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Efficacy of leisure intervention groups in rehabilitation of people with an Acquired Brain Injury.

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Table of Abbreviations

ABI	Acquired brain injury
AMI	Acute myocardial infarction
BIRP	Brain Injury Rehabilitation Program
CARN	Centre Active Recreation Network
CETI	Clinical Education and Training Institute
GSAHS	Greater Southern Area Health Service
HREC	Human Research Ethic Committee
ICF	International Classification of Functioning Disability and Health
LAS	Leisure Attitude Scale
LSS	Leisure Satisfaction Scale
NSW	New South Wales

QOL	Quality of life
PTSD	Post traumatic stress disorder
PUP	Potential Unlimited Program
RRCBP	Rural Research Capacity Building Program
RSES	Rosenburg self-esteem scale
SCI	Spinal Cord Injury
SSA	Site specific assessment
SWBIRS	South West Brain Injury Rehabilitation Service
TBI	Traumatic brain injury
TLU	Transitional living unit
USA	United States of America
WHO	World Health Organisation
WHOQOL-BREF	World Health Organisation Quality of Life Scale – Short form

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Abstract

As individuals become less vocationally active such as after a brain injury, engagement in leisure and social activity increases in importance to the persons well-being. However it is often the case that following a brain injury some people have difficulty accessing what is available in their local area for a variety of reasons. The adult team at the South West Brain Injury Rehabilitation Service (SWBIRS) in Albury, NSW recognized 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 was 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, Rosenberg Self Esteem Scale and the World Health Organisation Quality of Life Scale –Bref 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 this rehabilitation 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, with a mean age of 36 years (range 19-49 years). The majority of participants (7/12) had acquired their injury more than two years previously and for most (10/12) 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 month 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 *Pushing the Boundaries* leisure program can experience improvements in leisure satisfaction, self esteem and quality of life following the program. 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**

Executive Summary

Context:

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. Leisure intervention groups can provide an opportunity for participants to explore recreational opportunities and discuss potential barriers.

This project reports on an investigation into the effects of a week long leisure intervention, namely a *Pushing the Boundaries* program, for persons with an Acquired Brain Injury (ABI) living in rural, regional and remote NSW. It attempts to answer the question does the participation in a *Pushing the Boundaries* program improve the leisure satisfaction, self esteem and quality of life amongst persons with an ABI living in rural, regional and remote NSW?"

It is well documented that leisure is an important component in the lives of persons with an ABI and it is often associated with community involvement, life satisfaction and self esteem. It is believed by some that as individuals become less vocationally active, voluntary engagement in leisure and social activity increases in importance to the person. Studies have suggested that psychological well-being in this population depends very much on satisfaction with leisure, in preference to satisfaction derived from job, family, finances or health. Active leisure programs for individuals with an ABI are relatively new and unexplored territory however there are many who believe they are not only valuable for their therapeutic value, but more specifically that they are an important tool in facilitating a redefining of ones "self" following an ABI.

The setting for this project was the Transitional Living Unit (TLU) at the South West Brain Injury Rehabilitation Service (SWBIRS). The Adult Team at SWBIRS recognised an ongoing need within the population they service for active leisure intervention as part of the rehabilitation and adjustment to injury process. A leisure intervention program called *Pushing the Boundaries* was developed and piloted in March 2009. The program was an attempt to trial leisure intervention through groups rather than on an individual basis which was our current practice. It was thought by staff that group therapy would provide a supportive environment, facilitate interaction among peers, reduce feelings of isolation, helplessness and improve mood. Other benefits of group therapy were thought to include easy implementation, replication and cost-effectiveness, however these benefits were yet to be proven.

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 participation and satisfaction within their own communities. The success of the week long pilot program saw three similar programs run in the seven months from August 2010 to February 2011 and these are the focus of this study.

Approach:

The evaluation utilised a pre and post intervention design examining the changes in leisure participation, leisure satisfaction, self esteem and quality of life (QOL) amongst ABI patients who completed an intensive leisure intervention program called *Pushing the Boundaries*.

