CHALLENGES IN ASSESSING AND IMPROVING OUTCOME FOLLOWING TRAUMATIC BRAIN INJURY?

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Epworth HealthCare

Traumatic brain injury….

- Most frequent in young males
- May occur in those with a history of learning disability, prior psychiatric or substance use problems and/or unemployment
- Causes diffuse and variable injury
- Affects cognitive, behavioural and emotional, as well as physical functions
- Recovery occurs over a lengthy time-frame
- Disrupts attainment of important life goals (independence, work/education, relationships)

Epworth Rehabilitation Centre

Head Injury Rehabilitation Programme

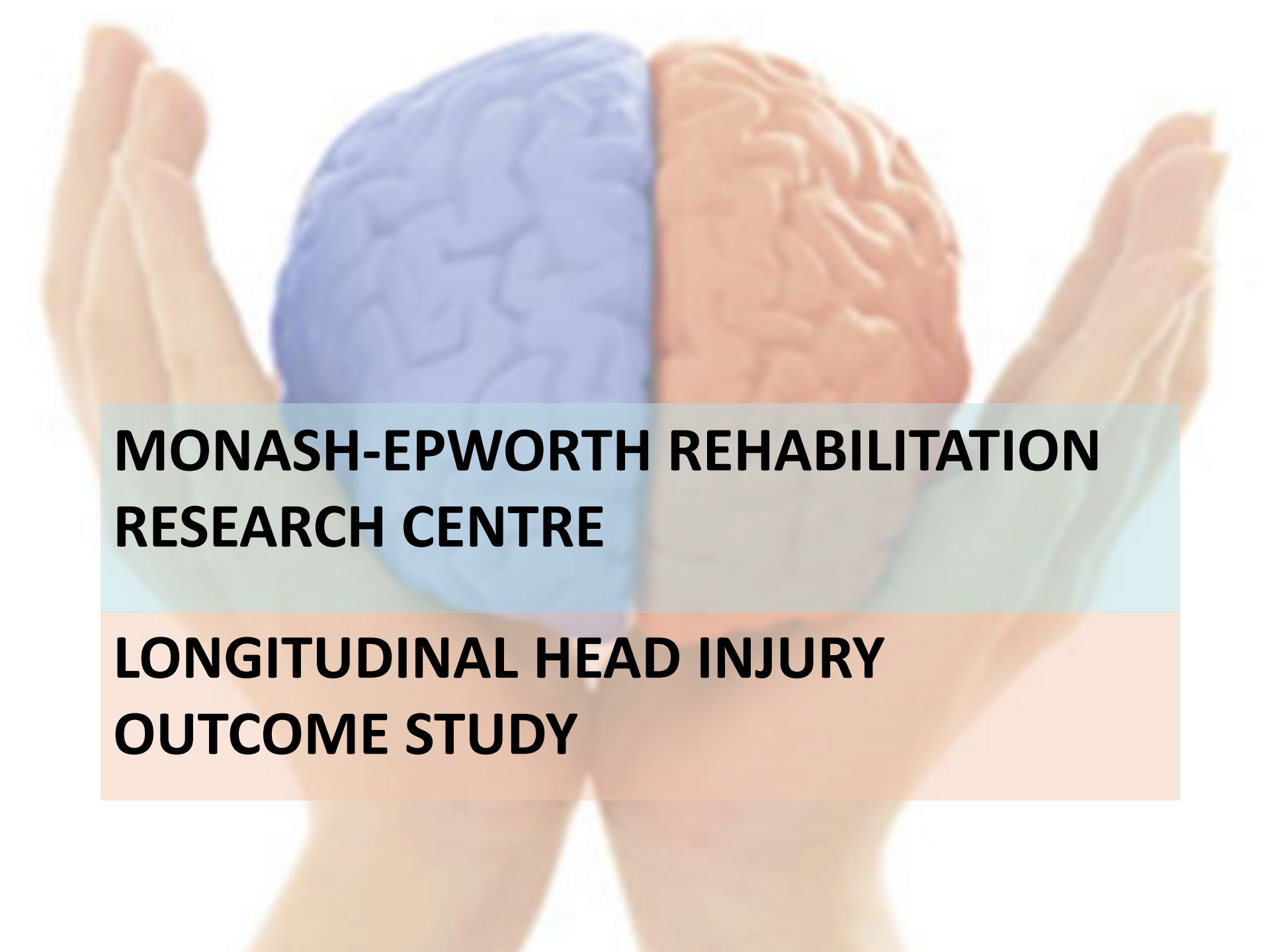
- Inpatient programmes at two hospitals - average length of stay 26 days
- Community-based rehabilitation programme
- Transitional Living Centre

Transitional Living Centre

TAC TRANSPORT ACCIDENT COMMISSION

Responsible for all costs of:

- hospital care,
- rehabilitation and
- long-term care needs, including attendant care, integration aides, sponsorship of work trials, home help, etc.



MONASH-EPWORTH REHABILITATION RESEARCH CENTRE

LONGITUDINAL HEAD INJURY OUTCOME STUDY

Aims of Longitudinal Head Injury Outcome Study

- To document outcome 1, 2, 3, 5 and 10 years following TBI, identifying ongoing needs as basis for programme changes
- To investigate factors predicting cognitive, functional, employment/study and psychosocial outcomes
- To evaluate interventions to improve outcomes

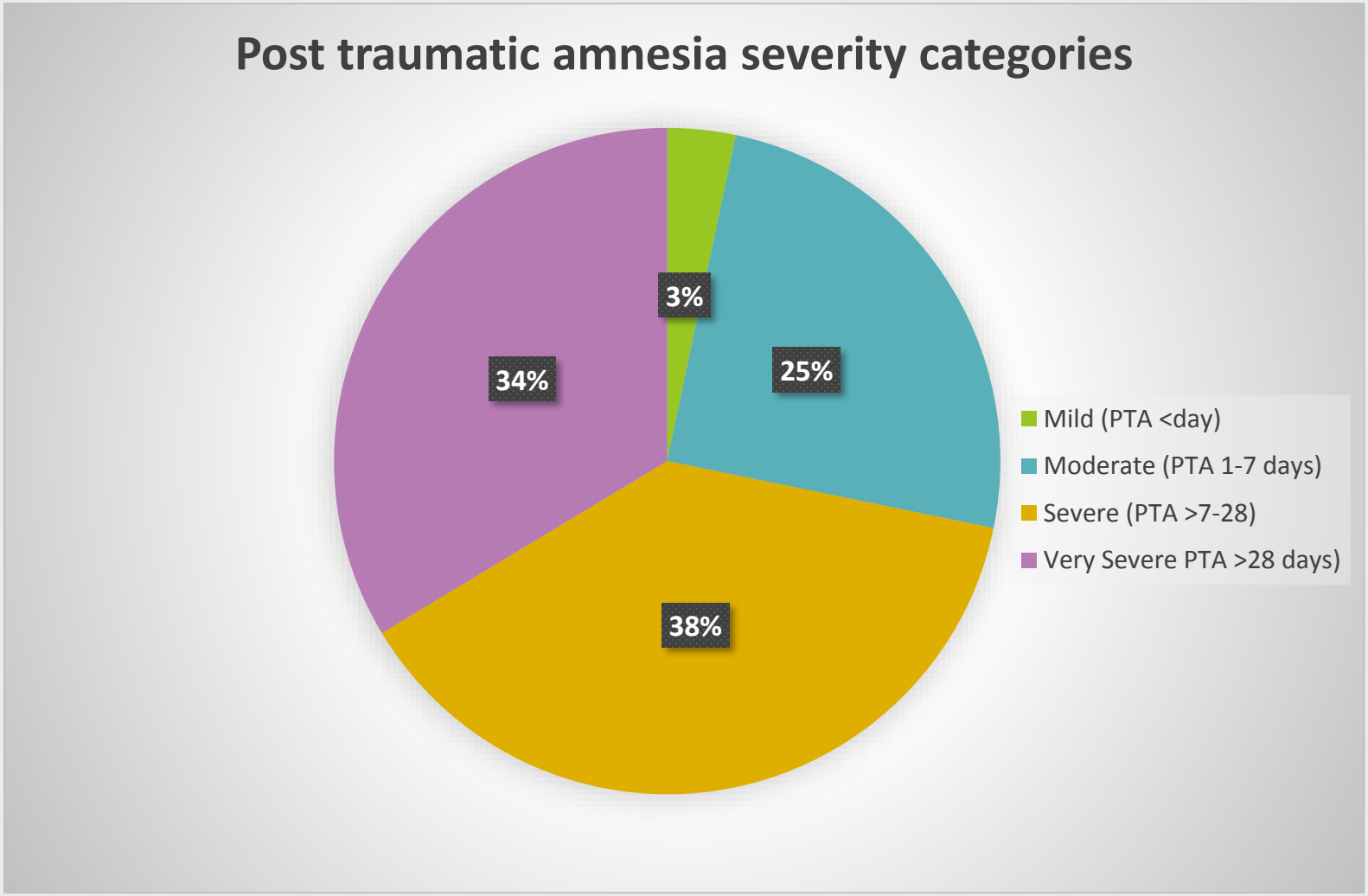
Longitudinal head injury outcome study

- Over 2600 TBI patients followed up:
  - 1734 at 1 year
  - 1655 at 2 years
  - 1249 at 3 years
  - 1177 at 5 years
  - 544 at 10 years
  - 208 at 20 years
- Funding:
  - 83% TAC
  - 14% Workcover
  - 3% other
- Injury Cause:
  - 57% motor vehicle accidents
  - 11% motorcycle accidents
  - 18% pedestrians
  - 4% cyclists
  - 10% other

Demographics and injury severity by sample

Years post-injury	1		2		3		5		10	
	M (SD)	range	M (SD)	range	M (SD)	range	M (SD)	range	M (SD)	range
Education (years)	11.29 (2.45)	3-22	11.30 (2.43)	3-22	11.35 (2.43)	3-21	11.32 (2.39)	3-21	11.41 (2.37)	3-21
Age at Inj	35.11 (17.31)	13-90	34.44 (16.71)	10-89	35.19 (16.48)	13-89	32.28 (15.54)	10-79	32.01 (14.54)	10-73
GCS	8.21 (4.34)	3-15	7.88 (4.32)	3-15	8.02 (4.30)	3-15	7.56 (4.16)	3-15	6.73 (3.98)	3-15
PTA (days)	25.52 (28.46)	.01-270	29.84 (33.22)	.01-270	27.62 (30.63)	.01-240	31.76 (35.29)	.01-270	36.39 (38.83)	.01-185

Injury severity



Control Group Demographics

(n=215, 101 males)

Years post-injury	Mean	SD	Range
Age (years)	34.3	15.8	15-84
Education (years)	13.1	2.8	6-21

Glasgow Outcome Scale-Extended (GOS-E)

