriented leisure activities as a bridge to the greater demands of the workplace and providing opportunities to build confidence with goal-oriented projects along with social and communication skills may be more effective (Wise et al., 2010).

2.8 Research questions & hypothesis

The literature investigated in the previous chapter sets the scene for this thesis which reports on an investigation into the effects of a week-long leisure intervention, namely a Pushing the Boundaries program, for people with an ABI living in rural, regional and remote NSW. I wanted to explore the following questions:

Does participation in a Pushing the Boundaries program improve the leisure satisfaction, self-esteem and quality of life among persons with an ABI living in rural, regional and remote NSW, and, if so, are those changes sustained?
Leisure intervention groups for people with ABI

The hypothesis was that adults with medium to severe ABI who participated in a *Pushing the Boundaries* program at SWBIRS would show measurable positive change in levels of self-esteem, leisure satisfaction and QOL three months post program.

### 2.9 Summary

Studies show the physical, cognitive and social importance of high quality, stimulating leisure activities in preventing degenerative diseases (Fratiglioni, Paillard-Borg, & Winblad, 2004). Physical activity should be a key component of ongoing management of people with an ABI if they are going to remain as healthy as possible (Hasset & Mosely et al., 2009). Increased participation in leisure can offer the opportunity and social space for meaningful relationships to develop through shared friendships and meeting new people (Lee, McCormick, & Austin, 2001), all of which can improve social integration. There have been many links made in the literature between leisure activities and improved psychosocial outcomes for people with an ABI (Fines & Nichols, 1994; Thomas, 2004; Tinsley et al., 1993). Leisure, however, is often a neglected part in rehabilitation programs and therapeutic recreation is often still viewed as an expendable service (Bier, Dutil, & Couture, 2009).

Over the past decade there have been a variety of interventions used to promote leisure satisfaction and leisure participation and to improve QOL for people who have suffered an ABI. While education programs, outdoor experiential activities, recreational kayaking and tai chi programs all have a part to play in the rehabilitation process, there is need for more evidence regarding the effectiveness of these programs. Results suggest that most interventions were associated with improvement in a variety of outcome measures including leisure satisfaction, QOL and self-efficacy. However, most of the studies suffered from common methodological problems and there have been few randomised controlled trials in this field. With small sample sizes in the majority of the
studies, it is difficult to generalise the findings to other settings or to conclude that the changes experienced by participants were exclusively due to the programs. It is noteworthy that many of the papers recommended replication of their study on a larger scale. Many of the studies focus on the early transition phase and therefore do not capture how people’s experiences may change over an extended period of time.

Recovery in a broader sense may be impeded if the more usual goals of rehabilitation (i.e., mobility, independence in self-care activities and cognition) are concentrated on exclusively (Parker, Gladman, & Drummond, 2001). Individuals with ABI frequently experience changes in their ability to undertake their previous roles in society, including leisure and social interaction. There is much evidence to indicate that individuals with ABI have a significant decrease in leisure participation both during inpatient and outpatient rehabilitation (Fleming et al., 2011) and that age-appropriate and relevant leisure activities need to be addressed during rehabilitation to improve future outcomes in this domain. These ideas are supported by Wise et al. (2010) and Bier et al. (2009) who also suggest increased participation in leisure activities during rehabilitation. By supporting the development of physical and cognitive skills required in activities in which the individual wishes to engage after rehabilitation, it is thought that better outcomes can be achieved following discharge. However, this does not imply that the desired goal is to improve frequency of participation in leisure activity to pre-morbid levels. Rather the desired long-term outcome is leisure satisfaction (Fleming et al., 2011).

More research is required to better meet the needs of this population. However, it is clear that programs that facilitate leisure satisfaction and community integration are a key component of long-term rehabilitation for patients with TBI. Rigorous program evaluation is an essential aspect of service delivery (Douglas, Dyson, & Foreman, 2006)
and increased understanding of the personal effects of this intervention can only add to the continued development of evidence-based practice. The findings from such studies are of relevance to policy makers, researchers and practitioners who work with people who have an ABI. The results may also be of interest to survivors of an ABI and their caregivers.
Chapter 3

Methods

3.1 Study design

This project used a pre and post intervention design examining the changes in leisure participation, leisure satisfaction, self-esteem and QOL among ABI patients who had recently completed a week-long intensive leisure intervention program called *Pushing the Boundaries*. Three programs were run in the seven months from August 2010 to February 2011 and these are the focus of this study. The study was conducted at the South West Brain Injury Rehabilitation Service (SWBIRS) transitional living unit (TLU) in Albury, NSW.

Data were collected at three intervals for participants of the program. Changes in scores on a number of outcome measures were tested using Wilcoxon signed-rank tests to compare measurements at baseline with measurements taken at the completion of the week-long program within individuals. Baseline measurements were then compared with measurements taken three months post intervention to determine if the changes had been sustained.

3.2 Ethics

Ethics approval for this study was obtained from the Greater Southern Human Research Ethics Committee (HREC) in February 2010 (see Appendix B Ethics approval). In August 2011 the HREC approval period was extended until January 2014 to allow the conduct of further programs and collect more data. (HREC reference number: HREC/09/GSAHS/53; see Appendix C Ethics approval extended).
3.3 The setting for the intervention

The setting for the intervention was the South West Brain Injury Rehabilitation Service (SWBIRS) Transitional Living Unit (TLU), Albury, NSW. SWBIRS employs a wide range of specialist brain injury health professionals who work with individuals and families to identify specific needs for each client and develop an individualised plan in a community rehabilitation setting.

SWBIRS has its service base in Albury, NSW, Australia and a regional office at Wagga Wagga 128 kilometres from Albury. It services the central and western sectors of the Murrumbidgee Local Health District. This region covers an area of 166,000 square kilometres with a population of approximately 468,000, and extends from Barham Koondrook in the west, to the Great Dividing Range in the east, the Murray River in the south and West Wyalong in the north.

Figure 1.  Map of Murrumbidgee Local Health District, NSW Australia

SWBIRS services all communities in the region, including those that are rural and remote, through air and road travel, phone contact, and increasingly through
videoconferencing. In addition, being located on the Victorian border, SWBIRS services clients who are residents of north east Victoria and are referred and funded by the Transport Accident Commission (TAC) and Victorian Workcover. The transitional living unit at Albury enables people from anywhere in the region to live in and access intensive rehabilitation. This facility looks like a normal house on the street and is located across the road from SWBIRS’s offices.

3.4 The Leisure Intervention *Pushing the Boundaries*

The Adult Team at SWBIRS recognised an ongoing need within the population they service for direct leisure intervention as part of the rehabilitation and adjustment to injury process. SWBIRS provides no other formal program for clients transitioning into the community. Opportunities for support in planning and implementing leisure programs is often limited especially for clients returning to regional and remote areas of NSW where community programs are often nonexistent. Some clients receive a limited number of individualized outreach sessions with a therapist but because of limited resources, staffing and distances involved many do not. A leisure intervention program called *Pushing the Boundaries* was developed by the team and piloted in March, 2009. The program was an attempt to trial leisure intervention through groups rather than on an individual basis which had been prior practice. The week-long program was designed to provide clients with the opportunity to trial a range of leisure activities so that they could increase their leisure satisfaction within their own communities. The duration of one week was determined by constraints around the availability of the Transitional Living Unit (TLU) and also recommendations from the therapists suggesting one week to be the optimal time frame to achieve the aims of the program without causing the clients undue fatigue.
There has been little written in the literature in regards to leisure intervention and what is “standard intervention” in terms of rehabilitation after an acquired brain injury. The program was based on four components of Peterson and Gunn’s (1984) leisure education model i.e. leisure awareness, leisure resources, social interaction skills, and leisure activity skills. No literature reported on the impact of duration so 5 days was chosen due to a series of parameters including service-related constraints, the number of activities to trial, and fatigue issues which affect the majority of SWBIRS clients. The inclusion of social skills training into the program was deemed appropriate as the majority of clients have problems with maintaining friendships and socialisation following their brain injury and the literature supports this notion (Morton & Wehman, 1995, Callaway, Sloan & Winkler, 2005). Therefore the week also involved sessions on social communication and how to engage in conversation appropriately with the opportunity of practising these techniques daily.

Anecdotal evidence from staff deemed the program a success and, with some modifications, three similar programs were run in the seven-month period from August 2010 to February 2011 with four participants successfully completing each program. These three programs are the focus of this research project. This innovative program was held after inpatient rehabilitation was completed and was focused on recovery in a much broader and holistic sense.

The aim was that during the program each participant would a) participate in a minimum of six recreational activities, b) experience increased satisfaction with their leisure experiences c) improve confidence in social situations, c) experience improved self-esteem and e) make gains towards their individual social and recreation goals for when they returned home.
A leisure participation survey was designed by the SWBIRS team to gather information from the participants prior to them attending the program. The leisure activities chosen to trial throughout the week were influenced by the responses of the participants. Questions were asked around what leisure activities they currently participated in, what activities they would like to try, what activities were available in their local community and what obstacles they saw to their participation in leisure activities in their home area. The content of the intervention was developed around the needs and desires of the participants in order to make the intervention truly client-centred. Experience within the service along with literature searches on other leisure interventions influenced the final structure and content of the intervention.