The intervention consisted of participation in a week long residential program which was designed to provide clients with the opportunity to trial a range of sporting and recreation activities so that they could increase their leisure participation in their own community. One hundred current or previous clients of SWBIRS were invited to attend one of three programs run between August 2010 and February 2011. A Leisure Participation Survey aimed to gather information from the clients prior to the intervention was sent out to those who registered an interest in attending and the leisure activities chosen to trial throughout the week were influenced by the responses of the participants. With the assistance of the Centre Active Recreation Network (CARN) based in North East Victoria the most popular activities for each group were run during the week. Activities in the programs included sailing, clay target shooting, bushwalking, tai chi, fishing, pool, tennis, table tennis, wii nintendo, volleyball, netball, soccer games, socialising, swimming and eating out.

Changes in leisure satisfaction, quality of life and self esteem were measured using the Leisure Satisfaction Scale (LSS), the four domains of the World Health Organisation Quality of Life scale - Bref (WHOQOL-BREF) i.e. physical, psychological, social relationships and environment and the Rosenberg Self-Esteem Scale (RSES) respectively. Data were collected from the group participants prior to each program, immediately following and at three months post program. Individual leisure goals generated by participants during the week long program were also investigated to gain further insight into the personal effects of this rehabilitation program.

Subjects were used as their own controls and compared only with themselves. Wilcoxon signed-rank tests were performed to compare measurements at baseline with measurements taken at the completion of the program to determine if these values were significantly different from each other. In order to gauge if any sustained change had occurred baseline measures were then compared with measures taken three months post the intervention.

Results:

Of the 13 participants who commenced the leisure intervention program one person withdrew from the program due to illness and 12 participants completed the program. The results are based on those 12 subjects all of whom consented to participate in the research. The average age of the clients was 36 years with ages ranging from 19 to 49 years. The majority of participants were male (8/12) and time since injury for the majority of the participants (7/12) was greater than two years post their ABI. Cause of injury for the majority of participants (10/12) was a trauma.

The project results highlighted a number of key findings that have implications for brain injury rehabilitation services and service delivery. In summary:

- **Leisure satisfaction** - There was an overall significant improvement in the leisure satisfaction of participants from baseline to post intervention ($z = -2.35, p = 0.02$) and also from pre intervention to three months post intervention ($z = -3.06, p = 0.002$).
- **Quality of life**- There was an overall significant improvement in QOL from baseline to post intervention in the environment domain ($z = -2.59, p = 0.03$) and a significant improvement in QOL from baseline to three month post intervention in all four domains i.e. physical ($z = -2.67, p = 0.008$), psychological ($z = -2.4, p = 0.02$), social relationships ($z = -2.27, p = 0.02$) and environment ($z = -2.59, p = 0.01$).
- **Self Esteem**- There were no significant differences from baseline to post intervention ($z = -1.34, p = 0.2$), however there was a significant improvement in self esteem from baseline to three months post intervention ($z = -2.22, p = 0.03$).
- **Individual goals**- Of the 27 goals specified during the week long program, 22 of these goals were reported to have been achieved three month post intervention, with 11 of the 12 participants reporting to have achieved at least one of their goals.

Implications:

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. There are clearly indications of continued impact of learning for these people, and the demonstrated continued improvement in outcomes was indeed an important finding. 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.

Recommendations:

- That active leisure intervention groups 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 sample size 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 other brain injury rehabilitation services (BIRP's) and similarly evaluated.
- Further study to be carried out in relation to cost benefit or reduced re-hospitalisation.

Introduction

Acquired Brain Injury (ABI) is a traumatic life event for the majority of people who experience this condition. Individuals with ABI frequently experience changes to their ability to undertake their previous roles in society including work and social interaction. There are a range of therapies traditionally used to stimulate the engagement of people into leisure activities. This report presents the effects of group-based leisure intervention trialled in rural residents with ABI.

This paper includes a literature review of leisure participation, leisure satisfaction, community integration and quality of life following a brain injury and some of the various leisure intervention programs that have been trialled throughout Australia and other parts of the world to try to improve the quality of life within this population.