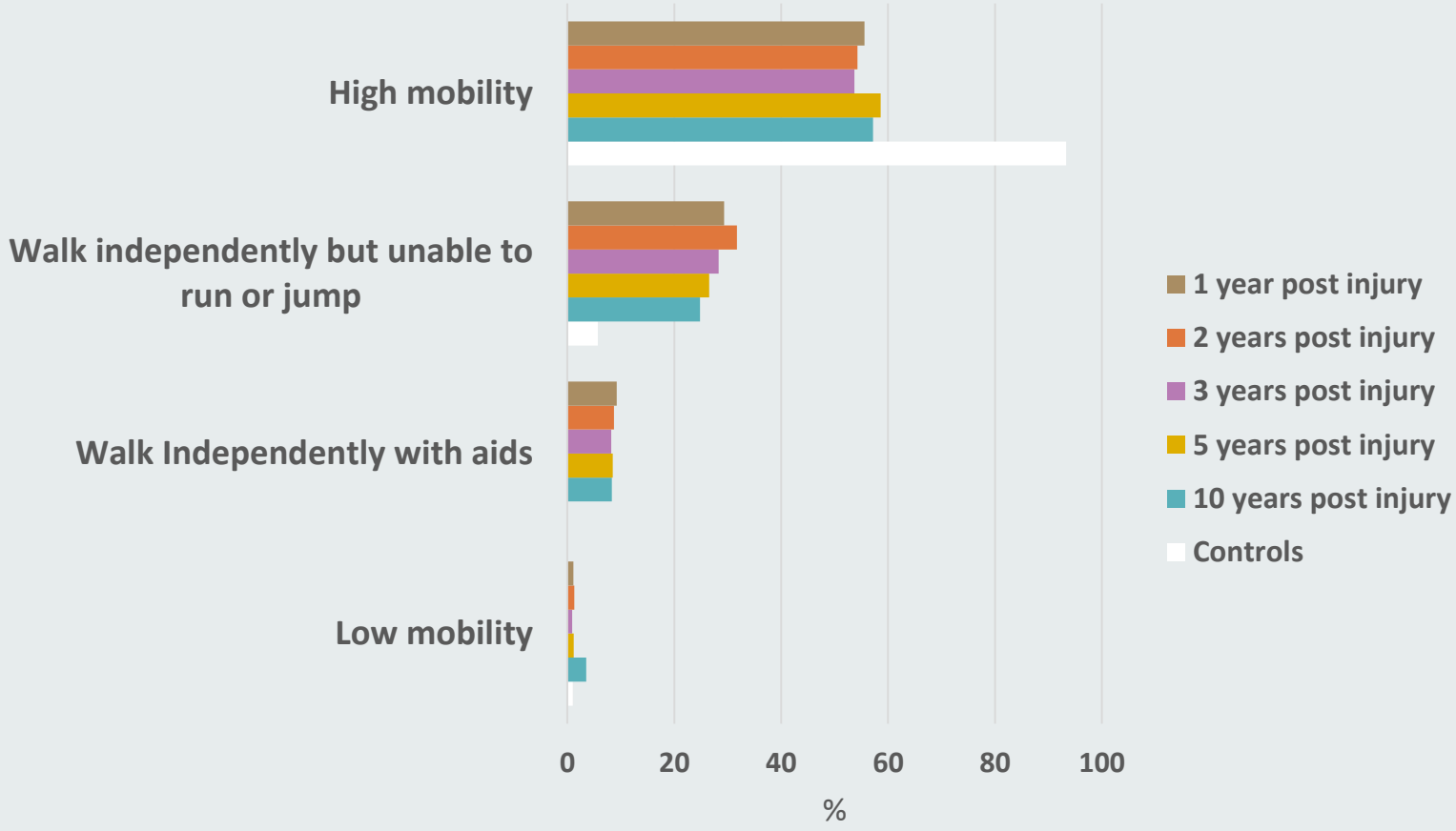
1 – Dead **2 – Vegetative State (VS)**	**Condition of unawareness with only reflex responses but with periods of spontaneous eye opening.**
3 – Low Severe Disability (SD-) **4 – Upper Severe Disability (SD+)**	**Patient who is dependent for daily support for mental or physical disability, usually a combination of both. If the patient can be left alone for more than 8h at home it is upper level of SD, if not then it is low level of SD.**
5 – Low Moderate Disability (MD-) **6 – Upper Moderate Disability (MD+)**	**Patients have some disability such as aphasia, hemiparesis or epilepsy and/or deficits of memory or personality but are able to look after themselves. They are independent at home but dependent outside. If they are able to return to work even with special arrangement it is upper level of MD, if not then it is low level of MD.**
7 – Low Good Recovery (GR-) **8 – Upper Good Recovery (GR+)**	**Resumption of normal life with the capacity to work even if pre-injury status has not been achieved. Some patients have minor neurological or psychological deficits. If these deficits are not disabling then it is upper level of GR, if disabling then it is lower level of GR.**

Glasgow Outcome Scale – Extended (GOS-E)

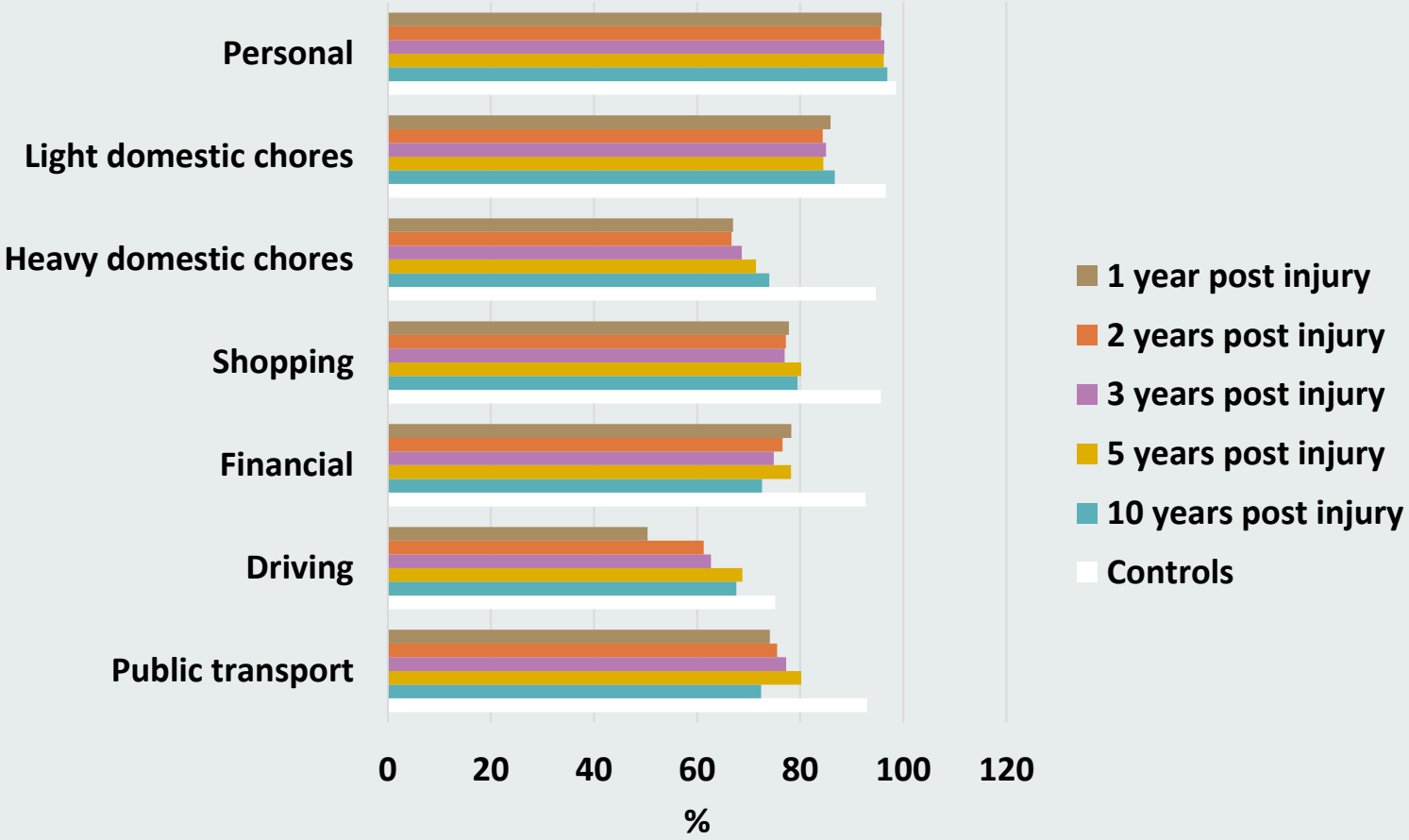
% in each category 1 - 10 years post-injury

	1 year post-injury	2 years post-injury	3 years post-injury	5 years post-injury	10 years post-injury
Lower severe disability	6.0	5.0	5.8	4.7	7.3
Upper severe disability	13.5	12.2	10.7	10.2	13.4
Lower moderate disability	15.5	18.9	17.8	13.3	16.9
Upper moderate disability	29.4	26.3	24.3	25.8	22.2
Lower good recovery	18.2	18.5	19.6	20.3	16.9
Upper good recovery	17.3	19.0	21.5	25.5	23.0

Mobility


High mobility
Walk independently but unable to run or jump
Walk Independently with aids
Low mobility
0
20
40
60
80
100
%
1 year post injury
2 years post injury
3 years post injury
5 years post injury
10 years post injury
Controls

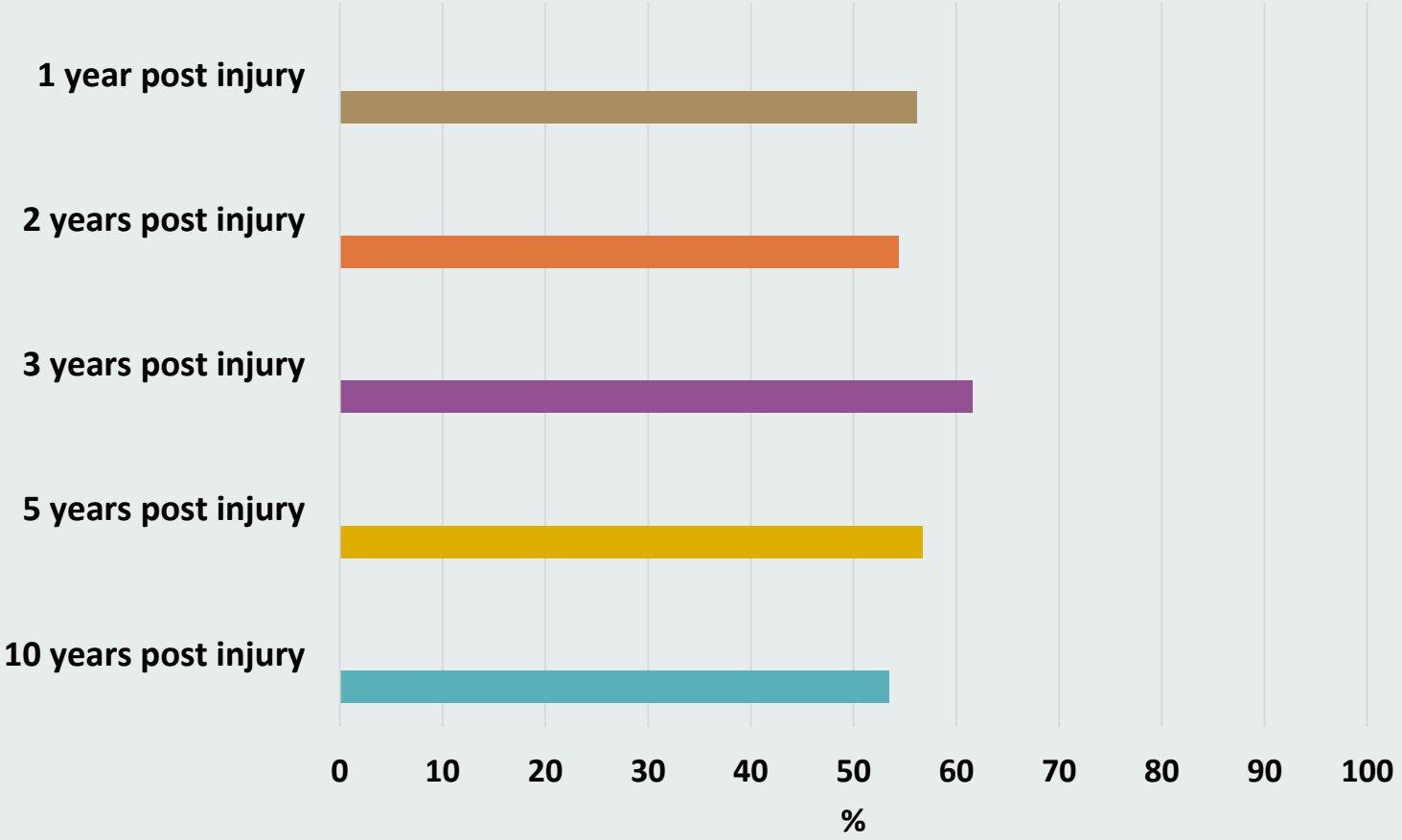
Independence in Activities of Daily Living



Return to Previous Leisure Activities

	1 %	2 %	3 %	5 %	10 %
All or most	53.4	48.3	51.0	51.9	47.7
A few or none	46.6	51.7	49.0	48.1	52.3