Participants were grouped according to their age and the geographical location of their home for the purposes of making programs as relevant as possible. Some participants travelled up to 450 km to attend the program. The residential week was designed to provide clients with the opportunity to sample a range of sporting and recreation activities so that they could increase their participation in their own community. With the assistance of Centre Active Recreation Network (CARN) based in North East Victoria, a variety of activities was planned for each week. Activities included in the programs were sailing, clay target shooting, bushwalking, Tai Chi, fishing, pool, tennis, table tennis, wii nintendo, volleyball, netball, soccer games, movies, socialising and eating out. During the week there were numerous opportunities to discuss as a group what is appropriate conversation and how people get what they want in an appropriate way. Thus the week was a mixture of recreation activities, where the group tried different activities, and interesting discussion about communicating with others.
The program provided a supportive and structured environment in which to develop achievable leisure goals. Time was allocated for participants to review their own goals at either the start or finish of every day. A member of staff or key person was allocated to each participant prior to each program, and time was allocated within the week for participants to meet with this person and make enquiries into recreational activities within their own local communities. Consistent with SWBIRS contextualised rehab approach, clients were asked to think of one to three leisure goals for the week and an additional three leisure goals for when they went home. Clients’ interests, strengths, likes and options in terms of leisure activities were discussed with their key person throughout the week. Using this information client Goal Maps were utilized to structure the client’s goals into SMART goals, broken down into steps the client needed to take in order to achieve the goal. They were encouraged to sit down daily with their key person and plan ahead for implementing the program at home. These debriefing, goal setting and planning sessions remained consistent over all three programs. Minor modifications to outdoor activities were necessary in just one of the programs due to wet weather; however all three programs were relatively consistent overall.

Over the three month period following the leisure intervention, participants were contacted at regular intervals by their key worker, to discuss the progress made with their goals. The first call was made within two weeks of the residential program finishing and the second call within the next two weeks. Thereafter contact was made 1-2 times monthly. Any difficulties clients were having in undertaking the tasks associated with achieving their goals were discussed. If the key person was unavailable to make the follow-up phone contact, one of the outreach workers made the call for them. The majority of the participants (9) had 4 follow-up calls over the 3-month period. Three participants required greater than 4 calls. Duration of the follow-up phone
calls ranged from 5–15 mins each. Follow up phone calls were minimal and focussed on the subject of clients goals.

3.5 Participants

Clients of the South West Brain Injury Rehabilitation Service are adults aged between 18 and 60 years who have suffered a sudden onset ABI either traumatic or non-traumatic (i.e. due to a motor vehicle accident, assault, stroke, work-related injury, fall, tumour or meningitis) that has resulted in either mild, moderate or severe ABI. Exclusion criteria for the service include any serious co-morbid physical or psychiatric illness and drug and alcohol problems currently not under control.

Participants of the leisure intervention program named “Pushing the Boundaries” were selected as follows: Invites were sent to the most recent 100 clients of the service’s Adult team. These dated back to clients admitted to the service in January 2007. Clients who failed to respond to the invite within two weeks received a telephone call from a member of the SWBIRS team inviting them to participate in the program. Inclusion criteria for the program were:

1) Current or previous client of SWBIRS
2) Have completed their inpatient rehabilitation program i.e. currently not receiving centre-based rehabilitation services from SWBIRS
3) Have the cognitive capacity to take on new skills

Involvement in the research was entirely voluntary, and verbal and written information on the research and risks involved was distributed individually by the researcher to each participant prior to the program. Cognitive capacity to consent was not an issue. Program participants were all self-selected adult volunteers who were capable of filling out forms independently or with minor assistance (e.g. vision
improvement) and inclusion criteria for the program implied a certain level of cognitive capacity”.

Of the 100 most recent clients posted an invitation to participate in both the leisure program and the research project, 13 were enrolled into the program. All of these people gave their informed consent to be involved in the research component. Twelve participants completed the program and one withdrew from both the program and the research due to illness. The apparently low response rate for those with mild TBI was not investigated. However, information gained during follow-up phone calls made to past clients who had failed to respond to the invitation suggest that those with a mild TBI had gone on with their lives and were back in the workforce, returned to previous leisure activities, maintaining friendships and, in general, satisfied with their lives.

3.6 Data collection

Clinical data used in this research were extracted from the medical records of participants, all of whom had given written consent for inclusion in the study. To determine if the LEP resulted in increased satisfaction with leisure participation, along with increased self-esteem and QOL, three quantitative measures were used. Participants completed a Leisure Satisfaction Scale (LSS), World Health Organisation Quality of Life – Bref (WHOQOL-BREF) and Rosenberg Self-Esteem Scale (RSES) by individual interview with the researcher prior to each program, immediately following, and three months post program as part of SWBIRS normal clinical practice.

Individual goals generated throughout the week-long program along with comments on goal attainment’s and program in general were also investigated in this study. Participants were interviewed at the three-month follow-up and asked, if they felt
they had achieved the leisure goals they had set themselves. The data collection schedule is shown below (Table 2).

Table 2

<table>
<thead>
<tr>
<th>Day 1 of intervention</th>
<th>Day 5 of intervention</th>
<th>Three months post intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>LPS</td>
<td></td>
<td>Individual interview</td>
</tr>
<tr>
<td>LSS</td>
<td>LSS</td>
<td>LSS</td>
</tr>
<tr>
<td>WHOQOL-BREF</td>
<td>WHOQOL-BREF</td>
<td>WHOQOL-BREF</td>
</tr>
<tr>
<td>RSE</td>
<td>RSE</td>
<td>RSE</td>
</tr>
</tbody>
</table>

Abbreviations

LPS- Leisure participation survey
LSS- Leisure Satisfaction Scale
WHOQOL The World Health Organisation Quality of Life BREF
RSE- Rosenberg Self-Esteem Scale

3.7 Instruments

The Leisure participation survey (LPS) was designed by the SWBIRS team to gather information from the participants prior to them attending the program. The leisure activities chosen to trial throughout the week were influenced by the responses of the participants. The LPS (Appendix D) gathered information on what leisure activities participants currently undertook, what activities they would like to try, what activities were available in their local community and what obstacles they saw to their participation in leisure activities in their area.

Leisure Satisfaction Scale (LSS). Leisure satisfaction was measured with the LSS. The LSS (Appendix E), consisting of 24 questions, was developed by Beard and Ragheb (1980). It is designed to measure the extent to which individuals perceive that certain personal needs are met or satisfied through leisure activities. The scale ranges
Leisure intervention groups for people with ABI

from 0 – 120, with 120 indicating the highest score possible. The instrument has been validated and found to be reliable (Lysyk et al., 2002).

**World Health Organisation Quality of Life – Bref (WHOQOL-BREF)** (Appendix F) is a shorter version of the original instrument and has been developed to provide a short QOL assessment comprising 26 items that measure the broad domains of 1) physical health, 2) psychological health, 3) social relationships and 4) environment. The scale ranges from 0 – 130, with 130 indicating the highest score possible. It has been validated and is reported as being a reliable tool (World Health Organization, 2011).

**Rosenburg Self-Esteem Scale (RSES)** (Appendix G) contains a total of 10 questions and is a widely used self-esteem measure in social science research. The scale ranges from 0 – 30, with 30 indicating the highest score possible. It demonstrates concurrent, predictive and construct validity and correlates in the predicted direction with measures of depression and anxiety (Rosenberg, 1979).

**Semi-structured interviews.** Individual goals generated throughout the week-long program were also investigated in this study. Brief semi-structured interviews conducted with participants at the three month follow-up were used to gather information about whether their goals had been achieved. Participants were asked if they felt they had achieved the leisure goals they had set themselves, with a yes/no reply. They were also invited to give unstructured comments about their goal attainments and the program in general (see Appendix H).

### 3.8 Data analysis

All statistical analyses were performed using the Instat Plus Package (University of Reading, 2006). Changes in scores on the LSS, WHOQOL-BREF and RSES were tested using Wilcoxon signed-rank tests to compare measurements at baseline with
measurements taken at the completion of the program within individuals. Baseline measurements were then compared with measurements taken three months post intervention to determine if the changes had been sustained.

The Wilcoxin signed-rank test is a non-parametric statistical hypothesis test used when comparing two related samples, matched samples, or repeated measurements on a single sample to assess whether their populations mean ranks differ; i.e. it is a paired difference test (“Wilcoxin signed-rank test”, 2013). On this occasion it was used in preference to the paired t-test because it is a robust and efficient test and the sample size was small.

Other outcome measures used were the individual goals generated by clients during the intervention. Brief semi-structured interviews were conducted with participants at the three month follow-up to gather information about whether their goals had been achieved. Participants were asked if they felt they had achieved the leisure goals they had set themselves, with a yes/no reply. There was no thematic analysis of this data as the replies were either a yes or a no. Participants were also invited to give unstructured comments about their goal attainments and the program in general and these comments were grouped into themes and have been included throughout the results and discussion sections of this thesis.
Chapter 4 Results

4.1 Participant characteristics

General demographic data were extracted from the patients’ medical records, together with each participant’s individual goals that were generated during the intervention program. The results from the 12 participants who completed the program are reported here. Baseline data from the participant who withdrew from the program were not included in the analysis.

Characteristics of the participants are presented in Table 3. The mean age of the clients was 36 years (range 19-49 years), and all of them had sustained a medium to severe ABI. The majority of participants were male (8 men and 4 women) and educated to at least secondary school. Time since their ABI for the majority of the participants was greater than 2 years and for the majority of participants (10/12) the cause was trauma. All 12 participants were either employed or studying full-time prior to their ABI. At the time of baseline data collection 11 were unemployed and one was self-employed part-time.

