



Participation following traumatic brain injury in rural New South Wales

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Abstract

'Participation' refers to involvement in life activities, from work and study through to recreation and socialising. Participation is acknowledged as important not just at an individual level but also for the well-being of the community and society as a whole. The assumption is that where there are significant levels of social participation there is a healthy community.

Participation is also the end goal of most rehabilitation. Yet relatively little is known about participation in country people with chronic diseases. This paper will outline the concept of participation and then present the preliminary findings of a two-year state-wide project on participation following traumatic brain injury (TBI) amongst people living in rural areas of NSW. It relates to two of the conference themes: 'evidence, access and equity in rural and remote areas' and 'chronic disease in rural and remote Australia'.

The aim of our Participation Project is to describe participation following TBI rehabilitation for up to 180 people living in rural, regional and remote NSW, using both quantitative and qualitative methods, and to consider possible associated internal and external factors such as demographic variables, location of residence, severity of injury, rehabilitation, cognitive status and self-efficacy.

This information will then be used to inform policy and practice regarding rehabilitation guidelines for enhancing participation of people with brain injury, especially those in non-metropolitan areas.

By the end of 2006 (the first year of the Participation Project), all surveys with people with brain injury and their significant others will have been completed. This paper will include a summary of the results including descriptive statistics and stepwise regression used to examine the relative contributions of rurality and other variables to participation.

This paper will discuss the implications of our findings for clinical practice, including how clinicians may enhance their rural clients' participation through more effective rehabilitation programs.

Finally we will outline the relevance of the findings for other rural health service providers. Given that participation is a concept of importance to most clinicians, the outcomes are likely to be of interest to a range of rural health practitioners.

The Participation Project is funded by an Australian Research Council Linkage Grant and NSW Health. It is a joint initiative of Charles Sturt University, the South West Brain Injury Rehabilitation Service (in Albury) and the seven other rural Brain Injury Rehabilitation Services in NSW.

Presenter

Alison Winkworth, PhD, is a speech pathologist and academic, currently the speech pathology course co-ordinator in the School of Community Health at Charles Sturt University based in Albury, NSW. She has worked at the University of Sydney, the University of Queensland and in 2004 was a visiting professor at Gothenburg University in Sweden. She has clinical, research and case management experience in brain injury and is a member of the collaborative interdisciplinary Rural Rehabilitation Research – Brain Injury group.

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Charles Sturt University
South Western Brain Injury Rehabilitation Service
and the 7 other regional Brain Injury services

The Participation Project

- To describe participation outcomes following TBI in rural, regional and remote areas

- Collaboration
- ARC Linkage grant
- NSW Health funding





NEW SOUTH WALES



BROKEN HILL

DUBBO

BATHURST

SYDNEY

GOULBURN

WAGGA WAGGA

CANBERRA

ALBURY / WODONGA

People with TBI living in country areas

- Finished rehab
- Participation outcomes
- Factors associated
- Two stage project: Questionnaire study and qualitative interviews



The Participation Project: Stage 1 – Quantitative measures.

Describe participation

- Participation objective and subjective
- Self efficacy
- Relationship
- Does *where* you live matter? (RRR)
- Injury, rehab and demographic factors
- Cognitive factors, behaviour difficulties

More specifically:

- Describe participation according to regionality: regional, rural and remote (ARIA index)
- Explore demographic and other factors in participation: age, gender, SES, injury severity, rehabilitation, cognitive function, self-efficacy, close relationships.
- Factors associated with 'strong' versus 'weak' participators
- Clients' and significant others' views
- Ultimately inform policy and practice, re rehab guidelines

The impact of TBI on an individual:

- Internal: cognitive, social skills, coping, emotion, self esteem, motivation, self control, neurological, medical....
- External: lifestyle changes, financial, transport, relationships, life roles, independence.....
- The association with participation?

Participation is good because....

- Best practice rehab - integration and participation
- Participation linked with positive social support
- Improved recovery from illness
- Reduced likelihood of death

Rural communities

- Close knit, friendly, helpful, civic minded
- or
- Less diverse, more wary, less likely to accept difference
- stigma, isolation,
- lack of privacy,
- long distances,
- lack of services



The Participation Project: Stage 2

Qualitative study –
interviews

- views of participation, identity, community
- Satisfaction with own participation
- Facilitators of participation



Preliminary results: who are the participants in the project?

- N= 164 people with TBI, finished rehab, 2 yrs or more post injury
- Living rural, regional or remote
- Identified and surveyed by 8 regional BIRPs in NSW
- 70% male

Age range and distribution



Years post injury (min=2)

- 62% of participants 2-7 years post injury
- Remaining 38% ranged from 8 to 32 years post injury

Where do participants live?