The project has two main aims firstly to measure the efficacy of a *Pushing the Boundaries* program in promoting leisure satisfaction amongst persons with an Acquired Brain Injury (ABI) living in rural, regional and remote NSW. The second aim is 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 have participated in this intervention as part of their rehabilitation.

Rigorous program evaluation is an essential aspect of service delivery and increased understanding of the personal effects of this intervention can only add to the continued development of evidence-based practice. This research is particularly relevant to health care and leisure professionals who work with people who have an ABI. The results may also be of interest to survivors of an ABI and their caregivers.

Background

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 and EBSCOhost (Health and Psychology). 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 groups, recreation, leisure satisfaction, leisure participation, quality of life, self esteem and community rehabilitation. International literature was considered, but only those papers written in English were included. Searched literature covered the period of 1980-2011. The most pertinent literature was found from 2003 onwards, indicating that leisure programs as a part of ABI rehabilitation is a relatively recent area of interest.

The burden of Acquired Brain Injury in Australia

Acquired brain injury (ABI) refers to any damage to the brain that occurs after birth. That damage can be caused by an accident or trauma, a stroke, brain infection, by alcohol or other drugs or by diseases of the brain. Brain Injury is a common condition with over half a

million people estimated to be living with ABI in Australia (Brain Injury Australia 2011). The features of Australians with ABI are as follows:

- three out of four are under age 65
- two out of every three of these people acquired their ABI before they turned 25
- three out of every four people with an ABI are men (Brain Injury Australia 2011).

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, however it is common for people with an ABI to suffer from the following:

- they may fatigue quickly and have difficulty with concentration and memory
- they may experience long-term changes in their ability to think and learn (cognition) and in their behaviour and personality (psychology)
- they may also experience communication difficulties and changes in their physical and sensory abilities (Brain Injury Australia 2011)
- at least 20% of individuals with Traumatic Brain Injury (TBI) will be re-hospitalized in the three years following their accident (Cifu et al. 1999)

As medical science improves so to does the number of people surviving ABI increase. This growing number of survivors has resulted in an increased need for rehabilitation services (Fines & Nichols 1994). Survivors of a moderate to severe traumatic brain injury (TBI) may have a life span approaching normal, but they often have to deal with permanent cognitive, physical, emotional, behavioral and psychological impairments (Brandstater et al 1991; Direnfeld 1990; & Kaplan 1988). The presence of ABI can often be associated with symptoms of depression, behavioral problems and substance abuse (Ommaya et. al 1996), post traumatic stress disorder (PTSD) or 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. Some believe 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 the ABI client must address their living environment, work life, recreational pursuits and maintenance of social networks (Dryovage and Seidmen 1992) .

ABI and leisure activities

Research on leisure indicates that involvement in leisure activities can have several positive effects on physical health, mental health, life satisfaction and psychological growth for adults without disabilities (Tinsley et al, 1993), and several studies have found that leisure seems to have similar benefits for people with acquired disabilities (Fines & Nichols 1994; Thomas 2004).

It is well documented that leisure is an important component in the lives of persons with disabilities and it is often associated with community involvement, life satisfaction, self esteem and depression (Danial & Manigandan 2005; Douglas, Dyson & Foreman 2006; Gemmell & Leathem 2006). 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 that rehabilitation services that can successfully increase leisure satisfaction, self esteem and QOL are likely to reduce the social burden and indeed re-hospitalisation associated with severe ABI (Douglas, Dyson & Foreman 2006).

Leisure pursuits, defined as “occupations for enjoyment” (Canadian Association of Occupational Therapists 1997), is just one area of role participation often adversely affected by ABI. A significant behavioral deficit experienced by persons with ABI is the decreased initiation of purposeful activity that may be especially important during leisure time (Davis & Chittum 1994). There are several studies that indicate that people with an ABI are often unable to return to previous leisure activities and have fewer interests than they did prior to their injury (Sloan, Winkler & Callaway 2004; Brown & Vanderdergoot 1998). They 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).