Participants suffered a variety of physical problems, including significant balance and mobility issues, hemiplegia, chronic pain, fatigue and speech problems. Two participants required stand-by assistance while mobilising in the community, while the remainder of the participants were independently mobile.
Table 3

Demographic Information for Participants of Pushing the Boundaries

<table>
<thead>
<tr>
<th>Participant demographics</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean age in years (range)</td>
<td>36 (19-49)</td>
</tr>
<tr>
<td>Sex</td>
<td>8 Males, 4 Females</td>
</tr>
<tr>
<td>Marital status</td>
<td>8 Unmarried, 4 Married</td>
</tr>
<tr>
<td>Time since injury</td>
<td></td>
</tr>
<tr>
<td>&lt; 12 months</td>
<td>1</td>
</tr>
<tr>
<td>12 – 24 months</td>
<td>4</td>
</tr>
<tr>
<td>24 months – 48 months</td>
<td>7</td>
</tr>
<tr>
<td>Cause of injury</td>
<td></td>
</tr>
<tr>
<td>Traumatic brain injury</td>
<td>10</td>
</tr>
<tr>
<td>Non traumatic ABI</td>
<td>2</td>
</tr>
<tr>
<td>Residence (RRMA Classification)</td>
<td></td>
</tr>
<tr>
<td>Large regional centre</td>
<td>3</td>
</tr>
<tr>
<td>Rural/remote centre</td>
<td>9</td>
</tr>
</tbody>
</table>

4.2 Individual goal attainment

The efficacy of the program can be considered in terms of the number of individual goals that were achieved at the end of the three-month period. Participants were asked to identify individual leisure goals throughout the week-long program. Some participants set themselves relatively indistinct goals such as “to try a new leisure activity in my area” while others set themselves multiple and quite complex goals. Participants’ goal achievements were subjectively determined by the individual participants at the three month follow-up session. Of the 27 goals specified during the week-long program, 22 were reported to have been achieved three months post intervention, as shown in Table 4. Four of the participants also reported that they had developed new goals when they got home and that they were now participating in leisure activities that were more meaningful to them than were their original goal. This
was not entirely unexpected as it is a well-recognised part of the process of healing and adjustment to injury that occasionally goals need to be altered and new goals will emerge. Part of the reason for this is that frequently the person does not know what is involved, what skills they have and what is required until they try something out. There was no obvious trend happening with goal attainment. Links between goal achievement and rurality were not explored.

Table 4

Goals Specified Throughout the Pushing the Boundaries Program and the Participants Subjective Rating of Goal Achievement 3 Months Post Intervention

<table>
<thead>
<tr>
<th>Goal</th>
<th>No. specified</th>
<th>Activities pursued</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>New Activities</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>To try a new leisure activity in my area</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>To get fit</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Identify leisure activities that work with my daily schedule</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Achieve better balance between work and leisure</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Start soccer training</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Play a game of golf with my Pop</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Play ten pin bowling once per fortnight</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Play pool at the club each week</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Take up Zumba dancing</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Start Tai Chi</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>To investigate what is needed to get a pilot’s license</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td><strong>Increasing previous activities</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Play golf regularly</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Go fishing regularly</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Return to playing social netball</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Return to playing cricket</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Get involved in coaching the Under 12 cricket team</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>To do more horse riding</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>To do more bike riding</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Attend the gym regularly</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Investigate the possibility of getting a personal trainer</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>27</strong></td>
<td><strong>22</strong></td>
</tr>
</tbody>
</table>
4.3 Impact on self-esteem, leisure satisfaction and quality of life

In this section, changes in participants’ LSS, WHOQOL and RSES, pre and post intervention are considered. Table 5 shows the baseline and post intervention scores on the LSS, WHO QOL-BREF and RSES.

Table 5

<table>
<thead>
<tr>
<th>Leisure Satisfaction, Quality of Life and Self-Esteem Scores Before and Immediately After Completing a Pushing the Boundaries Program</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
<tr>
<td>Leisure Satisfaction Scale</td>
</tr>
<tr>
<td>WHOQOL-Bref</td>
</tr>
<tr>
<td>Physical</td>
</tr>
<tr>
<td>Psychological</td>
</tr>
<tr>
<td>Social relationships</td>
</tr>
<tr>
<td>Environment</td>
</tr>
<tr>
<td>Rosenberg Self-Esteem Scale</td>
</tr>
</tbody>
</table>

* Indicates significant finding with P < 0.05.

There was a significant improvement in the LSS and Domain 4 (Environment) of the WHOQOL– BREF following the intervention. Changes made from pre to post intervention for the physical and social relationship domain of the WHOQOL–BREF were approaching significance. There was some change depicting a positive trend in self-esteem and the psychological domain of the WHOQOL–BREF, although those changes were not statistically significant from baseline to post intervention.

It is noteworthy that this tendency for improvement in all of the outcome measures made throughout the week continued over time, so much so that from baseline to three months after the intervention there was a significant improvement in all the outcome measures. Table 6 shows the baseline and 3 month post intervention scores for
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the LSS, WHO QOL-BREF and RSES. A comparison of the changes in scores before and 3 months after the intervention depicts a significant positive trend in the LSS, all domains of the WHOQOL-BREF (physical, psychological, social relationships, environment) and the RSES. This indicates significant increases in the subjects’ leisure satisfaction, QOL and self-esteem.

Table 6

Leisure Satisfaction, Quality of Life and Self-Esteem Scores Before and 3 Months Post Completing a Pushing the Boundaries Program

<table>
<thead>
<tr>
<th></th>
<th>Pre-intervention Median (IQR)</th>
<th>Post-intervention Median (IQR)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Leisure Satisfaction Scale</td>
<td>70.5 (60-82)</td>
<td>101 (97-110)</td>
<td>0.002*</td>
</tr>
<tr>
<td>WHOQOL-Bref</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Physical</td>
<td>25 (19-28)</td>
<td>29 (21-30)</td>
<td>0.008*</td>
</tr>
<tr>
<td>- Psychological</td>
<td>18 (16-21)</td>
<td>22 (21-23)</td>
<td>0.02*</td>
</tr>
<tr>
<td>- Social relationships</td>
<td>9 (7-12)</td>
<td>12 (10-14)</td>
<td>0.02*</td>
</tr>
<tr>
<td>- Environment</td>
<td>27 (21-35)</td>
<td>33 (31-37)</td>
<td>0.01*</td>
</tr>
<tr>
<td>Rosenberg Self-esteem Scale</td>
<td>15 (14-19)</td>
<td>20.5 (17-24)</td>
<td>0.03*</td>
</tr>
</tbody>
</table>

* indicates significant finding with P<0.05

4.4 Barriers to participation

A review of the leisure participation surveys completed prior to the intervention revealed that four types of barriers to participation were operating within the sample. These included access, physical, psychological and financial barriers. These are summarised in Table 7.

Transportation difficulties were reported as being the most common barrier to participants’ involvement in leisure activities, along with other issues such as pain and fatigue. Other major barriers included physical health problems such as balance, deconditioning and weakness; access issues such as distance from the activity and not
having anyone to go with; and psychological barriers including lack of motivation, social anxiety, disorganisation and erratic sleep patterns. These issues and their longer-term ramifications will be discussed in the following chapter in relation to participants’ experiences and the literature.

Table 7

**Barriers to Participation in Leisure Activities Reported by Pushing the Boundaries Participants at Program Commencement**

Barriers to participation were identified as:

- **Access**
  - transportation (5)
  - geographical isolation (2)
  - don’t have anyone to go to the activity with

- **physical problems**
  - Pain (back, neck, hand, elbow, shoulder, legs)(4)
  - fatigue/deconditioning (4)
  - balance problems (3)
  - weakness (3)
  - mobility problems
  - eyesight problems
  - I have a brain injury – no contact sport allowed for 12 months

- **psychological**
  - lack of motivation (2)
  - lack of confidence in a crowd (2)
  - disorganisation
  - erratic sleep patterns

- lack of finance (2)
4.5 Participants’ Comments

A summary of the participants’ comments noted at the three month post intervention visit revealed a very positive trend. Some participants commented on specific activities:

I wouldn’t have thought about playing golf without attending the program. The program was an eye-opener. It made things more realistic. Made things more clear about what’s available and showed me the issues that have arisen that I didn’t see in the first place.

and

Yes I have achieved my goal of fixing up my pushbike and riding it and playing lawn bowls each Thursday and Sunday. The week made a big difference.

Other participants focused on a more global increase in confidence and willingness to undertake new tasks:

My goal was to try a new activity in my area. I now go to the picnic races weekly, play lawn bowls every second week and I hope to start water-skiing again soon.

and

My goal was to get fit and have a better balance between work and leisure. I have been to the Conservatorium of Music at a nearby town, got a list of events and have attended several events since. I am now walking regularly on the wetlands and am reading more.
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Reaching outside their comfort zones, facing fears and doubts also contributed to many regaining confidence in themselves and improving self-esteem along with a new sense of self:

I have achieved my goal of going fishing once per fortnight and attend football training with my 12 year old son each week and assist with football training of the team. I wouldn’t have done either of these activities if I hadn’t done the program. The program gave me the motivation and confidence that I could do it. It pushed me through the pain barrier. The week certainly made a difference to me.

and

I lost confidence with the sailing but gained confidence when I tried new things such as golf, watching movies and going out socially again.

Over the week, participants talked about increased confidence after trialing most of the activities and their comments three months post intervention confirmed this:

My goal was to try a new sport. I have played several games of pool now and are more confident that I will continue to play now.

and

The program gave me the motivation and confidence that I could do it.

The development of social skills and opportunity to establish new friendships was very much evident in all three groups. Participants’ comments three month post program confirm this:
The program made me realize that I am a bit isolated in my situation and that I actually do like being with other people. I felt very at ease with all the people in the group.

I am also visiting friends that I have not visited since the accident over two years ago. I had been avoiding people (people annoyed me) but since the program I have started visiting people again and going for drives, going shopping and going out for counter lunches. The week has made a big difference in my life.

The feedback on the program itself was positive:

The week has made a big difference in my life. I didn’t realise it at the time and I was tired during the week but when I got home I could relax better and it has really helped me. I think you need to run these weeks pretty often.

Participant comments three months post program confirm that many of the barriers still remained following the program:

I have achieved my goal which was playing a game of golf with my pop, and I am still working on the goal of playing golf on a regular basis. Finance and transport are still a problem.
There were no negative comments or suggestions for change in the comments collected three months post program. A complete list of the comments can be found in Appendix H.
Chapter 5

Discussion

This research was conducted to gain insight into the experiences of adults with an ABI who live in rural, regional and remote NSW, and who have participated in a leisure intervention program called *Pushing the Boundaries*. The participants in this study align moderately well with the known profile of people with ABI in Australia in terms of age and gender. However, there is a higher percentage of TBI represented in this study. The leading cause of ABI in Australia is stroke (Brain Injury Australia, 2011) and 10/12 of the sample in this study had received their injury from trauma.