Employment status for those employed prior to injury



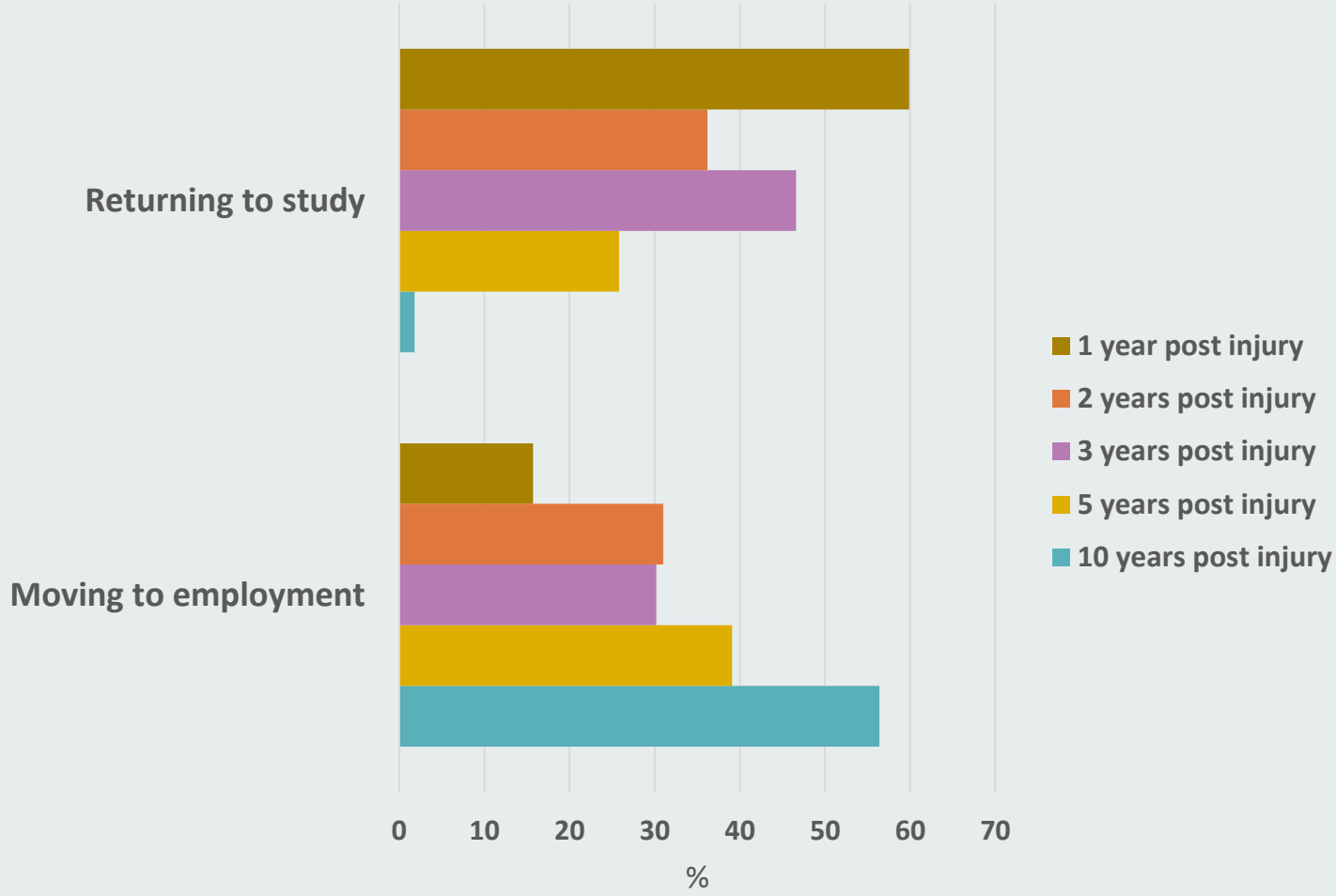
Employment stability

- Of those employed at one year post-injury, 85% were employed at 2 years, and 78% were employed at 5 years post-injury.
- Of those unemployed at one year post-injury, 18% were employed at two years, and 26% were employed at five years.

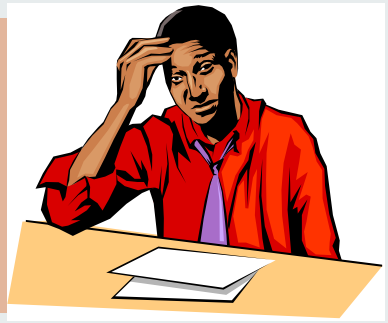
Quality of Experience of Return to Work

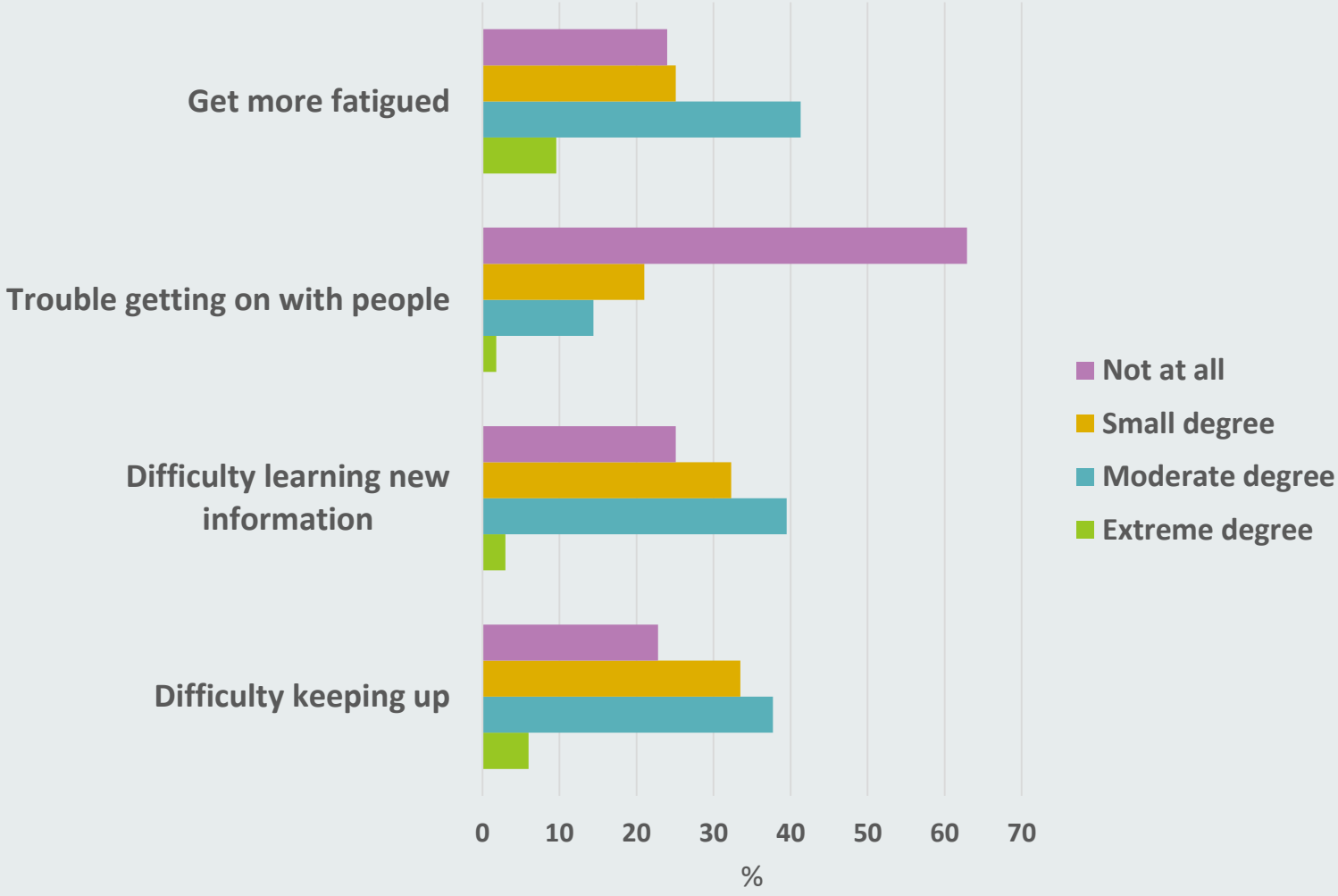
	Control %	1 year %	2 years %	3 years %	5 years %	10 year %
More mistakes	9.0	23.5	26.5	24.4	23.3	28.6
Problems keeping up	8.3	29.3	28.1	27.6	25.2	25.0
More fatigued	30.6	50.0	48.9	48.5	43.4	52.1
Difficulty with people	6.8	10.0	12.3	13.2	11.5	20.0

% of pre-injury students returning to study or employment

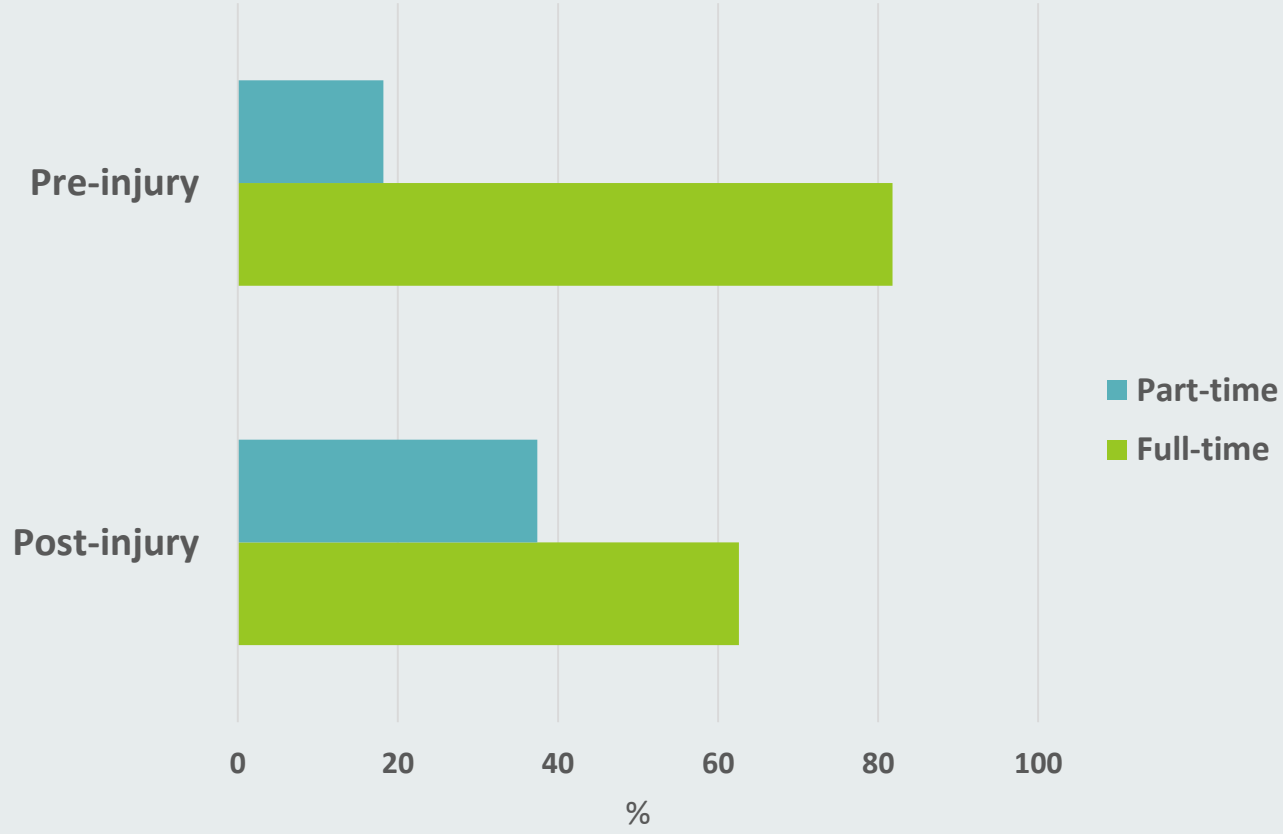


Quality of experience of return to study





Study mode pre- and post-injury



54.2% applied for special consideration compared with 5.8% pre-injury
36.4% of received individual tuition post-injury versus 6.5% prior to injury

Return to Study

- With support, 86% of students returning to study passed all of their subjects

Relationship status

- Of those married/defacto prior to injury, 11.7% were separated or divorced at 10 years post-injury
- Of those single prior to injury, 33.3% were married/defacto at ten years post-injury.
- At 10 years 37% reported difficulties in personal relationships and 34.9% difficulty getting on with friends.