Several studies were found that discussed some of the barriers to participation in leisure activities for people with disabilities. Common barriers appear to be associated with transport in terms of both cost and distance to venues. Activities being held at locations which were not disability- friendly environments and a lack of congruence between an individual’s interests and the activities offered in their region was 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 found to play a role in determining participation levels. People with an ABI may also 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 certain leisure activities (Fines & Nichols 1994).

Leisure and recreation is an important focus of study for several reasons. Leisure is an important component in the lives of persons 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) we have little understanding about the meaning of leisure amongst people with a disability. There is much literature focused on leisure-skill acquisition for persons 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).

ABI and social interaction

Social participation in the community can be seriously compromised following ABI primarily because of cognitive and emotional/behavioural changes which have shown to be challenges to the individuals’ social networks (Brown, Gordon & 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 (Douglass & Spellacy 1996 ; Callaway, Sloan & Winkler 2005). 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) (Douglass & Spellacy 1996). Studies also suggest that social isolation and dissatisfaction with social networks tends to increase over time and often leads to secondary psychological sequelae (Callaway et al. 2005; Burleigh et al. 1998). 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). Participation in leisure activity has been demonstrated as an important factor in terms of life satisfaction, subjective well-being, perceived quality of life and social integration following an ABI (Malley, Cooper & Cope, 2008).

As individuals become less vocationally active, such as after an ABI, voluntary engagement in social activity increases in importance to the person's well-being (Brown, Gorden & Spielman 2003). However research has demonstrated that after an ABI there is persistent disability in the two areas of interpersonal relationships and leisure activities (Douglas, Dyson & Foreman 2006; Dikman et al. 2003).

Rehabilitation and ABI

Engagement in leisure activities is increasingly recognised as an important determinant of QOL (Lynne Turner-Strokes 2003) and is now a recognised health domain in the World Health Organisation International Classification of Functioning Disability and Health (ICF) (Lynne Turner-Strokes 2003). Despite leisure gaining much more importance over the years and has now been accepted broadly as part of the triad of occupational performance (self-care, work & leisure) in rehabilitation literature, only a little has been written in terms of the effects of leisure interventions (Daniel & Manigandan 2005).

No studies were found that specifically evaluated leisure programs for rural people with ABI. However several research papers were found that have some similarities to this study. Thomas (2004) looked at the outcomes of two Potential Unlimited Programs (PUP) to determine participant outcomes related to adjustment to ABI and to investigate the contribution of the group work component of the program. 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. Thomas's study found 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 concluded that the combination of outdoor experiential education with extensive group work found 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.

Douglas, Dyson & Foreman (2006) found that adults with severe ABI 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 Community Integration

Questionnaire: Social integration subscale and the Depression subscale of the Neurobehavioral Functioning Inventory respectively. This program provided funding for transport to and from activities and this was seen as an important facilitator to the program. The group of six participants who were engaged regularly in community leisure activities also reported improved QOL, but these changes were not statistically significant. The small sample size and low statistical power of this study limit the ability of this particular study to detect potential treatment effects.

A study by Fines & Nichols (1994) explored the effects of a twelve week active rehabilitation program (kayaking) on the self-concept, leisure satisfaction and leisure attitude of eight adults who had sustained a TBI in the United States. The kayak program was offered once per week (60-90 minutes) for twelve 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" (TSCS) as well as all six components of the Leisure Satisfaction Scale (LSS). Significant changes were also noted in the Affective and Behavioral scores of the Leisure Attitude Score (LAS).

Many people with spinal cord injury (SCI) have similar personal and environmental factors as those with ABI, such as unemployment and subsequent lack of finances, lack of motivation, attitudinal and architectural barriers (Costilow et.al.1982) which deprive them of participation in a number of leisure activities. A study by Daniel & Manigandan (2005) attempted to improve QOL by improving leisure satisfaction in people with a SCI. They assessed the effects of a leisure intervention program conducted in a rehabilitation department in India amongst people with a SCI, and it was evident from the results of the study that leisure intervention groups facilitated both leisure satisfaction and improved quality of life amongst people with a spinal cord injury. This leisure intervention program was implemented early in the rehabilitation process. Similar to our intervention "importance of leisure", "problems faced in leisure participation", "strategies employed to overcome these problems" and "home tasks" were included for specific discussion. Danial & Manigandan (2005) attributed the success of this program to group therapy, which in their opinion provided a supportive environment, facilitated interaction amongst peers, reduced feelings of isolation, alienation and helplessness and enhanced active coping and improved mood. According to Danial & Manigandan (2005) the group therapy was easy to implement, replicate and cost effective.