The preceding chapter presented the results from the study which indicate that adults with an ABI participating in a *Pushing the Boundaries* program experience improvements in psychological well-being, in particular leisure satisfaction, self-esteem and QOL three months post program. The discussion focusses on the long term results because the purpose of this program was to develop in people, skills that they could take away from the program that would enable them to participate in leisure activities long term in their own communities. The three month follow up determined the sustainability of the skills learnt.

There are clearly indications of continued impact of learning for these people, and the demonstrated continued improvement in outcome measures was indeed an important finding. With only 12 participants and no control group, power is an obvious concern for this study. This makes the significant findings even more important. These results add to an increasing body of evidence indicating that participation in leisure intervention programs can have several positive effects on leisure satisfaction, QOL and

In this chapter I will discuss and interpret these results in the context of the hypothesis and research questions. The chapter is organised into ten sections: (1) Contextualised rehabilitation and goal setting, (2) Exploring self-identity to make leisure occupation more meaningful, (3) Building empowerment following an ABI, (4) Addressing psycho-social problems and community integration, (5) Other benefits of leisure participation, (6) Overcoming barriers to leisure participation, (7) The question of rurality, (8) Group therapy, (9) Features of an effective leisure intervention program, and finally, limitations and strengths of this study along with directions for future research will also be discussed (10).

5.1 Contextualised rehabilitation and goal setting

Consideration also needs to be given to contextual issues. If you give people the skills but they cannot take it further because of contextual issues such as accessibility, community, culture etc. then they cannot benefit from the experience. Although the program was run for groups of people, at the individual level within the program activities, goals were always adapted to the individual participant’s known context.

The program was associated with the achievement of approximately 70% of the participants’ identified goals. However, evaluating the number of goals achieved should be considered an estimate only, as the goal achievement was self-determined by the participants, and although many of the goals were objective in nature (e.g., playing ten pin bowling once per fortnight), many of the goals changed and became more subjective over time. No data were formally collected about this it was purely an observation by the researcher. These findings suggest that the learning and skill development that was
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initiated throughout the week-long residential program continued over the three month period following the intervention. This is particularly impressive given that many participants were going home to rural and remote locations up to 450 kilometers away and were still returning strong results at the three month follow-up.

There is increasing evidence that goal setting influences client motivation and participation in rehabilitation (Trombly, Radomski, & Davis, 1998). For several years now SWBIRS has made a conscious effort to adopt a more collaborative context-sensitive approach to rehabilitation as described by Ylvisaker et al. (2002). This context-sensitive rehabilitation is more about helping the individual to achieve practical objectives in the real-world environment in comparison to more traditional cognitive rehabilitation that aims for improvement or behaviour change by improving knowledge base and skills (Walker et al., 2005). There was a real emphasis on the goal planning process and the development of client-centred goals throughout the Pushing the Boundaries program. There was daily assistance from therapists in establishing meaningful yet realistic client-centred goals for when participants went home to their own communities. This goal setting process involved some degree of problem solving, organisation and planning along the way. Participants’ goals quite often changed throughout the week as they explored the options open to them and became more aware of their own capabilities. This was not surprising as the link between difficulties with impaired self-awareness after ABI and difficulties with setting realistic goals is well known (Flemming & Strong, 1995).

The findings of this study suggest that the program provided a framework and structure in which to develop and work on client-centred leisure and social goals within a supportive group environment. It has been suggested that having a structured plan to guide activities can be particularly valuable for a person who has executive problems
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such as poor planning skills (Doig et al., 2009). The following strategies taken throughout the week may also have contributed to the success of the program. These include:

1) the value in providing daily support with setting realistic goals (and remembering/documenting them)
2) an increase in motivation provided by the goal setting process itself
3) the opportunity to trial a range of leisure activities within a group setting
4) provision of daily sessions with a key person (therapist) to discuss performance in activities and plan ahead for the future
5) facility for brainstorming common difficulties and barriers to participation individually and in a group
6) building of rapport over the week between participant and therapist and also between participants themselves.

It is not possible to estimate how much or how little was contributed by each of the above factors, or whether it was the unique combination of just a few of these factors. However, it is reasonable to surmise that having a plan to guide activities when participants went home, plus phone contact from therapists, assisted participants in achieving their goals. The additional motivation provided by other participants of the group is something that was not measured in this study but may have been a contributing factor. These results suggest that this program provided a unique model to assist people with an ABI to develop and work on tangible leisure goals within a real-world context.
5.2 Exploring self-identity to make leisure occupation more meaningful

For a leisure occupation to be truly meaningful it should include opportunities for achievement, purpose and meaning for the individual, as well as exploring self-identity (Fenech & Baker, 2008) which it appears this intervention did. The week allowed participants to trial a range of activities, some of which they had never tried before and had not thought of. If a participant felt the experience might be too risky physically, psychologically or emotionally, the participant had the responsibility for letting their key person know that they preferred not to participate in that specific experience. Trialing a number of leisure activities allowed participants to experience each activity and decide whether they liked or disliked it and whether it was a realistic and achievable activity for them to become involved in. It was very much an exercise in self-awareness for many participants as they learnt to overcome difficulties in a certain task, for example holding a golf club or pool cue, or whether they decided that activity was just not for them.

For those who have experienced trauma the comfort zone from which they operate often becomes smaller and there is less trust of themselves and their abilities (Lemmon, 1996). Similar to many of the outdoor challenge programs, one of the goals of the Pushing the Boundaries program was to create a safe and supportive environment in which the participants could push the outer limits of their comfort zones and explore the various barriers that may have arisen as a result of their brain injury. There was time allocated daily for participants to catch up with their key person in an opportunity to discuss how they had gone in the various activities of the day and build a greater awareness of their own strengths and difficulties. The use of challenge by choice can be a significant factor in helping a person with ABI in regaining a sense of control in their
lives (Lemmon, 1999). Successful completion of an activity with some degree of perceived risk by the participant can have a significant positive effect on self-esteem (Lemmon, 1999) which appears to be the case in this program. Over the week, participants talked about increased confidence after trialing many of the activities and participants’ comments three months post intervention confirmed this:

The program gave me the motivation and confidence that I could do it. It pushed me through the pain barrier.

The *Pushing the Boundaries* program increased participants’ leisure skills and knowledge of community resources, which has been demonstrated to increase self-confidence and leisure participation and, in turn, increase leisure satisfaction (Prvu, Navar, Yaffe, & Hagar, 1999). It has been suggested that self-efficacy, i.e., the measure of the belief in one’s own ability to complete tasks and reach goals (Ormrod, 2006), may play an important role in this process (Wise et al., 2010).

People frequently report a feeling of disempowerment following a brain injury. They report feeling they have no control over their own minds, bodies and emotions and that they are at the mercy of a number of systems, such as the medical, legal and insurance systems, over which they feel they have no control (Lemmon, 1996). Choosing whether or not to accept a challenge and participate in a specific activity, or decline the experience, and taking responsibility for the decision can be a step towards regaining a sense of control in one's life (Lemmon, 1996).

Comments from *Pushing the Boundaries* participants are illustrative of the impact this program has had on them. Reaching outside their comfort zones, and facing
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fears and doubts, contributed to many regaining confidence in themselves and improving self-esteem along with a new sense of self.

I lost confidence with the sailing but gained confidence when I tried new things such as golf, watching movies and going out socially again.

5.3 Addressing psychosocial problems and community integration

Psychosocial problems such as decreased social contact, loneliness and depression, which can remain persistent long-term problems after a brain injury, are often the most significant concern of family members, and continue to be a major challenge for improving community re-entry (Morton & Wehman, 1995). The findings of this study suggest that the program provided a framework and structure in which to develop and work on client-centred leisure and social goals within a supportive group environment. The results show that participation in the program has resulted in significant improvements in leisure satisfaction, self-esteem and quality of life for its participants. Links between social participation and improved psychosocial outcome similar to those described by the participants of this study have been reported in the literature (Douglas, Dyson, & Foreman, 2006; Douglas, & Spellacy, 2000). The current study’s findings add to this literature by providing evidence for the notion that programs that successfully facilitate regular involvement in activities and provide opportunities for social engagement will promote improved leisure satisfaction, self-esteem and quality of life outcomes, for people with medium to severe brain injury. Rehabilitation services that can successfully increase leisure satisfaction and QOL are likely to reduce the social burden associated with severe ABI and facilitate the restoration of the QOL of
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survivor, one of the fundamental aims of community-based ABI rehabilitation (Thomas, 2004). Facilitating leisure participation should start as early as possible in order for the individual to start redefining a sense of self, roles and goals, and to avoid occupational deprivation (Fenech, Shaw, & Fisher, 2012).

As discussed in the literature review, individuals frequently become less vocationally active after an ABI and voluntary engagement in social activity often becomes more important to the person (Brown, Wayne, Gordon, &, Spielman, 2003). The majority of the participants in this study reported that they had been unable to establish new leisure activities prior to the program. During the intervention there was opportunity to document and discuss the various barriers to participation both individually with their key person and in a group.

As discussed in Chapter 2, Morton and Wehman (1995) described four primary themes around the psychosocial and emotional sequelae of individuals with traumatic brain injury (TBI). The first theme describes a population group that is at high risk for a significant decrease in their friendships and social support. The second theme concerns the lack of opportunity for establishing new social contacts and friends. The third theme relates to a decrease in leisure participation for people with a TBI, and the fourth theme is concerned with the high levels of anxiety and depression that people with a severe TBI can experience. The *Pushing the Boundaries* program attempted to address the four themes described by Morton and Wehman (1995) in the following ways:

a) Increasing participants’ social and communication skills, along with their confidence in social situations, contributed to an improvement in their ability to form friendships and social supports

b) By participants becoming more involved in their communities there is increased opportunity for establishing new social contacts and friendships
c) The program increased participants’ involvement in leisure activities in their own communities

d) By increasing leisure participation in their communities, there is increased opportunity for friendships, building confidence and redefining a sense of one’s self.