- Locations classified by ARIA codes, categorised as highly accessible to very remote
- 44% of participants live in major regional centres considered “highly accessible.”
- 51% live in “accessible” places
- 4% live in “moderately accessible” places

Examples of “highly accessible” places (44%)

Albury

Wollongong &
suburbs

Alstonville

Ballina

Berkeley

Booragul

Cabarita

Cardiff

Carrington

Clarencetown

Downside

Eleebana

Farmborough
Heights

Glendale

Goulburn

Hawker

Kanahooka

Kiama Downs

Kirra

Macquarie Hills

Maryland 2

Metford

Minamurra

Murrumbateman

Newcastle etc

Nowra

Oak Flats

Ourimbah

Port Kembla

Rothbury Nth

St James

Swansea

Jerrabomberra

Thirroul

Tweed Heads

Wagga

Wahgunyah

Womborra

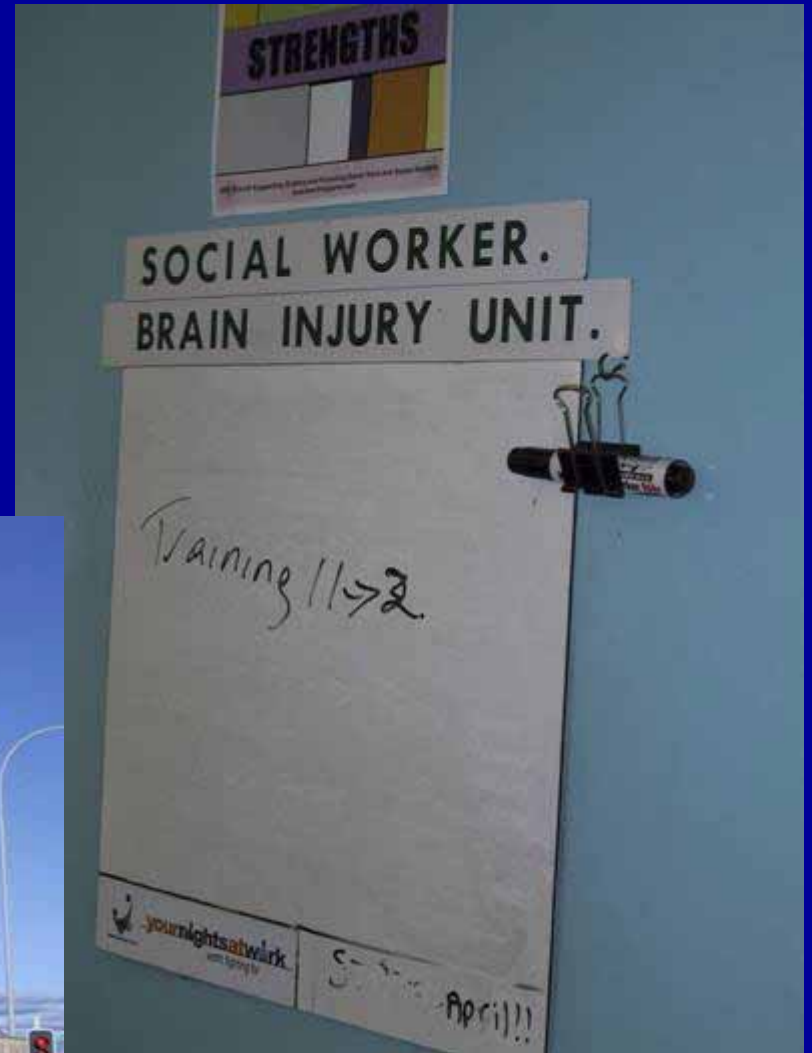
Wonoona



Examples of “accessible” places (51%)

Armidale	Euchareena	Oberon
Attunga	Finley	Orange
Batemans Bay	Glen Innes	Parkes
Bathurst/Kelso	Glenthorne	Port Macquarie
Billimari	Gloucester	Rylstone
Bingi	Gulgong	Sandy Beach
Boambee	Gunnedah	Stuart Town
Bogan Gate	Junee	Tallangatta
Booroowa	Kootingal	Tamworth
Broulee	Lake Cathie	Temora
Canowindra	Lithgow	Tocumwal
Casino	Lockhart	Tuncurry
Coffs Harbour / Sawtell	Merrima	Walbundrie
Cooma	Moruya	Wauchope
Cowra	Myrtleford	Werris Creek
Cullendulla	Narooma	Woomargama
Deniliquin	Narrandera	Yanco
Dubbo		Young





Examples of “moderately accessible” places (4%)

- West
Wyalong
- Griffith
- Narrabri
- Merimbula
- Narromine
- Gilgandra

Participation survey “POPS”

Participation Objective, Participation Subjective

- Typical activities including socialising:
 - how **often** (“*objective*”);
 - is that amount **satisfactory** for you (“*subjective*”);
 - how **important** is that activity for you (“*subjective*”).
- Brown, Dijkers, Gordon, Ashman, Charatz & Cheng (2004)

Item content of the POPS

- Shopping, preparing meals, cleaning, caring for children or others, organising social things, paying bills, home repairs, gardening, other, working for pay, volunteering, studying, driving, socialising (with friends at home or by phone, with relatives, coworkers), going out, intimacy, meeting new people, speaking with neighbours, speaking with strangers, going to the movies, eating out, attend religious services, attend sports events.....

Sample items - POPS

In a typical day / week / month, how many
TIMES do you.....

14. Socialise with friends, by phone or at your
home? _____ D W M

15. Socialise with relatives, by phone or at your
home? (*NB does not include relatives you live
with.*) _____ D W M

What are the most important activities?