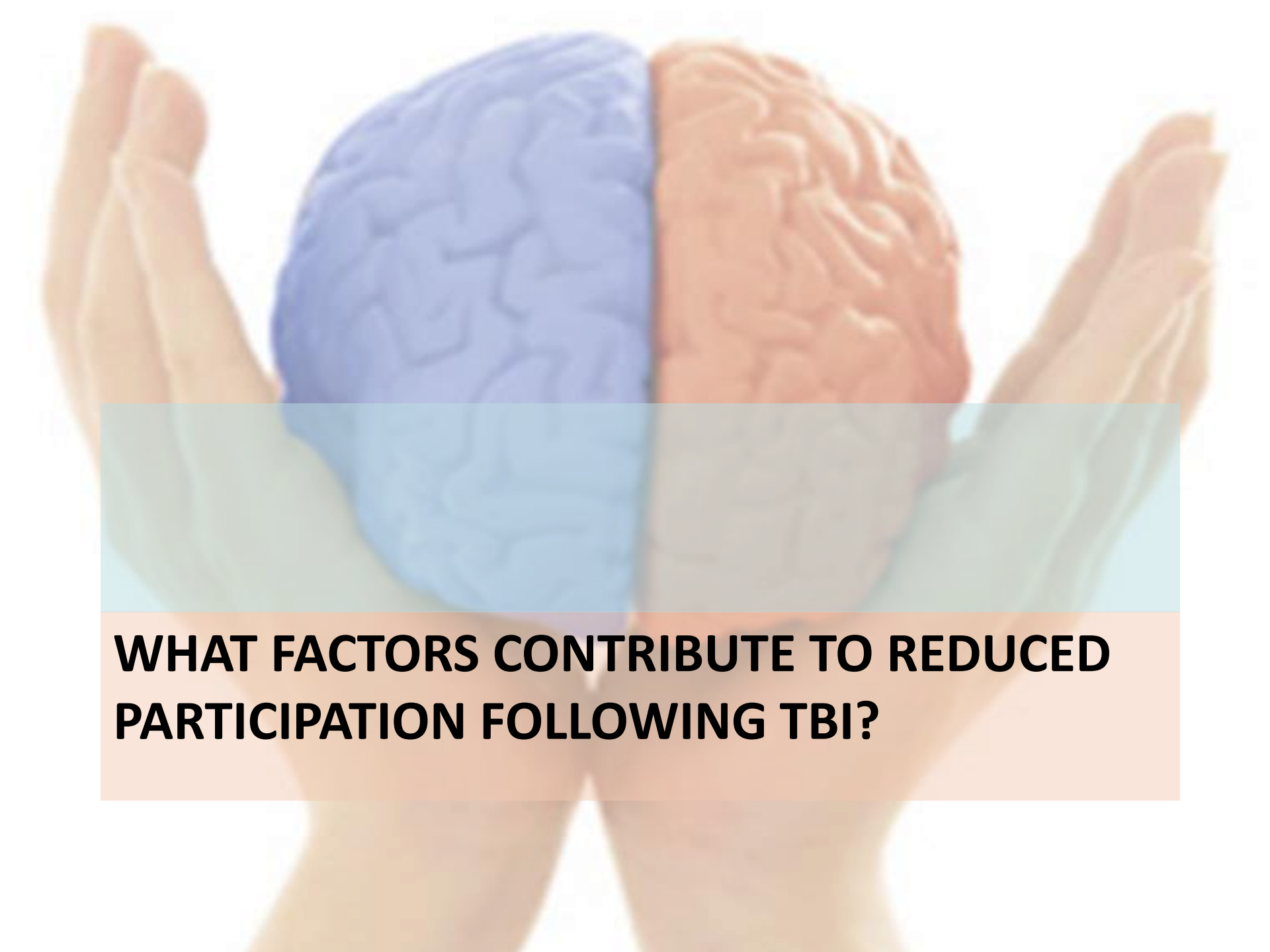
Social Isolation

- At 1 year 29.4% of TBI participants reported having lost friends or become socially isolated since the injury
- at 2 years 40.8%
- at 3 years 39%
- at 5 years 39.8%
- at 10 years 46.6%.

Families

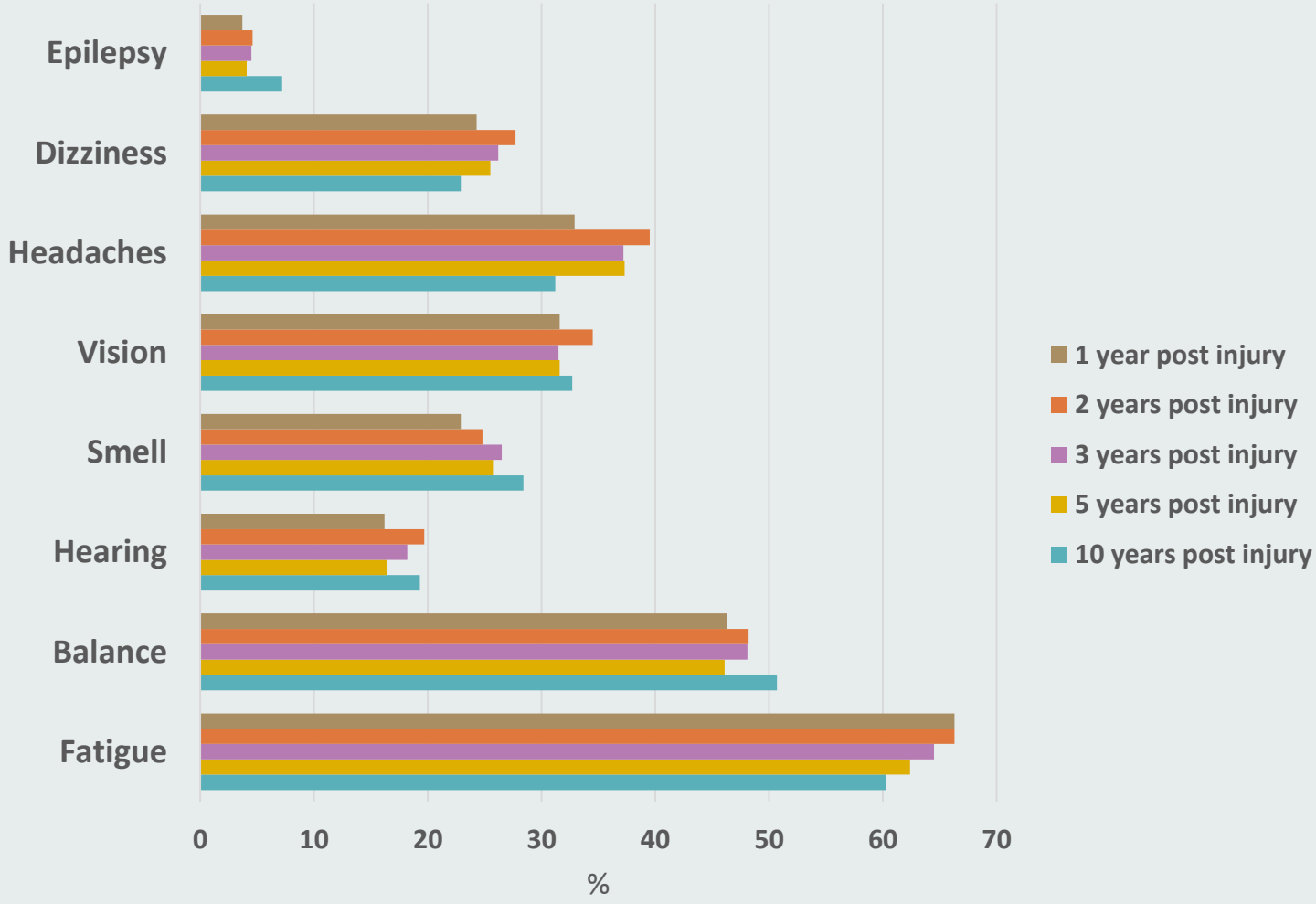
- There are increasing levels of anxiety and depression 1-5 years post-injury in relatives in a direct caregiving role
- Cognitive and behavioural changes in the TBI relative are the greatest sources of stress
- Family stress is associated with unhealthy family functioning and poorer psychosocial adjustment in injured relative.
- Healthy family functioning and family support associated with resilience and better psychosocial adjustment (Perlesz et al., 1999, Douglas, 1994)

Ponsford & Schönberger (2010)*JINS*, *16*, 306-317; Schönberger, Ponsford, Olver & Ponsford (2010) *Neuropsychological Rehabilitation, 20*(6):813-829
Alway, McKay & Ponsford (2012) *Neuropsychological Rehabilitation*, 22(2) 374-390.

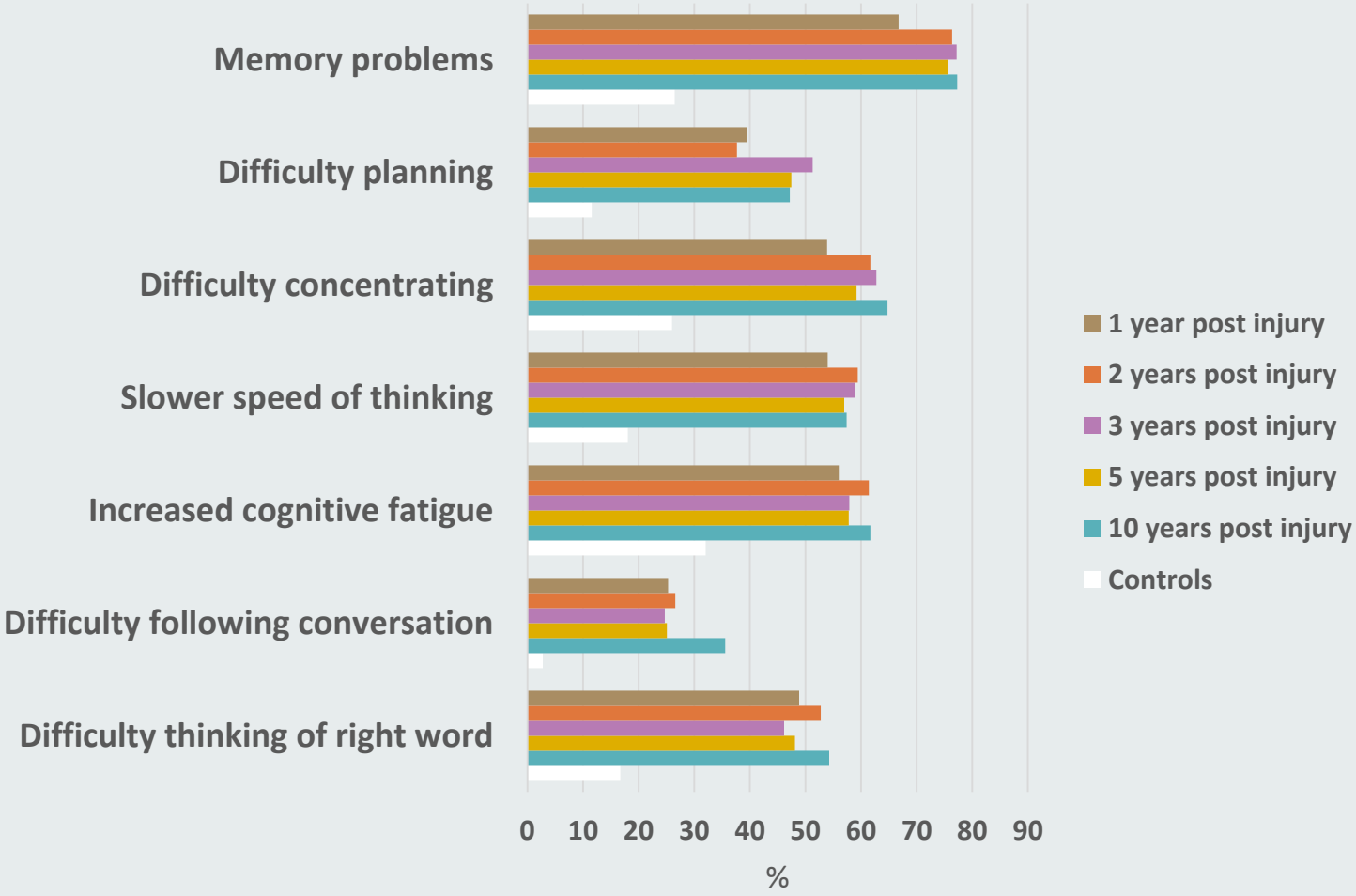


WHAT FACTORS CONTRIBUTE TO REDUCED PARTICIPATION FOLLOWING TBI?