The program resulted in an improvement in participants’ leisure satisfaction, self-esteem and QOL, and it is reasonable to surmise that it may have been due to some of the above factors. It was evident in the groups that participation in leisure activities over the week gave the opportunity and social space for friendships and meaningful relationships to develop, although no data were collected to confirm this. These friendships were still continuing three months post intervention with several reports of group members driving long distances regularly to meet with each other and socialise. It is a possible that this research has captured the afterglow of having made new peer friends in a fun setting and that it is not actually indicative of increased leisure engagement that is sustainable in the long term. A longer term study would likely determine the sustainability of such outcomes.

The many definitions of community integration often talk about the resumption of valued social roles and the facilitation of social access. Some describe community integration as more than just a physical presence and the resumption of social roles. They believe it should also ideally include ongoing meaningful relationships of mutuality and reciprocity (Duck, 1994) that are formed through the development of shared phenomena (Younghill, McCormick, & Austin, 2001). Duck’s (1994) theory is based on the notion that ideally community integration should include ongoing meaningful relationships of mutuality and reciprocity that are formed through the development of shared phenomena. Duck’s social relationships formation model
describes a process that starts when two individuals share a common experience and, from this a *mutuality of understanding* may follow, thereby creating a mutual *frame of reference*. Through continued interaction, the two people may reach another level where they begin to recognise *equivalence of evaluation* that is shared around the common experience that, finally, may then expand beyond a single common experience to other unrelated domains leading to a *sharing of meaning* (Duck, 1994). Lee, McCormick and Austin (2001) argue that most leisure activities have the potential for social interaction, and, with joint participation in an activity, there is often the opportunity for two individuals to create mutual interests that may trigger a relationship.

The development of social skills and opportunity to establish new friendships was very much evident in all three groups. There was a lot of opportunity for social interaction before, during and after most of the activities. Sharing a common experience throughout the day and the discussions that ensued was seen as a real trigger for bonding to develop between individuals within the group and there were indeed friendships formed. There were numerous occasions throughout the week where discussions were shared around common experiences, later expanded from the common experiences to other unrelated topics where mutuality of understanding was evident. Improved confidence in social situations possibly also played a part in this. Participants’ comments three months post program confirm this:

I am also visiting friends that I have not visited since the accident over two years ago. I had been avoiding people (people annoyed me) but since the program I have started visiting people again and going for drives, going shopping and going out for counter lunches. The week has made a big difference in my life.
In summary, it is well documented that individuals who experience ABI are at high risk for a significant decrease in their friendships and social support. It is also apparent that this reduction in social contact is a chronic problem that often results in prolonged loneliness and social isolation (Morton & Wehman, 1995). Therefore it is important that techniques and programs are developed to counteract these problems. The relationship between decreased leisure activities, reduction in friendships, loneliness and depression is unclear and needs clarifying, and many are calling for specific research in this area (Morton & Wehman, 1995). Links between social participation and improved psychosocial outcome similar to those described by the participants of this study have been reported by other researchers (Douglas, Dyson, & Foreman, 2006; Douglas, & Spellacy, 2000) and these findings add further to this literature. This study provides further justification for rehabilitation programs to focus on these psychosocial issues by developing programs that facilitate regular involvement in leisure activities and provide opportunities for social engagement.

5.4 Other benefits of leisure participation

The quantitative results and participants’ comments three months post intervention indicate that participants were more physically active three months following the intervention than at the start of the intervention however this was not measured or quantified. Improvements made on the Leisure Satisfaction Scale over the three month period following the intervention suggest that participants felt that their general needs were being satisfied through leisure to a greater extent than prior to the intervention. The results suggest that during the week-long program some of the physical, cognitive and psychological barriers preventing participation in leisure activities were addressed. The results may indicate an increase in participants’ confidence. Regardless, the results suggest that physical activity should be a key
component of the ongoing management of people with an ABI if they are going to remain as healthy as possible (Hassett et al., 2009) and for this particular group of people the intervention resulted in an increase in physical activity, social engagement and improved QOL.

There are many reasons why people are less physically active following an ABI. These include physical, cognitive and psychological deficits along with environmental and societal barriers (Hassett et al., 2009). The importance of an active lifestyle following an ABI is increasingly being recognised for its benefits to QOL and the prevention and management of secondary health conditions resulting from a sedentary lifestyle (Blake & Batson, 2008). Leisure also assists people in overcoming difficulties, possibly by buffering the effects of stress (Iwasaki, Zuzanek, & Mannell, 2001) and in adults with ABI has been shown to increase self-confidence and promote feelings of well-being (Prvu, Navar, Yaffe, & Hagar, 1999). These benefits were all evident in each group of participants.

5.5 Overcoming barriers to leisure participation

Identifying barriers for each group of participants enabled discussions, both individually and within the group, about the barriers, along with suggestions for overcoming them. Transportation was the most commonly reported barrier to participants’ involvement in leisure activities, along with other access issues such as distance from the activity and not having anyone to go with, which is consistent with the findings of other research (Douglas, Dyson, & Foreman, 2006). This is hardly surprising given that the majority of participants lived in rural and remote locations some distance from their regional centre. Other major barriers identified in common with other research (Douglas, Dyson, & Foreman, 2006) included physical health
problems and social anxiety. Balance deficits, fatigue, deconditioning and weakness, disorganisation and erratic sleep patterns were also identified as problems for some. Many of the problems identified by participants such as transport and physical health issues are not things that can be solved easily. The limited comments given by participants three months post intervention suggest that there may have been changes in some of the perceived barriers particularly around increased confidence and motivation to participate. However, no data were collected to confirm this.

People with an ABI may also have more time to engage in leisure activities, but a lack of finances can deprive them of the enjoyment of some leisure activities that would be available to the general population (Brown et al., 2003). This was the case for a number of study participants. During each of the three programs a group session was held that specifically explored some of the perceived barriers to participation and some thought-provoking solutions were shared within the group. Recreation on a budget, attending with a friend, developing a buddy system and public transport options were some of the topics discussed. Participant comments three months post program confirm that many of the barriers still remained following the program:

I have achieved my goal which was playing a game of golf with my pop, and I am still working on the goal of playing golf on a regular basis.

Finance and transport are still a problem.

and

I am still working on returning to netball, when the winter season starts.

Main barriers still remain money and transport.
However, the fact that leisure participation and satisfaction increased substantially following the program suggests once again that there may have been changes in some of the perceived barriers, or perhaps participants had found means to modify the impact of these barriers.

5.6 The question of rurality

No studies were found that specifically evaluated leisure programs for rural people with ABI. However rurality has been associated with both positive and negative factors in the literature. Living in a rural area has been linked to more openness to seeking social support and better QOL following an ABI (Farmer, Clark, & Sherman, 2003). On the other hand, limited rehabilitation services along with limited work opportunities in rural areas make employment more difficult to achieve following a brain injury, which generally leads to increased strain on the injured person and their family (Coetzer, Hayes, & Toit, 2007).

The literature tells us that health outcomes generally tend to be poorer outside major cities. Whether differences in access to services, risk factors and the regional/remote environment are responsible for these differences we don’t know (Australian Institute of Health and Welfare, 2013). We do know that rural environments expose residents to unique hazards and we also know that the rural environment influences attitudes and behaviours that are not always conducive to safety or good health and well-being (Veitch, 2009). According to Veitch (2009) three elements shape health and well-being in rural areas: access to and availability of health services, behaviour (beliefs and attitudes to health) and the context in which rural people live and work. Rurality can often exacerbate the effects of socio-economic disadvantage, ethnicity, poorer service
availability, higher levels of personal risk and more hazardous environmental, occupational and transportation conditions (Smith, Humphries & Wilson, 2008).

As a rural and remote intervention, rurality was a key feature of the Pushing the Boundaries Program. Nine participants were classified as coming from a rural/remote centre (RRMA 4-6) and three a large regional centre (RRMA 3). Transportation difficulties were reported as being the most common barrier to participants’ involvement in leisure activities and this is hardly surprising given that many had to drive over an hour to get to their nearest town. Participants were grouped according to their age and the geographical location of their home as described on p.44. It was apparent in at least two of the groups that participants formed strong friendships within the group and some car-pooling occurred. Additionally, over the three month follow-up period it appeared that participants were getting more motivation and encouragement from their peers than from their key person.

5.7 Group sessions

For the purpose of this thesis the term “group sessions” will be used to refer to any sessions that were conducted in a group included leisure activities, brainstorming sessions and skills training. The results of this study provide some insight into the positive effects of involvement in group sessions. The action of discussing barriers to participation in a group setting was reported by participants as being informative and helpful. Many of the participants reported developing friendships that lasted beyond the life of the program. Much of the success of this program could possibly be attributed to group sessions, which appeared to provide a supportive environment, facilitate interaction among peers and reduce feelings of isolation. Experienced clinicians
observed that these programs appeared to have better outcomes in terms of leisure participation and building relationships than had been observed in the past with other types of individual leisure intervention. The group format could have been a contributor to this however this is purely speculative. The group format seemed to produce better outcomes in terms of leisure participation, efficiency and cost effectiveness however once again there are no objective data to confirm this so we cannot be sure about these things. Similar links between group sessions and successful outcomes have been reported in the literature (Daniel & Manigandan, 2005) and the findings of this study add further evidence to the assumption that involvement in group sessions is beneficial.

Studies investigating the effects of tai chi groups on individuals with TBI found that tai chi practised in a group was associated with significant improvement in mood, such as decreased sadness, confusion, anger, and tension fear, and increased energy and happiness (Gemmell, & Leathem, 2006). There are other examples of group activities that have had beneficial results for participants. In one study, a group of adults with severe TBI living in metropolitan Melbourne, Australia, who participated regularly in facilitated and organised community leisure activities over a six month period study reported significant improvement in social integration and mental health (Douglas, Dyson, & Foreman, 2006). This worked well in a metropolitan area. However, it may be difficult to replicate for people living in a rural or remote region due to the distances involved and absence of public transport.