Top ranked:

Working for pay

Intimacy

Paying bills

Driving a car

Socialising with relatives (phone or at home)

What are “very important” activities?

Top ranked:

- Socialising with friends (phone/home)
- Going out
- Socialising with relatives (phone/home)
- Paying bills

Participation subjective

- Is the amount of that activity **satisfactory** for you?
No = negative score.
- How **important** is that activity to you?
=rating 1 (a little bit) to 4 (most)

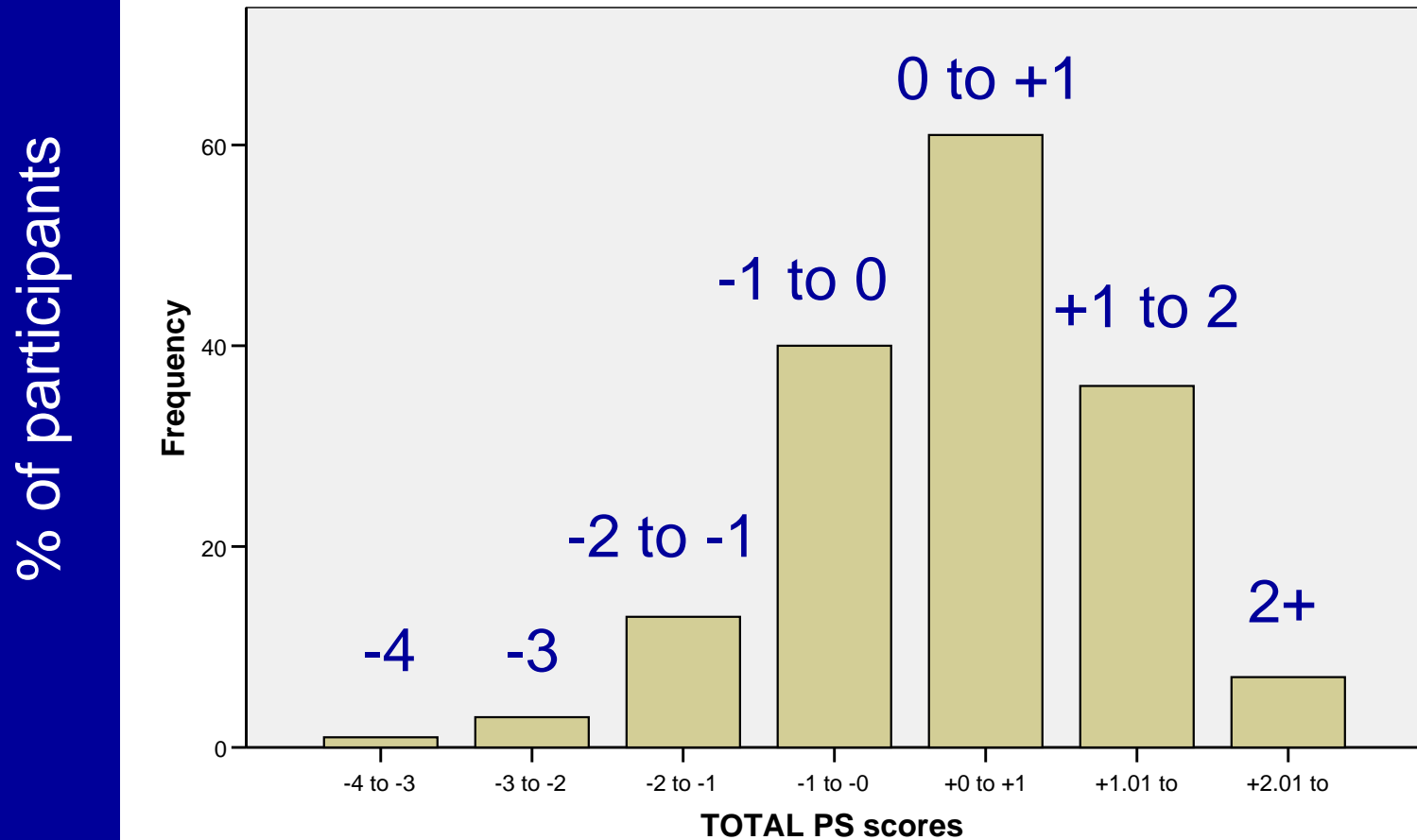
Satisfaction X Importance = subjective score, averaged over all items.

= the overall importance of all activity items, multiplied by how satisfied you are with how often you do that activity.

Range possible = -4 to +4

Participation Subjective Scores

Frequency of Total Participation Subjective Scores (-4 to +4)



Own definition of community integration - people with TBI

(McColl et al., 1998)

- Know how to blend, conform
- Oriented
- Accepted
- Form relationships
- Leisure
- Occupations that allow engagement
- Be independent or
- Live independently



PARTICIPATION

- We can't change things like injury severity
- But rehab works, if people complete it.
- How do we improve take up and completion of rehab?
- Internal factors: coping skills, attitude, resilience
- We can *influence* internal factors in rehab
- For example, adaptive responses to challenges; attitudes, improving emotional control, insight