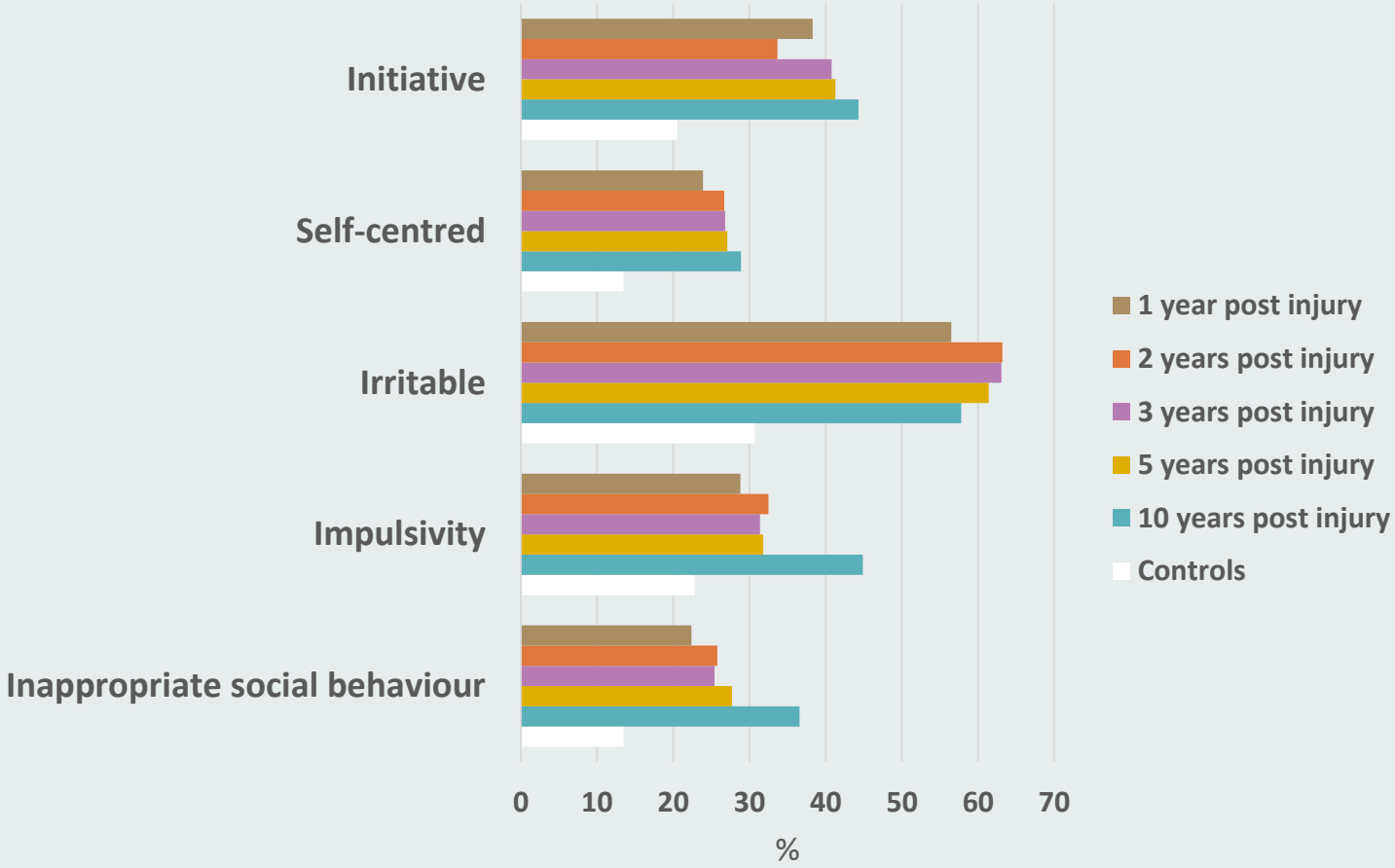
Neurological complaints



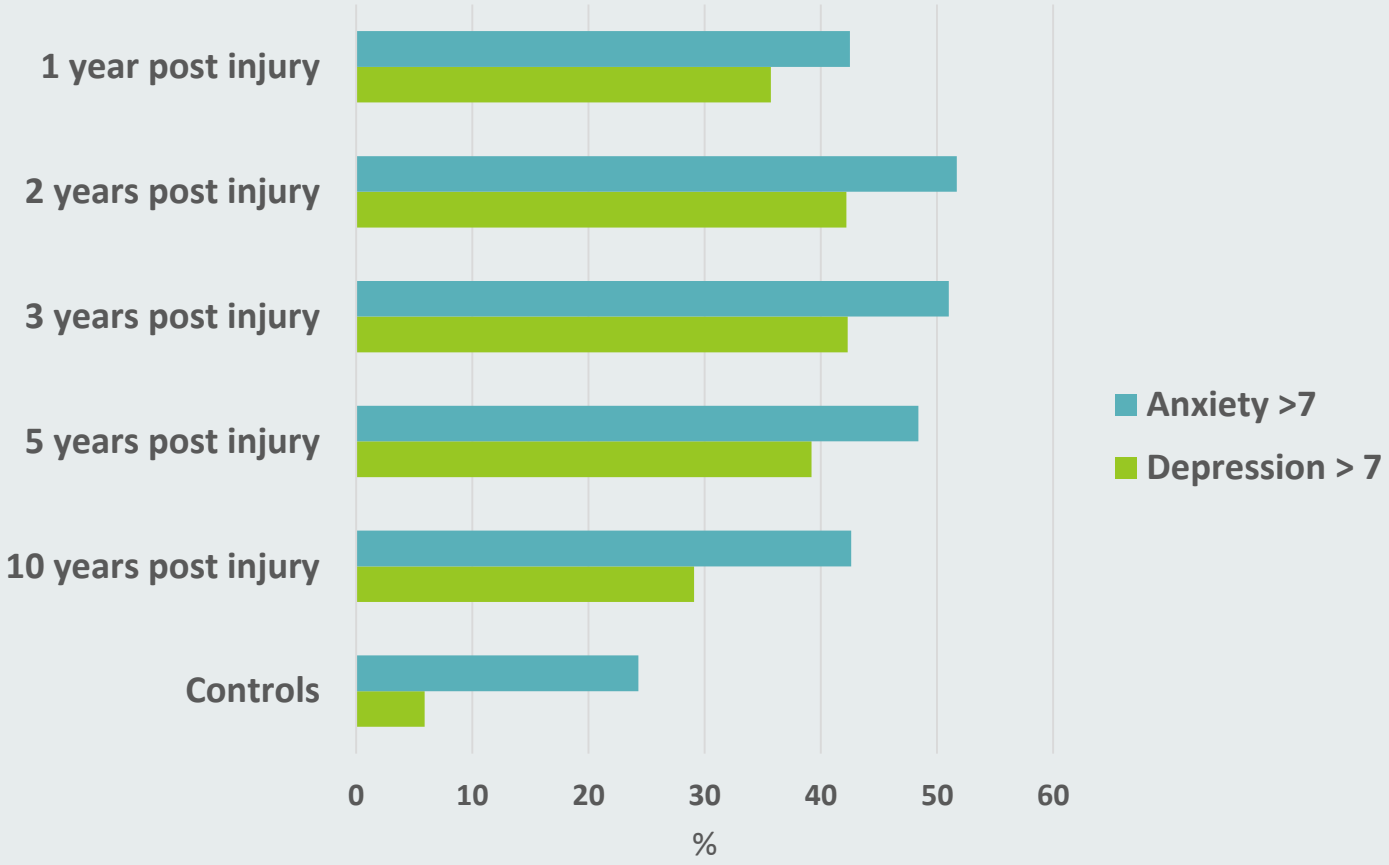
Cognitive & communication changes



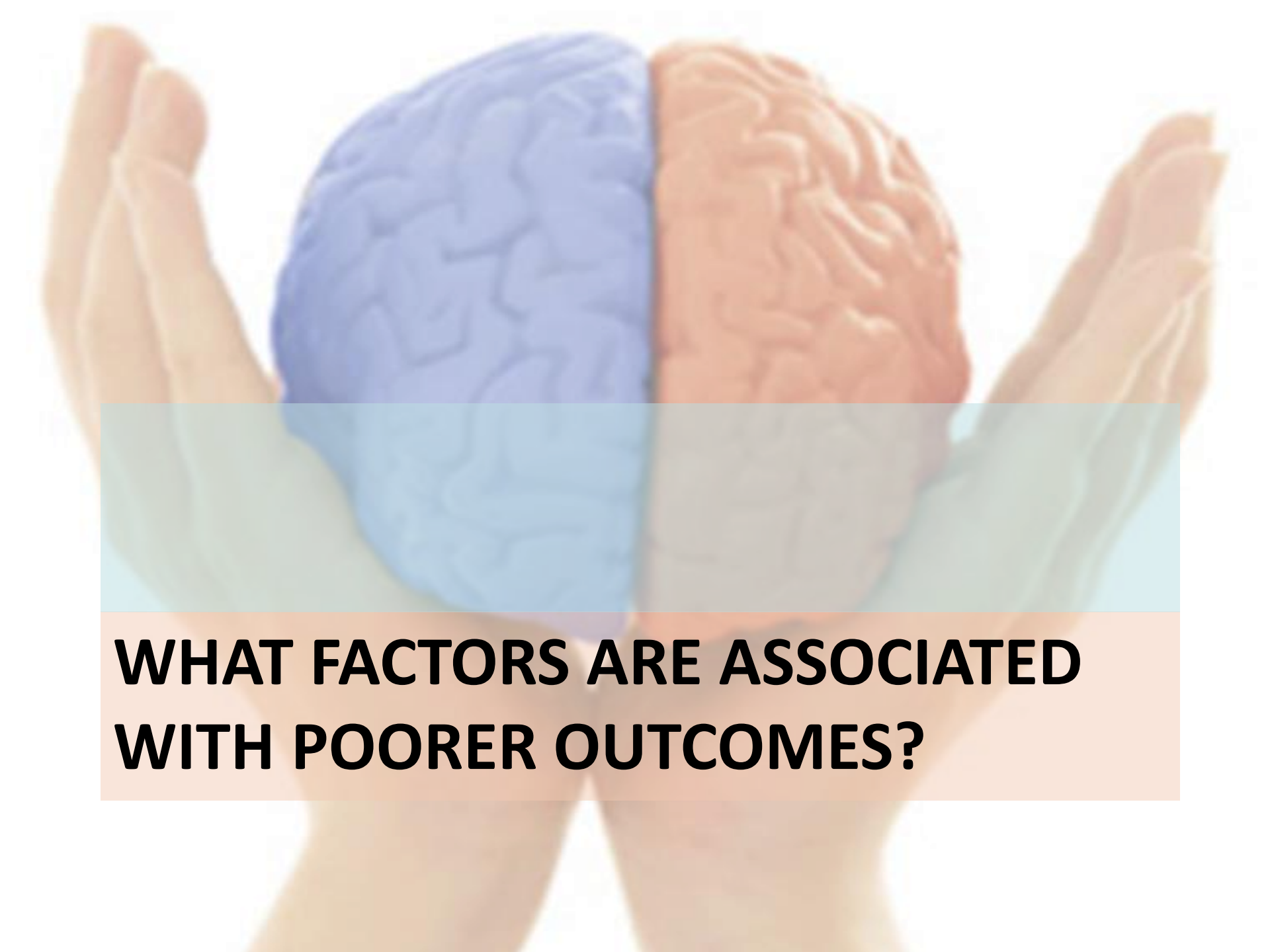
Behavioural changes



HADS Anxiety & Depression

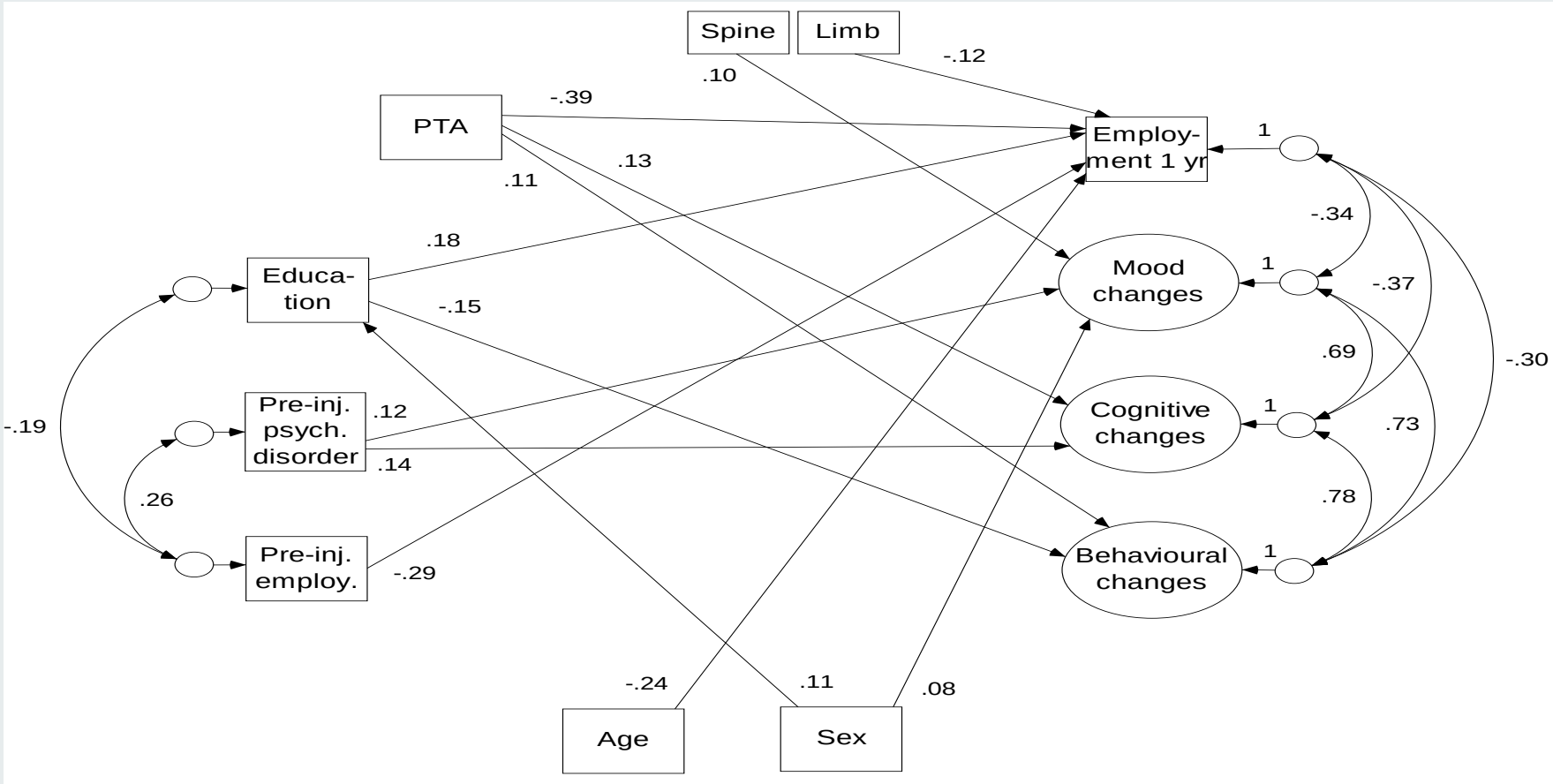


Percent with clinically significant scores at each time-point post-injury



WHAT FACTORS ARE ASSOCIATED WITH POORER OUTCOMES?

Final predictive model of employment outcome

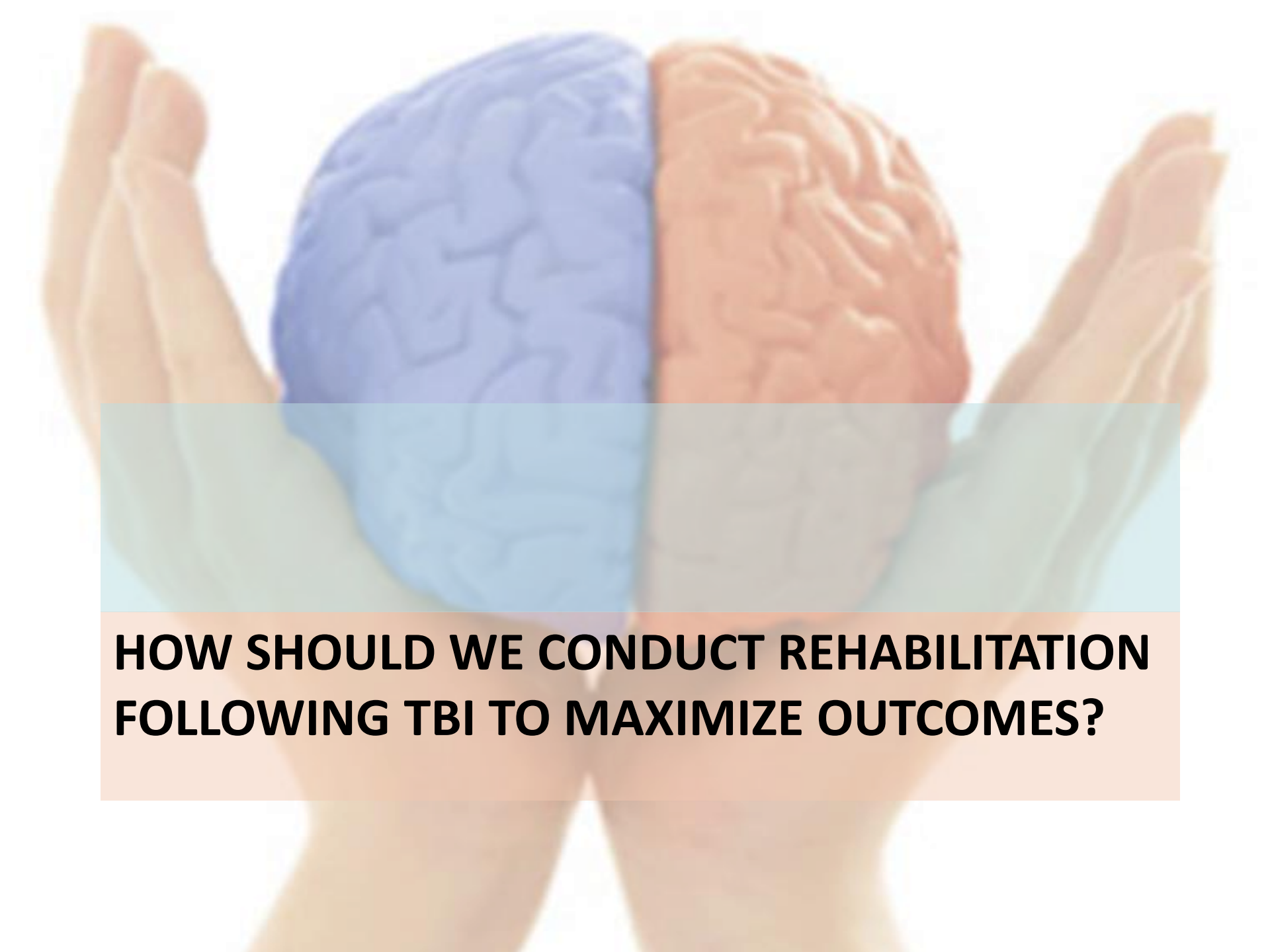


X^2 (59)=103.4, p<.001; CFI=0.99; RMSEA =0.03