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 clients towards leisure and assisting them to choose a leisure activity that interests them. Following an ABI there are many variations to how the individual adjusts to their deficits which may be cognitive, physical or both, and whether they are satisfied with their QOL (Willer & Corrigan 1994). Many people who sustain an ABI experience long term disability and are unable to return to their usual

activities in the workplace, community and at home. Rehabilitation services that can successfully increase leisure satisfaction and QOL are likely to reduce the social burden associated with severe ABI. Facilitating the restoration of the QOL of survivors is one of the fundamental aims of community-based ABI rehabilitation (Thomas 2004).

Much research continues to be required to better meet the needs of this population, however it is clear that programs that facilitate leisure satisfaction are a key component of their long term rehabilitation and rigorous program evaluation is an essential aspect of service delivery (Douglas, Dyson & Foreman 2006).

The findings of this study should prove useful in determining the efficacy of the program and supporting the assumption that leisure satisfaction is an important component in the lives of adults with an ABI living in rural, regional and remote NSW and can lead to an improved QOL.

The South West Brain Injury Rehabilitation Service (SWBIRS)

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. 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 persons and extends from Barham Koondrook in the west, the Great Dividing Range in the east, the Murray River in the south and West Wyalong in the north.

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. The transitional living program at Albury means that up to six distant residing clients can have access to intensive brain injury specialist services. 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 Leisure intervention *Pushing the Boundaries* program

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. 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 was our current 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 week also involved sessions on social communication skills and how to engage in conversation appropriately with the opportunity of practicing these

techniques daily. Anecdotal evidence from staff deemed the program a success and with some modifications three similar programs were run in the seven months from August 2010 to February 2011 with four participants successfully completing each program. This innovative program was held after the inpatient rehabilitation was completed and was focused on recovery in a much broader and holistic sense.

Participants of the program were recruited by open invitation sent to 100 past and present clients of SWBIRS. Inclusion criteria for participation in the program required them to :

- a) be adults aged between 18 and 60 years
- b) 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
- c) be a current or previous client of SWBIRS
- d) have completed their inpatient rehabilitation program and
- e) have the cognitive capacity to take on new skills.

Exclusion criteria included any serious co-morbid physical or psychiatric illness and drug and alcohol problems currently not under control.

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 area.

Participants were grouped according to their age and the geographical location of their home. Some participants travelled up to 450 km to attend the program. The residential week was designed to provide clients with the opportunity to trial 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 included sailing, clay target shooting, bushwalking, tai chi, fishing, pool, tennis, table tennis, wii nintendo, volleyball, netball, soccer games, movies, socialising and eating out.

The objective of the week was twofold, that is for clients to trial a range of recreational activities with support so that they may participate in some of these activities in their own community with increased confidence and secondly for clients to improve their communication skills and strategies to enable them to meet people and form friendships in their own community.

During the week there were numerous opportunities to discuss as a group what is appropriate conversation and how do you get what you 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. Our aim was that during the

program each participant would a) participate in a minimum of six recreational activities, b) improve confidence and participation in social situations, c) develop communication skills to interact within their community in a meaningful way and d) make gains towards their individual social and recreation goals for when they return home. There was time 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 there was time allocated within the week for participants to meet with this person and make enquiries into recreational activities within their own local communities. They were encouraged to sit down daily with their key person and plan ahead for implementing the program at home. The program provided a supportive and structured environment in which to develop achievable leisure goals within an encouraging group environment.

This project attempted to answer the question does the participation in a leisure intervention program such as *Pushing the Boundaries* improve the leisure satisfaction, self esteem and quality of life amongst persons with an ABI living in rural, regional and remote NSW?"