From my limited experience with providing leisure intervention in both an individual and group capacity within a BIRP service it appears that there can be distinct advantages in delivering a leisure intervention in a group environment. Firstly, there appears to be a greater capacity to trial a wider range of leisure activities when delivering a service to a group along with some significant cost savings. Additionally,
the facilitation and encouragement given by peers appears to be invaluable and not something that can be easily replicated. To observe someone having similar difficulties in an activity as oneself, and to observe how others address their various difficulties creates a bond in itself. Thus, some of the success of this program may be attributed to group sessions which provided a supportive and structured environment, facilitated interaction among peers, reduced feelings of isolation, and enriched the learning and skill development for all involved. It is a strong possibility that the group format contributed to the successful outcome in terms of leisure participation and building friendships but one of the things this study did not do and what would be good to follow up on would be to tease out what other aspects there might have been that contributed to the success of the program.

5.8 Features of an effective leisure intervention program

Following an ABI a substantial number of people are not engaged in employment nor are they engaged in meaningful and satisfying leisure activity (Carbonneau, Martineau, Andre, & Dawson, 2011). Thus there is a clear need for programs that are able to facilitate participation in meaningful leisure activities for adults post ABI. Recovery from ABI may be impeded if the more usual goals of rehabilitation i.e., mobility, independence in self-care activities and cognition, are concentrated on exclusively (Parker, Gladman, & Drummond, 2004). Some argue for rethinking the approach to rehabilitation of individuals with an ABI by placing more emphasis on leisure activities. These activities could be included into a therapy program designed to promote reintegration into society and work (Bier, Dutil, & Couture, 2009). Using participation in purposeful goal-oriented leisure activities as a bridge to the greater demands of the workplace and providing opportunities to build confidence with
goal-oriented projects along with social and communication skills may be more effective (Wise et al., 2010).

There has been little written in the literature in regards to leisure intervention and what is “standard intervention” in terms of rehabilitation after a brain injury. However, leisure has gained more importance over recent years as part of the rehabilitation process and in Chapter 2 I outlined the growing evidence base that demonstrates the effectiveness of leisure intervention groups and the part they might play in the rehabilitation of people with a brain injury. No other program such as this has been reported in the literature. Prior to these programs being run at SWBIRS, it was standard practice at SWBIRS, as in many brain injury rehabilitation programs, for leisure intervention to be implemented on an individual basis, not within a specialised group.

Increasing the leisure skills and knowledge of community resources among those with a brain injury can improve self-confidence and leisure participation and, in turn, increase leisure satisfaction (Prvu, Navar, Yaffe, & Hagar, 1999) and it has been suggested that self-efficacy may play an important role in this process (Wise et al., 2010). It is also known that leisure occupation can give the person with an ABI an opportunity to be *fully human*, to experience a sense of belonging, health and capability while alleviating the boredom and occupational deprivation that may occur if one has too much free time (Fenech & Baker, 2008). It is important that the chosen leisure occupation has meaning and is engaging to the individual (Molineux & Whiteford, 1999), and it has been suggested that experimentation, personal growth (Miller, Polgar, & Landry, 2004) and giving the individual control over the choice of the activity (Ryan & Deci, 2000) are important ways of investing meaning to an activity.

The findings suggest that the success of this program can be attributed, in part, to the fact that participants were given individual control over the choice of the activities
trialed throughout the week. This is an important factor in investing meaning to an activity (Miller, Polgar, & Landry, 2004). Many of the participants’ comments support this assertion and are illustrative of the impact this program has had on them. Barriers to participation were addressed both individually and in group format. Many participants indicated that they were taken out of their comfort zones, faced their doubts and fears and as a result regained a sense of confidence in themselves and in their abilities. Participants also had opportunities to improve self-efficacy by modelling, experiencing and social persuasion, as described by Bandura’s (1977) social cognitive theory. They also had opportunity to experiment with a variety of leisure activities and build awareness of where their strengths and weaknesses might lie. This opportunity to “try it out” and to make an informed choice about whether to pursue an activity or not contributed to meaningful goal setting and was an important contributor to the success of the program. They were assisted in improving their knowledge of the resources available in their local communities and supported in establishing meaningful yet realistic client-centred goals for when they went home. At the same time, they were able to work on developing their communication and social skills in a safe environment with others who had similar uncertainties. Problem solving skills, organisational and time management skills were also developed. It is expected that the real world context in which this learning and development of skills was delivered may be transferrable to other areas of their life, but this was not assessed.

It is noteworthy that the tendency for improvement in all of the outcome measures made throughout the week continued over time, so much so that from baseline to three months after the intervention there was a statistically significant improvement in all outcome measures. The results of this study are highly encouraging given the particularly good outcomes and the efficient use of resources. However, maintaining
gains with any intervention is difficult. This is one of the few studies that have demonstrated maintenance of gains over a three-month period. One of the strengths of this program appeared to be the motivation provided by participation in the various leisure activities and the group camaraderie that appeared to later encourage participants to work towards their individual leisure goals. Given that few interventions have successfully tackled issues of quality of life, self-esteem and leisure satisfaction among individuals with an ABI, the results of this study suggest that this innovative intervention may indeed be useful as an essential tool in the rehabilitation of adults with an ABI.

5.9 Limitations and strengths

The role of the intervention itself in helping participants to achieve improvements in leisure satisfaction, self-esteem and quality of life can only be inferred given that there was no control group and the small number of self-selected participants (n = 12). A larger study would likely provide greater generalisability and thus confidence in the findings. Follow-up of participants over a longer time period would also be advantageous to determine how well gains are maintained. An expanded qualitative component exploring how it affected their lives and their experience of the process, along with an exploration of whether and how it reduced the perceived barriers, would have added further to the study.

The strengths of this study include the high completion rate, the use of validated scales and the fact that this research has not previously been undertaken, thus making this research somewhat unique. The small number of participants showing significant results is also an indication that there are likely to be clinically relevant changes. The value of the results is strengthened by the analysis of the participants’ goal achievements and comments. We contextualised the program and made it highly
relevant to each individual, but were able to deliver in group format because of the underpinning structure of how the individual programs were run. This was a strength of the program. Future research might investigate whether adjusting or influencing the context, as well as the individual, results in a better or more sustainable outcome.

Further study in relation to cost-benefit and other impacts such as reduced re-hospitalisation would have added to this study. This should be a key consideration in future studies. The influences of specific types of activity (active/passive, social/individual) were not investigated in this study, nor could it be given the small numbers involved. It could be beneficial for future studies to look at this if the numbers allow.
Chapter 6

Conclusions and Recommendations

6.1 Conclusions

This thesis reports on an investigation into the effects of a week-long leisure intervention called Pushing the Boundaries. It attempts to answer the question does participation in a leisure intervention program such as Pushing the Boundaries improve leisure satisfaction, self-esteem and QOL among people with an ABI living in rural, regional and remote NSW? The results clearly show that participation in this program has resulted in significant improvements in leisure satisfaction, self-esteem and QOL three months post program for its participants.

Participation in this program assisted participants to develop and achieve realistic leisure goals within their own communities. Those who participated indicated that the program made a difference to their lives and how they felt. The reported differences were also evident in quantitative measures. These findings support the concept that leisure satisfaction is important in the lives of adults with an ABI living in rural, regional and remote NSW, that it is linked to QOL, and that it is possible to improve both leisure satisfaction and quality of life through such programs. The results of this study indicate that group therapy is indeed an effective method available to rehabilitation professionals to ensure that clients with ABI achieve better leisure satisfaction, self-esteem and QOL.

If the desired goal of rehabilitation following ABI is community integration and facilitating the restoration of the QOL of survivors, then facilities providing these services will need to develop interventions that are both practical and innovative. The
Pushing the Boundaries program developed by SWBIRS was demonstrated to be both a practical and innovative program that focused on recovery in a much broader and holistic sense than a more traditional therapy program. Rehabilitation services that can successfully increase leisure satisfaction, self-esteem and QOL are likely to reduce the social burden and perhaps even re-hospitalisation associated with severe ABI, making programs such as this one a valuable addition to community-based ABI rehabilitation. Programs that facilitate leisure satisfaction and improve self-esteem and quality of life need to be a key component of the long-term rehabilitation of people with an ABI. The findings of this study confirm the growing need for active leisure intervention programs to be included in the ongoing rehabilitation and reintegration of adults with an ABI in rural, regional and remote NSW. Results of this study justify replication of this program in similar rehabilitation settings.

6.2 Recommendations

The project results highlighted a number of key findings that have implications for brain injury rehabilitation services and service delivery. The findings of this project indicate that adults with an ABI participating in a Pushing the Boundaries program experience improvements in psychological well-being, in particular leisure satisfaction, self-esteem and quality of life three months post program. Results of this study could prove valuable in determining justification for the use of similar leisure intervention programs to aid in recovery following an ABI in similar rehabilitation settings. Four recommendations came out of the project:
Leisure intervention groups for people with ABI

- That active leisure intervention group activity be included in the ongoing rehabilitative care and integration of adults with an ABI.

- That the program and its evaluation be continued at SWBIRS. This would not only benefit additional participants but would also allow inclusion of a larger number of participants in the evaluation.

- That the surveys be repeated 12 months post intervention in order to measure the maintenance of change and compare with baseline and 3-month follow-up data.

- That the program be replicated in similar settings and other BIRPs.
References

Australian Institute of Health and Welfare. (2013). Retrieved 4\textsuperscript{th} December 2013 from:


Brain Injury Australia. (2012). Retrieved November 11\textsuperscript{th} 2012 from:

\url{http://www.braininjuryaustralia.org.au}

Brain Injury Network. (2013). Retrieved April 16\textsuperscript{th} 2013 from: \url{http://www.braininjury network.org/thesurvivorsviewpoint/definitionofabiandtbi.html}


Leisure intervention groups for people with ABI


Leisure intervention groups for people with ABI


Leisure intervention groups for people with ABI


Leisure intervention groups for people with ABI


Leisure intervention groups for people with ABI


Appendix A.