Schönberger, M. Ponsford, J.et al (2011) *Journal of Neurology, Neursurgery &Psychiatry.* 82:936-941

Major impediments to better outcomes

1. Higher level mobility problems
2. Memory difficulties
3. Executive dysfunction
4. Reduced attention and information processing speed
5. Fatigue and sleep disturbance
6. Social communication difficulties
7. Irritability and anger management
8. Anxiety and depression
9. Family stress



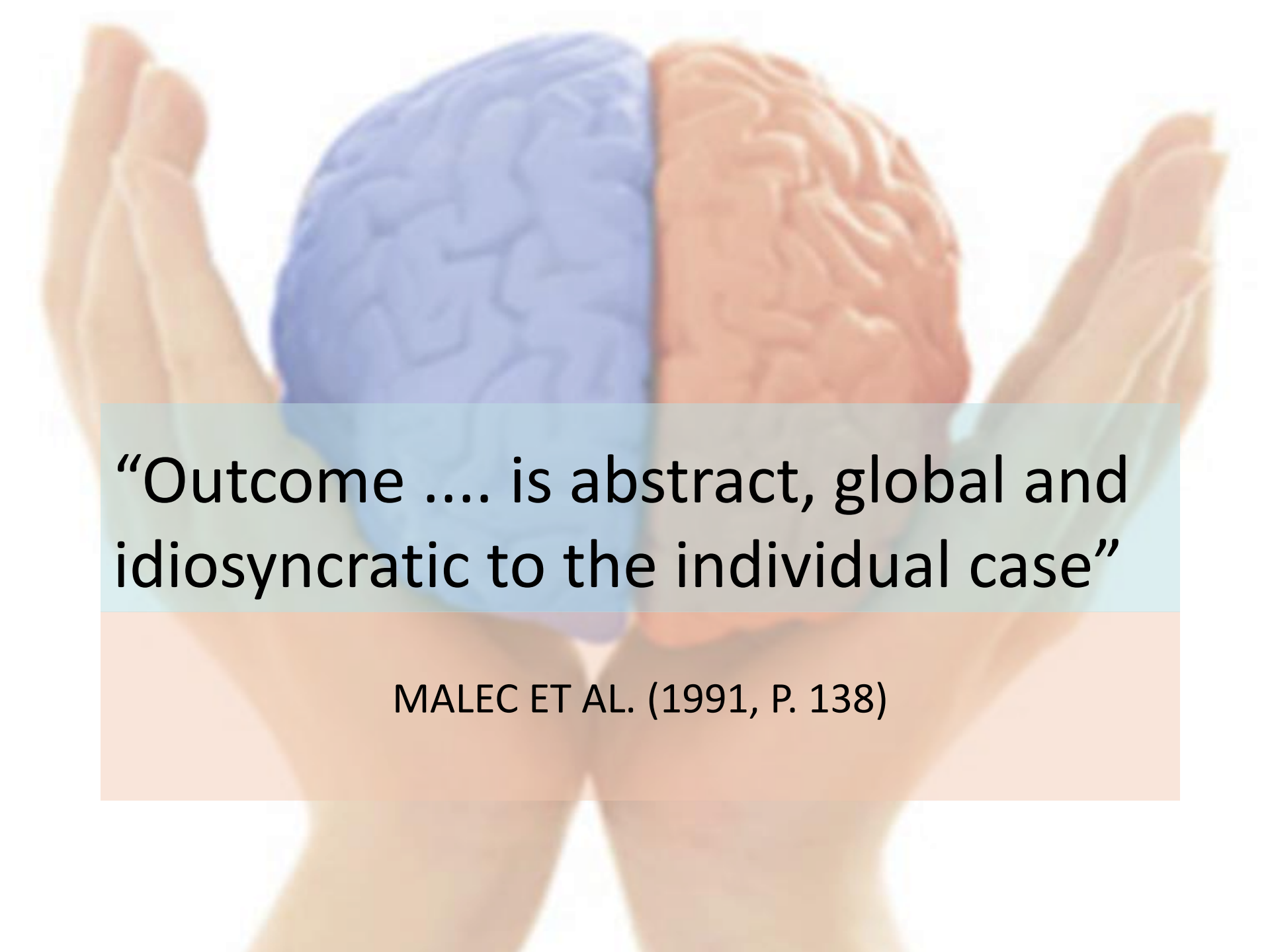
HOW SHOULD WE CONDUCT REHABILITATION FOLLOWING TBI TO MAXIMIZE OUTCOMES?