Method

Study design

This program evaluation utilised a pre and post intervention design examining the changes in leisure participation, leisure satisfaction, self esteem and QOL amongst ABI patients who had recently completed a week long intensive leisure intervention program at SWBIRS.

Recruitment

Participants of the research were self-selected adult volunteers with an ABI who attended the week long *Pushing the Boundaries* program at SWBIRS. 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.

One hundred of our most recent clients were posted an invitation to participate in both the program and the research and of these 13 were enrolled into the program. All 13 participants of the program gave their informed consent to be involved in the research. Twelve participants completed the program and one withdrew from both the program and the research due to illness.

Data collection

Participants completed the Leisure Satisfaction Scale (LSS), Rosenberg Self Esteem Scale (RSES) and the World Health Organisation Quality of Life –Bref (WHOQOL-BREF) by individual interview with the researcher prior to each program, immediately following and at three months post program as part of normal clinical practice. Data used in this research were extracted from the medical records of those participants who had given written consent for inclusion in the study.

Individual goals generated throughout the week long program were also investigated in this study and participants were interviewed at the three month follow up and asked whether their goals had been achieved.

Instruments used

At each time point participants completed the LSS, RSES and the WHOQOL-BREF.

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

The WHOQOL–BREF is a shorter version of the original instrument and has been developed to provide a short QOL assessment comprising of 26 items which measure the following 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).

The RSES 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. The RSES demonstrates a Guttman scale coefficient of reproducibility of 0.92, indicating excellent internal consistency. Test-retest reliability over a period of 2 weeks reveals correlations of 0.85 and 0.88 indicating excellent stability. It also demonstrates concurrent, predictive and construct validity and correlates in the predicted direction with measures of depression and anxiety (Rosenberg 1979).

General demographic data were extracted from the patients' medical records together with each participants individual goals that were generated during the intervention program and discussed daily with their key person. Three months post program participants were asked if they felt they had achieved the leisure goals they had set themselves with a yes or no reply. They were also invited to give comments about their goal attainments and the program in general (see Appendix 1).

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.

Other outcome measures used were the individual goals that each client generated during the intervention. The goals specified by clients during the week were compared to the

participants' subjective rating of goal achievement three months post program to see how many goals had been achieved.

Ethical approval

Ethics approval for this study was obtained from the Greater Southern Human Research Ethics Committee (HREC) in February 2010.

Results

Of the 13 participants who commenced both the leisure program and the research one withdrew from the program due to illness, 12 participants completed the program (8 men and 4 women) and the results from these 12 people are reported here. Baseline data from the participant who withdrew from the program was not included in the analysis. The mean age of the clients was 36 years (range 19-49 years) all of whom had sustained a medium to severe ABI. The majority of participants were male and educated to at least secondary school level with only one participant having employment (part-time) at the time of baseline data collection. Time since injury for the majority of the participants was greater than 2 years post their ABI. Cause of injury for the majority of participants (10/12) was a TBI. 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. Demographic information for the combined groups is provided in Table 1. The participants in this study match up 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 received their injury from trauma.

Table 1

Demographic information for participants of Pushing the Boundaries

Participant demographics

Mean age in years (min-max)	36 (19-49)
Sex	8 Males, 4 Females
Marital status	8 Unmarried, 4 Married
Time since injury	
< 12 months	1
12 – 24 months	4
24 months – 48 months	7
Cause of injury	
Traumatic brain injury	10
Non traumatic ABI	2
Residence (RRMA Classification)	
Large regional centre	3
Rural/remote centre	9

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 whilst mobilising in the community whilst the remainder of the participants were independently mobile.

Table 2 shows the baseline and post intervention scores for the LSS, WHO QOL-BREF and RSES. There was a significant improvement in the LSS ($p = 0.02$) and Domain 4 (Environment) of the WHOQOL – BREF ($p = 0.03$) following the intervention, with Domain 1 (Physical) ($p = 0.09$) and Domain 3 (Social relationships) ($p = 0.08$) approaching significance. There was no significant change in the RSES following the intervention.

