

MODELS OF RESILIENCE IN FAMILY CAREGIVERS OF RELATIVES WITH TBI OR SCI: A STRUCTURAL EQUATION MODELLING APPROACH



Grahame Simpson PhD
Professor
School of Human Services and Social Work
Griffith University

Research Group Leader
Brain Injury Rehabilitation Research Group
Ingham Institute of Applied Medical Research

RESILIENCE OBSERVATIONAL STUDY



Co – PIs

Malcolm Anderson, Bamini Gopinath,
Ian Cameron



Project officers

Maysaa Daher, Kate Jones, Michelle Genders

PARTICIPATING CENTRES

LIVERPOOL BIRU

Jason Hunt, Tina Khandu
Robina Moubarak, Lyly Chenh

ROYAL REHAB

Kate Jones, Candice Care-Unger, Helen
Oosthuizen, Angela Pong, Glenda McAllister,
Diane Turner, Jackson Singleton

WESTMEAD BIRU

Neeta Patel, Jyoti Chandra

PRINCE OF WALES

Jackie Francis

ILLAWARRA BI SERVICE

Rebekah Reurich

MID WEST BI SERVICE

Denise Young

PRINCESS ALEXANDRA HOSPITAL

Dr Annerley Bates, Simone Cahill

STRENGTH2 STRENGTH PROJECT



Kate Jones
S2S Development project



PARTICIPATING CENTRES

LIVERPOOL BIRU

Tina Khandu, Mary Cui

ROYAL REHAB

Helen Oosthuizen, Glenda McAllsiter

Diane Turner

WESTMEAD BIRU

Neeta Patel, Daniella Pfeiffer

PRINCE OF WALES

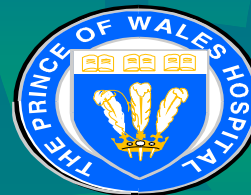
Jackie Francis

MID WEST BI SERVICE

Denise Young



Candice Care-Unger
S2S Translation project



IMPACT OF CNS ON FAMILIES

	TBI	SCI
↑ Depression, anxiety	Anderson et al 2013; Anderson et al 2009	Dreer et al 2007; Manigandan et al 2000
↑ Burden	Ponsford et al 2003	Post et al 2005 Middleton et al 2014
↓ Relationship impact couple satisfaction, family functioning	Anderson et al 2013; Anderson et al 2009; Kreutzer et al. 1994	Franzen-Dahlin et al 2007

POLICY, PLANNING AND SERVICE DELIVERY PERSPECTIVE

- Value of informal care
 - \$60 billion per annum in Australia (Access Economics 2015)
 - \$522 billion per annum in USA (Chari, Engberg, Ray, & Mehrotra, 2015)
- Resilience is associated with
 - reduced levels of morbidity (e.g., anxiety, depression)
 - positive wellbeing
 - sustainability of informal care

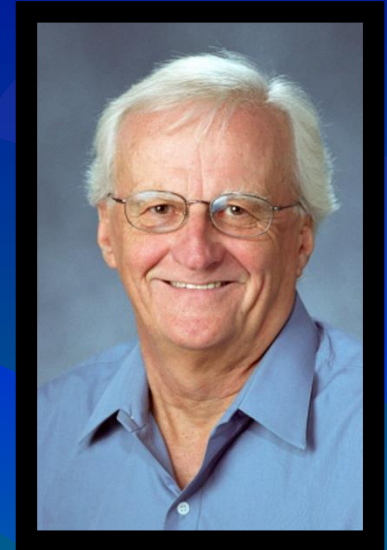
(White et al 2008; Godwin et al 2015)

POSITIVE PSYCHOLOGY AND STRENGTHS-BASED MOVEMENTS

- **Scientific study of positive emotion, character and institutions (Seligman et al 2005)**
- **Seeks to understand factors associated with happiness, well being and optimal functioning (Lee et al 2005)**
- **One application of PP has been to investigate recovery from traumatic injury and the concepts of resilience and post traumatic growth**

RESILIENCE – A PARADIGM SHIFT IN REHABILITATION?