South West Brain Injury Rehabilitation Service - Eligibility criteria

The South West Brain Injury Rehabilitation Service (SWBIRS) is a regional rehabilitation service based in Albury and Wagga, NSW. It provides rehabilitation and support to children and adults who have sustained a traumatic brain injury (TBI). SWBIRS work with people from the Murrumbidgee Local Health District and clients who are entitled to compensation from North East Victoria. SWBIRS is part of the NSW Brain Injury Rehabilitation Program (BIRP), a network of specialist brain injury rehabilitation providers throughout metropolitan and regional NSW.

Referrals to SWBIRS are considered for people who have:

- A primary diagnosis of traumatic brain injury, and aged between 3 and 65 years of age.
- Live in the Murrumbidgee Local Health District.
- Live in North East Victoria and are compensable (funded by insurance).
  - TAC, Workcover, Lifetime Care and Support Authority (LTCS), CTP
- Are medically stable.
- Are willing to participate in a rehabilitation program.

In line with the NSW BIRP, referral of people with an acquired brain injury, other than traumatic brain injury, may be considered at the discretion of the manager. Others who fall outside these eligibility criteria are denied access to this service.
Appendix B

GSAHS ethics approval

23 February 2010

Ms Elizabeth Jane Mitchell
Physiotherapist/Case Manager
SWBIRS
GSAHS, Albury 2640

Address to:
46 Johnston Road
Albury NSW 2640

Dear Elizabeth

HREC reference number: HREC/09/GSAHS/63
SSA reference number: SSA/10/GSAHS/9

Project title: Efficacy of leisure intervention groups and their impact on leisure satisfaction, self esteem and quality of life amongst people with an Acquired Brain Injury

Thank you for submitting an application for authorisation of this project. I am pleased to inform you that authorisation has been granted for this study to take place at SWBIRS.

The following standard conditions apply to this research project. These are additional to those conditions imposed by the Human Research Ethics Committee that granted ethical approval:

1. Please inform the research governance officer in writing if the project either:
   a. does not commence, or is
   b. discontinued before expected completion.

2. Proposed amendments to the research protocol or conduct of the research which may affect the ethical acceptability of the project, and which are submitted to the lead HREC for review, must be copied to the research governance officer.

3. Proposed amendments to the research protocol or conduct of the research which may affect the ongoing site acceptability of the project, must be submitted to the research governance officer.

4. Serious or unexpected adverse effects or unforeseen events that are reported to the HREC that approved the study should also be reported to the research governance officer.

Greater Southern Area Health Service
PO Box 1845 (34 Lowe Street) Queanbeyan NSW 2620
Tel 02 6226 9773 Fax 02 6229 0333
Email corporate@gsha.health.nsw.gov.au
Website www.gsha.health.nsw.gov.au
ABN 17 196 442 397
Appendix C

HREC ethics approval extended

HREC covering Southern and Murrumbidge LHDs
Wagga Wagga Area Office
63-65 Johnston St
Wagga Wagga
NSW 2550

27 September 2011
Ms Elizabeth Mitchell
46 Johnston Road
Albury
NSW 2640

Dear Elizabeth

**HREC reference number:** HREC/09/GSAHS/53  
**Project title:** Efficacy of leisure intervention groups and their impact on leisure satisfaction, self esteem and quality of life amongst people with an Acquired Brain Injury.  
**Amendment Number:** AM02  
**Amendment Date:** 16 August 2011

The above amendment was reviewed at a meeting held on 27 September 2011.

I am pleased to advise that the documents reviewed and approved at the meeting were:

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<th>Version</th>
<th>Date</th>
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<tr>
<td>Notification of amendment</td>
<td></td>
<td>16 August 2011</td>
</tr>
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The HREC approval period has been extended until January 2014 to allow you to conduct further programs and collect more data.

This HREC is constituted and operates in accordance with the National Health and Medical Research Council's *National Statement on Ethical Conduct in Research Involving Humans* and the *CPMP/ICH Note for Guidance on Good Clinical Practice*.

A copy of this letter must be forwarded to all Principal Investigators at every site for submission to the relevant Research Governance Officer.

Yours faithfully

Alison Mac Taggart  
Executive Officer  
HREC covering MLHD and SLHD
### Leisure Participation Survey

<table>
<thead>
<tr>
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<th>DOB</th>
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<th>Method of conducting survey</th>
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<td></td>
<td></td>
<td>☐ Phone ☐ Face to face ☐ Videoconference</td>
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<th>Question 1.</th>
<th>Currently participates in</th>
<th>Would like to try/do more of</th>
<th>Available in home community</th>
<th>Top Five (5)</th>
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<tr>
<td>Badminton</td>
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<td>Bike riding</td>
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<tr>
<td>Board games</td>
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<td>Boche</td>
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<tr>
<td>Bowling – lawn / Bowling– 10 pin</td>
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<tr>
<td>Bush walking</td>
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<tr>
<td>Canoeing /Kayaking</td>
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<td>Cards</td>
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<tr>
<td>Computer games</td>
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<tr>
<td>Cooking</td>
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<tr>
<td>Cricket – indoor</td>
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<td>Cultural interests - Music/Arts</td>
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<td>Darts</td>
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<tr>
<td>Eating out/pub</td>
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<tr>
<td>Fishing</td>
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<td>Gardening</td>
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<td>Gym</td>
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<td>Martial Arts</td>
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<td>Movie</td>
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<tr>
<td>Netball</td>
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<td>Painting</td>
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<td>Photography</td>
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<td>Pool</td>
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<td>Pilates</td>
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<tr>
<td>Sailing</td>
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<tr>
<td>Soccer – outdoor</td>
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Leisure intervention groups for people with ABI

<table>
<thead>
<tr>
<th>Soccer –indoor</th>
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<tr>
<td>Swimming</td>
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<tr>
<td>Table tennis</td>
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<tr>
<td>Tai chi</td>
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<td>Tennis</td>
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<td>Wii Nintendo</td>
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<tr>
<td>Yoga</td>
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<td>OTHER:</td>
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2) We are interested in knowing what, if any, barriers or obstacles there are to your ability to participate in leisure and recreational activities.

Please tell me two or three obstacles to your ability to participate in any of the activities that we have talked about:

a) ______________________________________________________________________
   ______________________________________________________________________

b) ______________________________________________________________________
   ______________________________________________________________________

c) ______________________________________________________________________
   ______________________________________________________________________

3) Tell me two or three things that would improve or increase your participation in any of the activities we have talked about:

a) ______________________________________________________________________
   ______________________________________________________________________

b) ______________________________________________________________________
   ______________________________________________________________________

c) ______________________________________________________________________
   ______________________________________________________________________

That’s the end of the survey. Well done! Thank you very much for your time.
Appendix E

The Leisure Satisfaction Scale

<table>
<thead>
<tr>
<th>Participants name</th>
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<td>DOB</td>
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<tr>
<td>Date(s) of survey</td>
<td></td>
</tr>
<tr>
<td>Method of conducting survey</td>
<td>Phone</td>
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In the blanks provided below, please write the number from the scale that best describes how you feel about each of the statements. These statements are designed to find out how you feel about things you do in your free time. There are no right or wrong answers. Please answer every question.

1 = Almost never true for you
2 = Seldom true for you
3 = Sometimes true for you
4 = Often true for you
5 = Almost always true for you

____ 1. My leisure activities are very interesting to me.
____ 2. My leisure activities give me self-confidence.
____ 3. My leisure activities give me a sense of accomplishment.
____ 4. I use many different skills and abilities in my leisure activities.
____ 5. My leisure activities increase my knowledge about things around me.
____ 6. My leisure activities provide opportunities to try new things.
____ 7. My leisure activities help me to learn about myself.
____ 8. My leisure activities help me to learn about other people.
____ 9. I have social interaction with others through leisure activities.
____ 10. My leisure activities have helped me to develop close relationships with others.
____ 11. The people I meet in my leisure activities are usually friendly.
____ 12. I associate with people in my free time who enjoy doing leisure activities a great deal.
____ 13. My leisure activities help me to relax.
____ 14. My leisure activities help me to relieve stress.
____ 15. My leisure activities contribute to my emotional wellbeing.
____ 16. I engage in leisure activities simply because I like doing them.
____ 17. My leisure activities are physically challenging.
____ 18. I do leisure activities which develop my physical fitness.
____ 19. I do leisure activities which restore me physically.
____ 20. My leisure activities help control my weight.
____ 21. The areas or places where I engage in my leisure activities are fresh and clean.
____ 22. The areas or places where I engage in my leisure activities are interesting.
____ 23. The areas or places where I engage in my leisure activities are beautiful.
____ 24. The areas or places where I engage in my leisure activities are well designed.

Appendix F

THE WORLD HEALTH ORGANIZATION
QUALITY OF LIFE (WHOQOL) -BREF
Leisure intervention groups for people with ABI
Leisure intervention groups for people with ABI
Leisure intervention groups for people with ABI
Appendix G

Rosenberg Self-Esteem Scale (Rosenberg, 1965)

Instructions: Below is a list of statements dealing with your general feelings about yourself. Circle either strongly agree, agree, disagree or strongly disagree based on how you feel about each statement. Don’t take too long over your replies: your immediate reaction to each item will probably be more accurate than a long thought-out response.