GUIDELINES FOR COGNITIVE REHABILITATION FOLLOWING TRAUMATIC BRAIN INJURY

Bayley, M., Bragge, P., Ponsford, J., Tate, R., Velikonja, D., Togher, L., Stergiou-Kita, M., Wiseman-Hakes, C.,Teasell, R., (2014). Guidelines for Cognitive Rehabilitation following Traumatic Brain Injury. *Journal of Head Trauma Rehabilitation, 29(4)*

Current Rehabilitation Challenges

- Limited evidence base to underpin practice
- Difficulty conducting evaluative research – heterogeneity of clients, cognitive limitations, other concurrent therapy, spontaneous recovery
- Gap between evidence-based interventions and real-world practice
- Focus on individual cognitive functions in training and outcome assessment
- Many different outcome measures – mostly neuropsychological - fail to capture what is meaningful to the individual



“Outcome .... is abstract, global and idiosyncratic to the individual case”

MALEC ET AL. (1991, P. 138)

What is a meaningful outcome?

Varies from one individual to the next, depending on their roles, priorities, pre- and post-injury strengths and weaknesses, environment and supports.

Identify individually meaningful goals

- Maximise motivation by setting personally meaningful goals in collaboration with client and family.
- Document objectively, e.g., using Goal Attainment Scaling

Goal Attainment Scaling

Target Area (Role) : .....

Goal: (sub-role or Activity) : .....

Levels of Outcome :

+2 (much better than expected)
+1 (better than expected)
0 (expected outcome)
- 1 (starting point)
- 2 (worse than expected)

Initial: Date: Score:	Review: Date: Score:	Review: Date: Score:

Case: Mike

- Age 35, Married, Stationmaster
- Very Severe TBI, PTA 9 weeks
- CT:
  - frontal skull fracture
  - left frontal haemorrhage
  - diffuse petechial haemorrhage
- Severe cognitive impairments
  - memory
  - attention
  - planning and organisation
  - initiative
  - flexibility
  - word-finding

Mike's Role Checklist

Role	Past	Present	Future
STUDENT:			
WORKER:	✓		✓
VOLUNTEER:			
CARE GIVER:	✓		✓
HOME MAINTAINER:	✓		✓
FRIEND:	✓		✓
FAMILY MEMBER:.	✓		✓
RELIGIOUS PARTICIPANT:	✓		✓
HOBBYIST/AMATEUR:	✓		✓
PARTICIPANT IN ORGANIZATIONS:			
OTHER:			

Mike's Sub-Role Analysis

VALUED ROLE:	Home Maintainer
SUB ROLE	**ACTIVITIES/TASKS**
Meal preparation	Select meal List ingredients & make shopping List Do shopping Collect ingredients Cook meal, following the necessary steps Clean up
Laundry	
Cleaning	
Bill-paying	

Mike's
Goal Attainment Scaling

Target Area (Role) : Home Maintainer

Goal: (sub-role or Activity): Cooking

Levels of Outcome :

+2 Able to cook evening meal with other activities going on
+1 Able to cook evening meal in distraction-free environment independently and safely
0 Able to cook an evening meal in a distraction-free environment with distant supervision
- 1 Requires verbal prompts to maintain safety when cooking
- 2 Requires physical assistance when cooking

Initial:	Review:	Review:
Date: 25/5/13	Date: 10/8/13	Date:
Score: -1	Score: +1	Score:

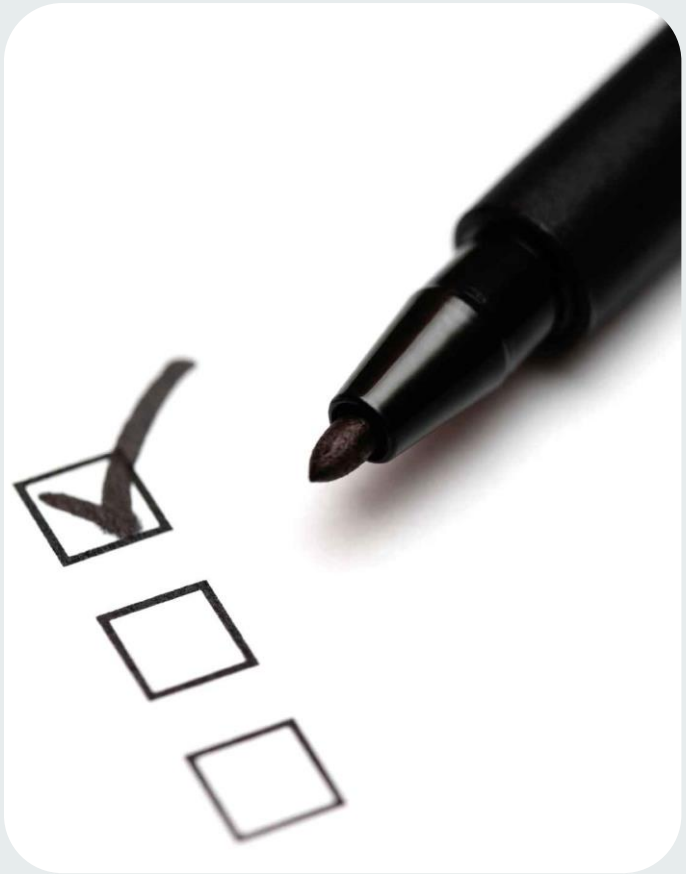
Embed intervention in injured individual's world

- Assess and treat in the community
- Consider the individual's pre-injury activities, interests, strengths and weaknesses, motivations, psychological state, family and social relationships

Consider the right approach for the client

- Training
- Metacognitive strategies
- Compensatory approaches
- Use of technology
- Environmental modification
- Pharmacological interventions – may be combined with training
- Consider pre-injury strategies/experience, cognitive function, availability of support
- Need for research examining factors influencing use/success of different strategies, as well as appropriate frequency and intensity of treatment

Evaluate outcomes in relation to goals



- Focus on goal attainment
- Community participation

Evaluating Models of intervention: Epworth's Community Team

- Established in 1998
- Team comprising OT, SP, PT, Psych, SW & Vocational
- Assess and treat in the home or relevant community setting
- Involve client and family in goal-setting
- Less intensive intervention

Role Checklist

Role	Past	Present	Future
STUDENT:			
WORKER:			
VOLUNTEER:			
CARE GIVER:			
HOME MAINTAINER:			
FRIEND:			
FAMILY MEMBER:.			
RELIGIOUS PARTICIPANT:			
HOBBYIST/AMATEUR:			
PARTICIPANT IN ORGANIZATIONS:			
OTHER:			

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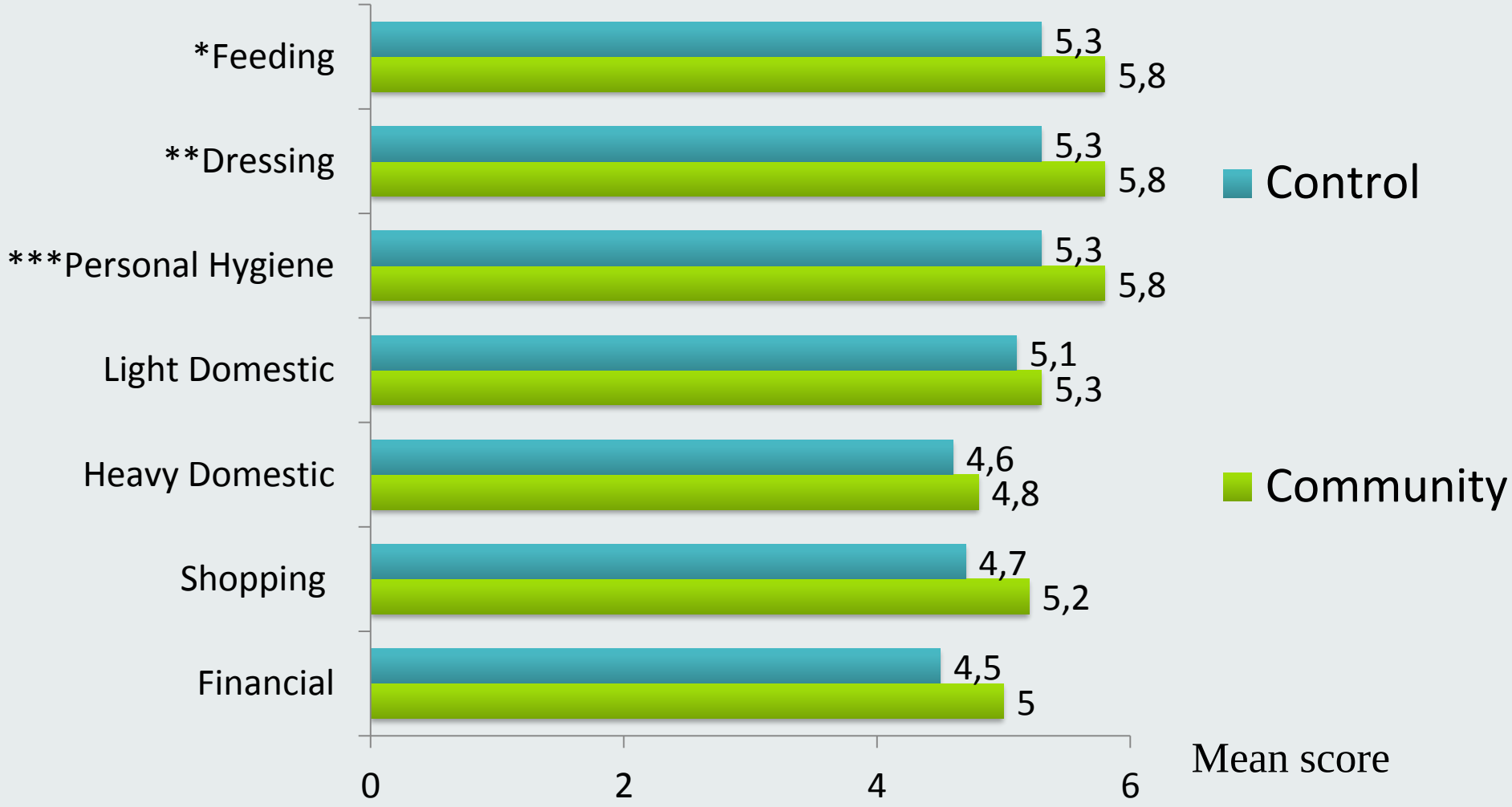
Study of Two Year Outcome

- Community Treatment vs Matched Controls (Centre-based)
- N=98

Ponsford, J., Harrington, H., Olver, J., & Roper, M. (2006). Effectiveness of community-based rehabilitation following traumatic brain injury. *Neuropsychological Rehabilitation, 16 (3), 315-328.*