Table 2

Leisure satisfaction, quality of life and self esteem scores before and immediately after completing a Pushing the Boundaries program

	Pre-intervention Median (IQR)	Post-Intervention Median (IQR)	p-value
Leisure satisfaction scale	70.5 (60-82)	100.5 (89-105)	0.02*
WHOQOL –Bref			
Physical	25 (19- 28)	26 (24-28)	0.09
Psychological	18(16-21)	20.5 (19-23)	<0.1
Social relationships	9 (7-12)	12 (8-14)	0.08
Environment	27 (21-35)	33 (30-37)	0.03*
Rosenburg self esteem scale	15 (14-19)	17.5 (16-19)	<0.1

* indicates significant finding with $P<0.05$

Table 3 shows the baseline and 3 month post intervention scores for 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 ($p = 0.002$), all domains of the WHOQOL –BREF (physical $p = 0.008$; psychological $p = 0.02$; social relationships $p = 0.02$; environment $p = 0.01$) and RSES ($p = 0.03$). This indicates significant increases in the subjects leisure satisfaction, QOL and self esteem.

Table 3

Leisure satisfaction, quality of life and self esteem scores before and 3 months post completing a Pushing the Boundaries program

	Pre-intervention Median (IQR)	3 month post intervention Median (IQR)	p-value
Leisure satisfaction scale	70.5 (60-82)	101 (97-110)	0.002*
WHOQOL –Bref			
Physical	25 (19-28)	29 (21-30)	0.008*
Psychological	18 (16-21)	22 (21-23)	0.02*
Social relationships	9 (7-12)	12 (10-14)	0.02*
Environment	27 (21-35)	33 (31-37)	0.01*
Rosenburg self esteem scale	15 (14-19)	20.5 (17-24)	0.03*

* indicates significant finding with $P<0.05$

Individual Goals

The efficacy of the program could also 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” whilst 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 of these goals were reported to have been achieved three month post intervention as shown in Table 4. Four of the participants also reported that they had developed new goals when they got home and they were now participating in leisure activities that were more meaningful to them than 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.

Table 4

Goals specified throughout the week long Pushing the Boundaries program and the participants subjective rating of goal achievement 3 months post intervention

Goal	No. specified	No. achieved
To try a new leisure activity in my area	3	3
To get fit	4	4
Identify leisure activities that work with my daily schedule	1	1
Achieve better balance between work and leisure	1	1
Return to playing cricket	1	1
Start soccer training	1	1
Play golf regularly	2	1
Play a game of golf with my Pop	1	1
Play ten pin bowling once per fortnight	1	1
Play pool at the club each week	1	1
Return to playing social netball	1	0
Take up Zumba dancing	1	0
Start Tai Chi	1	0
Go fishing regularly	1	1
Get involved in coaching the Under 12 cricket team	1	1
To do more horse riding	1	1
To do more bike riding	1	1
To investigate what is needed to get a pilots license	1	1
To go shooting and investigate getting a shooters license	1	0
Attend the gym regularly	1	1
Investigate the possibility of getting a personal trainer	1	1
Total	27	22

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 summarized in Table 5.

Table 5

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)
-

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, such as “I wouldn't have thought about playing golf”, and “I have played several games of pool now and are more confident that I will continue to play now”. Other participants focussed on a more global increase in confidence and willingness to undertake new tasks, “I wouldn't have done any 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 feedback on the program itself was positive, with comments ranging from “the program made me realise that I am a bit isolated in my situation and that I actually like being with other people” and “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”. A complete list of the comments can be seen in Appendix 1.

Discussion

This research was conducted to gain insight into the experiences of adults with an ABI who live in rural, regional and remote NSW who have participated in a leisure intervention program called *Pushing the Boundaries*. Results demonstrated significant improvement in leisure satisfaction, self esteem and quality of life scores from baseline to three months for participants of the program. These results add to an increasing body of evidence indicating that participation in leisure intervention programs can have several positive effects on leisure satisfaction, quality of life and self esteem for adults with an ABI (Lynne Turner-Strokes 2003; Kinney and Coyle 1992; Fines & Nichols 1994).