1. On the whole, I am satisfied with myself:
   \[\text{Strongly Agree} \quad \text{Agree} \quad \text{Disagree} \quad \text{Strongly Disagree}\]

2.* At times, I think I am no good at all.
   \[\text{Strongly Agree} \quad \text{Agree} \quad \text{Disagree} \quad \text{Strongly Disagree}\]

3. I feel that I have a number of good qualities.
   \[\text{Strongly Agree} \quad \text{Agree} \quad \text{Disagree} \quad \text{Strongly Disagree}\]

4. I am able to do things as well as most other people.
   \[\text{Strongly Agree} \quad \text{Agree} \quad \text{Disagree} \quad \text{Strongly Disagree}\]

5.* I feel I do not have much to be proud of.
   \[\text{Strongly Agree} \quad \text{Agree} \quad \text{Disagree} \quad \text{Strongly Disagree}\]

6.* I certainly feel useless at times.
   \[\text{Strongly Agree} \quad \text{Agree} \quad \text{Disagree} \quad \text{Strongly Disagree}\]

7. I feel that I’m a person of worth, at least on an equal plane with others.
   \[\text{Strongly Agree} \quad \text{Agree} \quad \text{Disagree} \quad \text{Strongly Disagree}\]

8.* I wish I could have more respect for myself.
   \[\text{Strongly Agree} \quad \text{Agree} \quad \text{Disagree} \quad \text{Strongly Disagree}\]

9.* All in all, I am inclined to feel that I am a failure.
   \[\text{Strongly Agree} \quad \text{Agree} \quad \text{Disagree} \quad \text{Strongly Disagree}\]

10. I take a positive attitude toward myself.
    \[\text{Strongly Agree} \quad \text{Agree} \quad \text{Disagree} \quad \text{Strongly Disagree}\]
Leisure intervention groups for people with ABI

**Scoring**
SA=3, A=2, D=1, SD=0. Items with an asterisk are reverse scored, that is, SA=0, A=1, D=2, SD=3.

Sum the scores for the 10 items. The higher the score, the higher the self esteem.
Appendix H

Participants’ Comments three months post program

Collated comments from the participants in regards to their goal achievement three months post intervention:

- My goal was to try a new sport. I have played several games of pool now and are more confident that I will continue to play the game now.

- Yes, I achieved my goal of fixing up my pushbike and riding it and playing lawn bowls each Thursday and Sunday the week made a big difference.

- My goal was to get fit and have a better balance between work and leisure. I have been to the Conservatorium of Music at a nearby town, got a list of events and have attended several events since. I am now walking regularly on the wetlands and am reading more. I am also visiting friends that I have not visited since the accident over two years ago. I had been avoiding people (people annoyed me) but since the program I have started visiting people again and going for drives, going shopping and going out for counter lunches. The week has made a big difference in my life. I didn’t realise it at the time and I was tired during the week but when I got home I could relax better and it has really helped me. I think you need to run these weeks pretty often.

- My goal was to try a new activity in my area. I now go to the picnic races weekly, play lawn bowls every second week and I hope to start water-skiing again soon.

- Yes I have achieved all three of my goals which included returning to playing cricket (twice weekly), soccer training (twice weekly) and golf once per week.
Leisure intervention groups for people with ABI

- I have achieved my goal which was playing a game of golf with my Pop and I am still working on the goal of playing golf on a regular basis. Finance and transport are still a problem.

- I have achieved part of my goal which was to play ten pin bowling once per fortnight and play pool either by myself or with my partner at the club each week. Still working on returning to netball when the winter season starts. Main barriers still remain money and transport.

- I have achieved my goal of going fishing once per fortnight and attend football training with my 12 year old son each week and assist with football training of the team. I wouldn’t have done either of these activities if I hadn’t done the program. I was in a rut before the program and sleeping a lot. The program gave me the motivation and confidence that I could do it. It pushed me through the pain barrier. The week certainly made a difference to me.

- I achieved my goal of attending the gym three times weekly and getting fit before I got sick. I also started to play golf once per fortnight. I wouldn’t have thought about playing golf without attending the program. The program was an eye-opener. It made things more realistic. Made things more clear about what’s available and showed me the issues that have arisen that I didn’t see in the first place. I lost confidence with the sailing but gained confidence when I tried new things such as golf, watching movies and going out socially again.

- The program reminded me that I like passing things on and helping other people. Since then I have taken a few mates out and taught them how to fish. The program also made me realise that I am a bit isolated in my situation and that I actually do like being with other people. I felt very at ease with all the people in the group.
I thought the week was good. I didn’t think I would like it so much but I did. Since then I have attended a Disabled pilot’s fly-in at Deniliquin and got all the necessary information and a plan of how to return to flying. I also did a 12 km ride.
WHOQOL-BREF

The following questions ask how you feel about your quality of life, health, or other areas of your life. I will read out each question to you, along with the response options. **Please choose the answer that appears most appropriate.** If you are unsure about which response to give to a question, the first response you think of is often the best one.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life **in the last four weeks.**

<table>
<thead>
<tr>
<th></th>
<th>Very poor</th>
<th>Poor</th>
<th>Neither poor nor good</th>
<th>Good</th>
<th>Very good</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. How would you rate your quality of life?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Very dissatisfied</th>
<th>Dissatisfied</th>
<th>Neither satisfied nor dissatisfied</th>
<th>Satisfied</th>
<th>Very satisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. How satisfied are you with your health?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

The following questions ask about **how much** you have experienced certain things in the last four weeks.

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>A little</th>
<th>A moderate amount</th>
<th>Very much</th>
<th>An extreme amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>3. To what extent do you feel that physical pain prevents you from doing what you need to do?</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>4. How much do you need any medical treatment to function in your daily life?</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>5. How much do you enjoy life?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>6. To what extent do you feel your life to be meaningful?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>A little</th>
<th>A moderate amount</th>
<th>Very much</th>
<th>Extremely</th>
</tr>
</thead>
<tbody>
<tr>
<td>7. How well are you able to concentrate?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>8. How safe do you feel in your daily life?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>9. How healthy is your physical environment?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
The following questions ask about how completely you experience or were able to do certain things in the last four weeks.

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>A little</th>
<th>Moderately</th>
<th>Mostly</th>
<th>Completely</th>
</tr>
</thead>
<tbody>
<tr>
<td>10. Do you have enough energy for everyday life?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>11. Are you able to accept your bodily appearance?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>12. Have you enough money to meet your needs?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>13. How available to you is the information that you need in your day-to-day life?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>14. To what extent do you have the opportunity for leisure activities?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

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<tr>
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<th>Good</th>
<th>Very good</th>
</tr>
</thead>
<tbody>
<tr>
<td>15. How well are you able to get around?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

<table>
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<tr>
<th></th>
<th>Very dissatisfied</th>
<th>Dissatisfied</th>
<th>Neither satisfied nor dissatisfied</th>
<th>Satisfied</th>
<th>Very satisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td>16. How satisfied are you with your sleep?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>17. How satisfied are you with your ability to perform your daily living activities?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>18. How satisfied are you with your capacity for work?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>19. How satisfied are you with yourself?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>How satisfied are you with your personal relationships?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>---</td>
<td>--------------------------------------------------------</td>
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<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>21.</td>
<td>How satisfied are you with your sex life?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>22.</td>
<td>How satisfied are you with the support you get from your friends?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>23.</td>
<td>How satisfied are you with the conditions of your living place?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>24.</td>
<td>How satisfied are you with your access to health services?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>25.</td>
<td>How satisfied are you with your transport?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

The following question refers to how often you have felt or experienced certain things in the last four weeks.

<table>
<thead>
<tr>
<th></th>
<th>How often do you have negative feelings such as blue mood, despair, anxiety, depression?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Never</td>
</tr>
<tr>
<td>26.</td>
<td>5</td>
</tr>
</tbody>
</table>

Do you have any comments about the assessment?

[The following table should be completed after the interview is finished]

<table>
<thead>
<tr>
<th></th>
<th>Equations for computing domain scores</th>
<th>Raw score</th>
<th>Transformed scores*</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>a. ≡ b:</td>
<td>c:</td>
</tr>
<tr>
<td>27.</td>
<td>Domain 1 ((6\cdot Q3) + (6\cdot Q4) + Q10 + Q15 + Q16 + Q17 + Q18)</td>
<td>(\boxed{\text{\circ}} + \boxed{\text{\circle}} + \boxed{\text{\square}} + \boxed{\text{\square}} + \boxed{\text{\square}} + \boxed{\text{\square}} + \boxed{\text{\square}})</td>
<td>(\boxed{\text{\circle}} + \boxed{\text{\circle}} + \boxed{\text{\square}} + \boxed{\text{\square}} + \boxed{\text{\square}} + \boxed{\text{\square}})</td>
</tr>
<tr>
<td>28.</td>
<td>Domain 2 ((Q5 + Q6 + Q7 + Q11 + Q19 + (6\cdot Q26)))</td>
<td>(\boxed{\text{\circle}} + \boxed{\text{\circle}} + \boxed{\text{\circle}} + \boxed{\text{\circle}} + \boxed{\text{\square}} + \boxed{\text{\square}})</td>
<td>(\boxed{\text{\circle}} + \boxed{\text{\circle}} + \boxed{\text{\circle}})</td>
</tr>
<tr>
<td>29.</td>
<td>Domain 3 ((Q20 + Q21 + Q22))</td>
<td>(\boxed{\text{\circle}} + \boxed{\text{\circle}} + \boxed{\text{\circle}})</td>
<td>(\boxed{\text{\circle}} + \boxed{\text{\circle}} + \boxed{\text{\circle}})</td>
</tr>
<tr>
<td>30.</td>
<td>Domain 4 ((Q8 + Q9 + Q12 + Q13 + Q14 + Q23 + Q24 + Q25))</td>
<td>(\boxed{\text{\circle}} + \boxed{\text{\circle}} + \boxed{\text{\circle}} + \boxed{\text{\circle}} + \boxed{\text{\circle}} + \boxed{\text{\circle}} + \boxed{\text{\circle}} + \boxed{\text{\circle}})</td>
<td>(\boxed{\text{\circle}} + \boxed{\text{\circle}} + \boxed{\text{\circle}} + \boxed{\text{\circle}} + \boxed{\text{\circle}} + \boxed{\text{\circle}} + \boxed{\text{\circle}} + \boxed{\text{\circle}})</td>
</tr>
</tbody>
</table>

* See Procedures Manual, pages 13-15