Independence in Activities of Daily Living Two Years Post-Injury

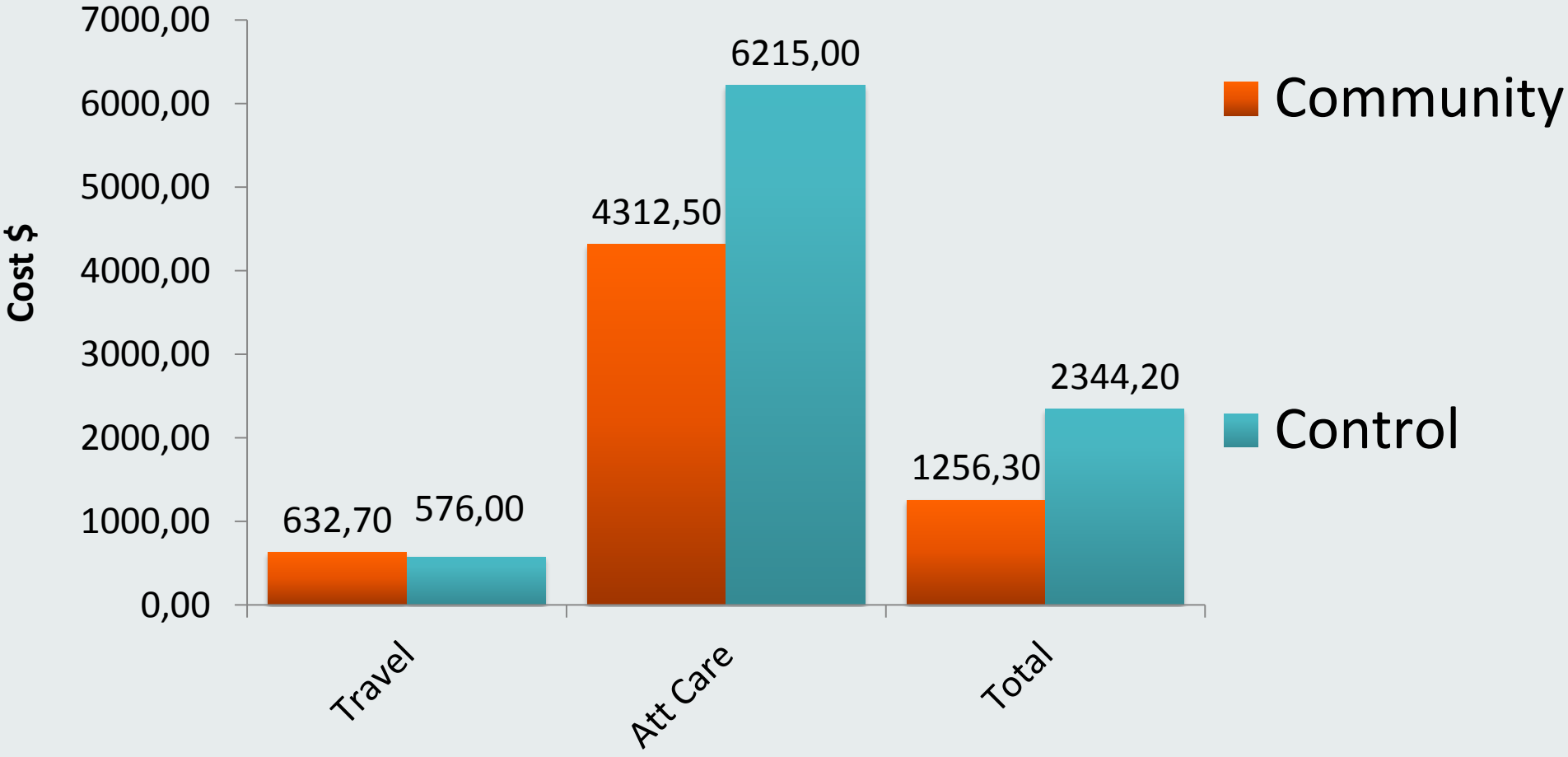


* t(33)=3.08, p<.01 **t(33)=3.06, p<.01 ***t(31)=2.9, p<.01

Conclusions from Community Rehabilitation Evaluation…

- Better rates of independence in ADL, particularly in personal and domestic activities
- No significant differences in rates of return to work or emotional status

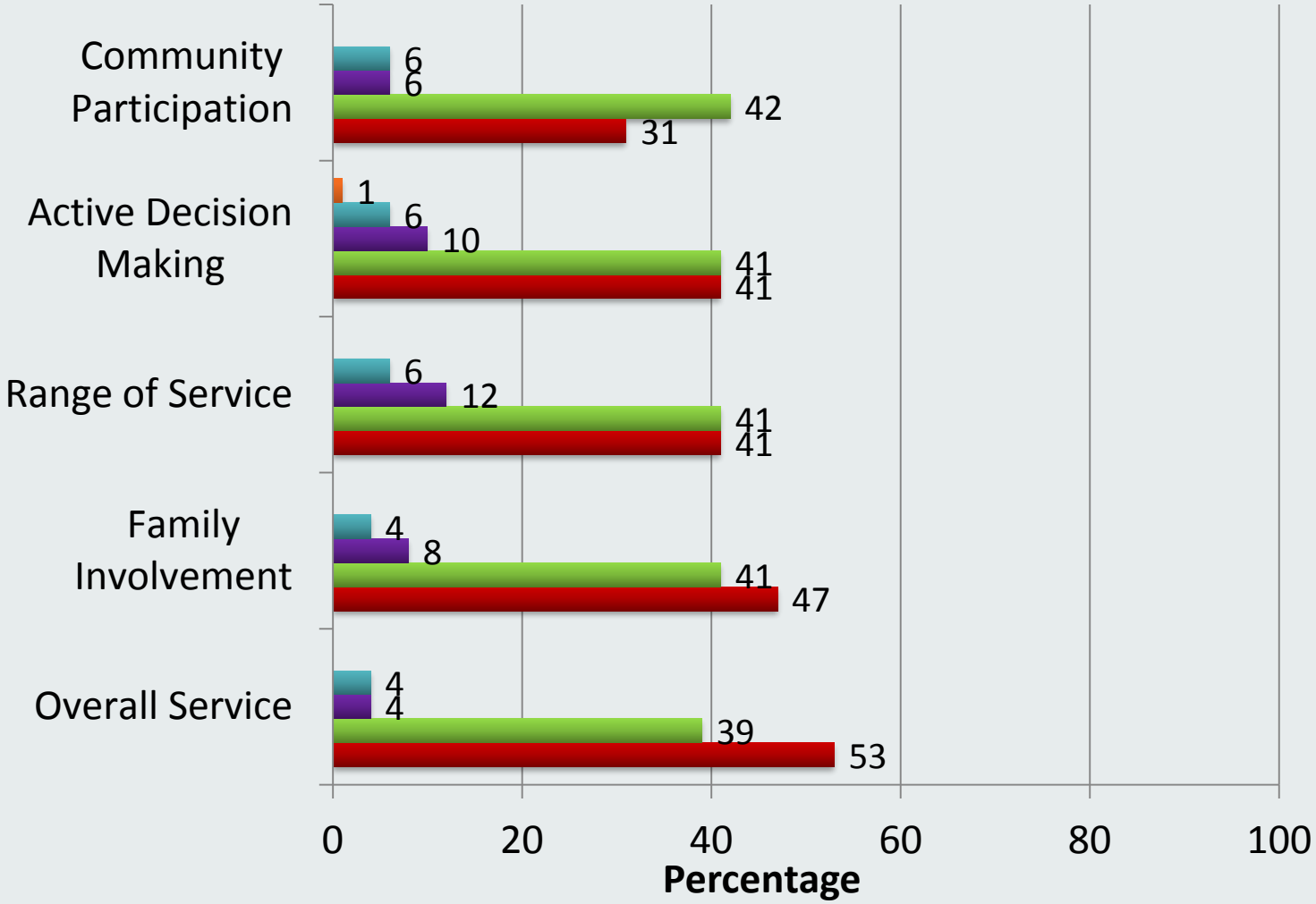
Median Costs by Treatment Group



Total includes costs for gym, childcare etc

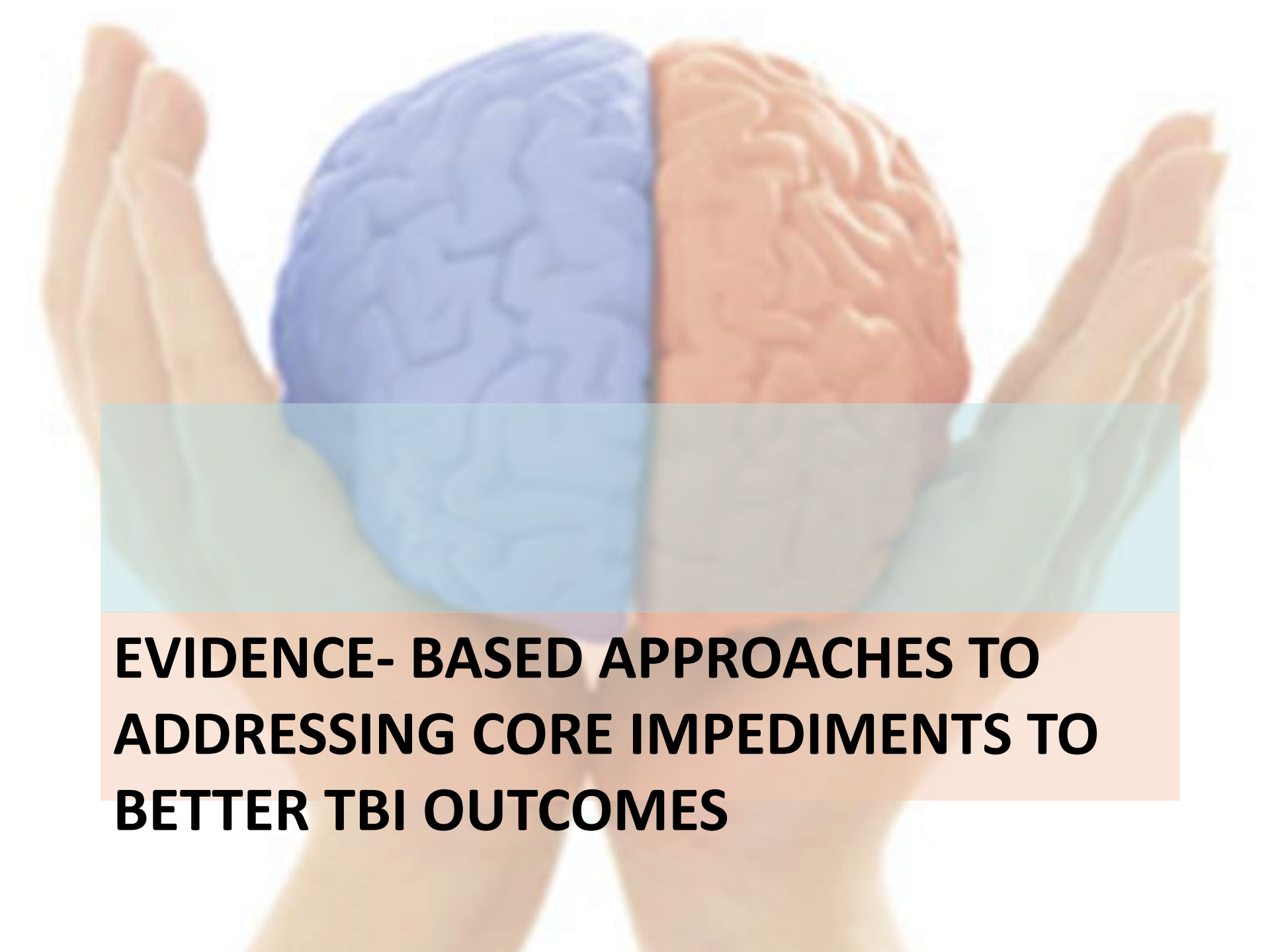
Median Number of Individual Sessions by treatment Group

Client Satisfaction



Conclusions…

- Greater flexibility with mix of outpatient and community-based treatment
- Set limits to distance travelled
- Introduction of Transitions Group over six weeks post-discharge
- Although differences in outcomes between intervention models are small we remain committed to the community-based model
- Other studies have shown community-based rehab may achieve similar outcomes to TLC models at lower cost (Hopman, Tate, & McCluskey, *Brain Impairment*, 2012)



EVIDENCE- BASED APPROACHES TO ADDRESSING CORE IMPEDIMENTS TO BETTER TBI OUTCOMES

Major impediments to better outcomes

1. Higher level mobility problems
2. Memory difficulties
3. Executive dysfunction
4. Reduced attention and information processing speed
5. Fatigue and sleep disturbance
6. Social communication difficulties
7. Irritability and anger management
8. Anxiety and depression
9. Family stress

CONCLUSIONS

Conclusions

- Progress is being made in building rehabilitation programs and an evidence base
- Need for greater access to rehabilitation services over the lifetime
- Need for larger trials deconstructing effective elements of therapy/adaptations and identifying what works for whom
- Need to translate study findings into clinical practice

The challenges are many....

- We need to work together towards surmounting the many complex barriers to a meaningful life following traumatic brain injury

BUT

- Meaningful outcomes necessitate a focus on the individual

Collaborators

- Yvette Alway
- Katie Anson
- Meagan Carty
- Peter Cameron
- Jamie Cooper
- Carolyn Curran
- Jane Dahm
- Marina Downing
- Kristy Draper
- Mark Fitzgerald
- Kate Gould
- Michele Grant
- Kerrie Haines
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- Lisa Johnston
- Felicity Klopper
- Nicole Lee
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- John Olver
- Michael Ponsford
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- Mary Ryan
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- Michael Schönberger
- Dawn Senathi-Raja
- Gershon Spitz
- Rene Stolwyk
- Rochelle Whelan
- Catherine Willmott
- Dana Wong

ISCRR

Institute for Safety, Compensation and Recovery Research

A joint initiative of

WorkSafe VICTORIA

TAC TRANSPORT ACCIDENT COMMISSION

MONASH University

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State Government Victoria