From pre intervention to post intervention the change in scores reflected significant improvement in the LSS and environment domain of the WHOQOL – BREF. Changes made from pre to post intervention for the physical and social relationship domain of the WHOQOL –BREF were approaching significance. For self esteem and the psychological domain of the WHOQOL –BREF although changes were not statistically significant from baseline to post intervention there was some change depicting a positive trend. The interesting thing is 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 outcome measures including the LSS, all domains of the WHOQOL –BREF and the RSES. These important findings suggest that the learning and skill development that was 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 kms away and were still returning strong results at the three month follow up.

The program was associated with the achievement of approximately 70% of the participants identified goals. However evaluating the number of goals achieved can only be considered an estimation, as the goal achievement was self-determined by the participants, and although many of the goals were objective in nature e.g. play ten pin bowling once per fortnight, many of the goals changed and became more subjective over time. None the less participants felt they had achieved their goal even if they hadn't.

Transportation was reported as being the most common barrier to the 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 studies (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 the study by Douglas, Dyson & Foreman (2006) included physical health problems and social anxiety. Major barriers reported by several of the participants included a wide range of physical problems including pain, balance problems, fatigue, deconditioning and weakness. There is limited information in the comments given by participants three month post intervention to suggest that there may have been changes in some of the perceived barriers particularly around an increase in confidence and motivation to participate, however no data was collected to confirm this.

Although *Pushing the Boundaries* and the program described by Danial & Manigandan (2005) are very different, similar improvements in leisure satisfaction and quality of life were achieved with a very different target population (ABI versus SCI) at a different stage in their rehabilitation. As discussed previously, many people with SCI experience similar personal and environmental factors as those with ABI, such as unemployment and subsequent lack of finances, lack of motivation, attitudinal and architectural barriers which may act as barriers to their participation in a number of leisure activities. Danial & Manigandan (2005) attributed the success of this program to group therapy, which in their opinion provided a supportive environment, facilitated interaction amongst peers, reduced feelings of isolation, alienation and helplessness and enhanced active coping and improved mood. The findings of this study add further weight to this assertion.

The results of this study are highly encouraging given the particularly good outcome, the efficient use of resources and the difficulty of maintaining gains following non-pharmacological interventions. 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 indicate that this innovative intervention may indeed be useful as a supplementary tool in the rehabilitation of adults with an ABI.

Limitations & strengths

The role of the intervention itself in helping participants to achieve improvements in leisure satisfaction and quality of life can only be inferred given that there was no control group and the sample size was small (12). In order to confirm the findings replication would be desirable. Likewise follow-up of participants over a longer time period would be advantageous to determine how well gains are maintained. A limited 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 may include the high completion rate, the use of validated scales and the fact that this research has not previously been undertaken making this research somewhat unique. The small sample size showing significant results is also an indication that there is likely to be clinically relevant changes. The value of the results is strengthened by the analysis of the participants' goal achievements and comments.

Conclusion

This project aimed to answer the question does the participation in a leisure intervention program such as *Pushing the Boundaries* improve the leisure satisfaction, self esteem and quality of life amongst persons with an ABI living in rural, regional and remote NSW? The results clearly show that participation in this program has lead to significant improvements in leisure satisfaction, self esteem and quality of life three months post program for its participants.

Participation in this program assisted these people to develop and achieve realistic leisure goals within their own communities. Those who participated described that the program made a difference to their lives and how they felt. The differences were also evident on 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 quality of life, 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 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. We believe the *Pushing the Boundaries* program developed by SWBIRS is both a practical and innovative program which is focused on recovery in a much broader and holistic sense. 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 could also prove valuable in determining justification for replication of this program in similar rehabilitation settings.

Recommendations

- That active leisure intervention groups 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 sample size 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 other brain injury rehabilitation services (BIRP's) and similarly evaluated.
- Further study to be carried out in relation to cost benefit or reduced re-hospitalisation.

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Appendix 1

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.
- 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 probably 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 on my bike and felt tired afterwards which a great feeling”.