....demanding and stressful experiences do not inevitably lead to vulnerability, failure to adapt, and psychopathology (Saleebey, 2006, p.13)



Within neurorehabilitation, the paradigm shift is away from a deficits-based to a strengths-based approach

(White et al 2008, Godwin & Kreutzer 2013)

DEFINITIONS

Resilience is the process of effectively negotiating, adapting to, or managing significant sources of stress or trauma. Assets and resources within the individual, their life and environment facilitate this capacity for adaptation and ‘bouncing back’ in the face of adversity. Across the life course, the experience of resilience will vary” (Windle and the Resilience Network 2010)

“... a dynamic process encompassing positive adaptation within the context of significant adversity.” (Luthar et al., 2000, p.543)

Resilience is a multi-dimensional construct

Comprises a mix of personal skills and attributes, social competence and spirituality

Not just a personality type but a skill that can be acquired (White et al 2008)

DOES RESILIENCE CORRELATE WITH REDUCED DISTRESS & BURDEN AFTER TBI or SCI?

Test hypothesised relationships between resilience and family member outcomes

Does resilience correlate to positive and negative affect?

Does resilience correlate to carer burden?

Article

 **CLINICAL REHABILITATION**

How important is resilience among family members supporting relatives with traumatic brain injury or spinal cord injury?

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Grahame Simpson and Kate Jones

RESILIENCE, AFFECT and BURDEN

Resilience scores  Positive affect (r= 0.67**) 

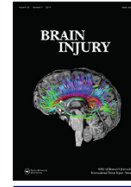
Resilience scores  Negative affect (r=-0.42**)

Resilience scores  Carer burden (r=-0.32*)

Independent of injury severity (FIM score)

N=61, *p<0.05; **p<0.01

DOES RESILIENCE CORRELATE WITH REDUCED DISTRESS & BURDEN?



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Family and TBI: an investigation using the Family Outcome Measure – FOM-40

Christine Migliorini, Libby Callaway, Sophie Moore & Grahame K Simpson



Family Outcome Measure

FOM-40
User Manual 1.0

Test hypothesised relationships between resilience and family outcome, as measured on the FOM-40

Strong levels of resilience observed
Positive correlations with coping, decreasing burden, adequacy of service access, and perceived sustainability of providing support

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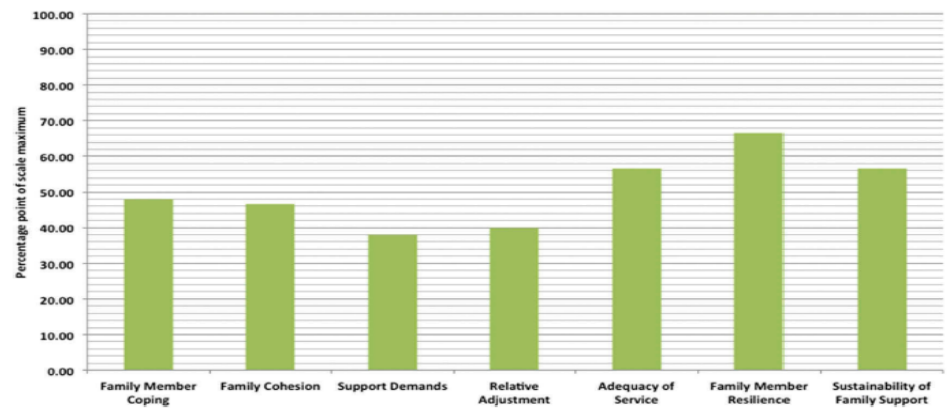


Figure 1. Median average endorsement of FOM subscales presented as percentage of scale maximum.

Table 4. Spearman's rho (r_2) correlational analyses of FOM domains ($n= 38$).

FOM subscale	1	2	3	4	5	6	7
1. Coping	-	.07	.53 **	.17	.42 **	.62***	.22
2. Cohesion		-	.05	.48 **	.07	.09	.55 ***
3. Burden			-	-.05	.11	.36 *	.11
4. Adjustment				-	.01	.07	.38 *
5. Adequacy					-	.40 *	.30
6. Resilience						-	.36 *
7. Sustainability							-

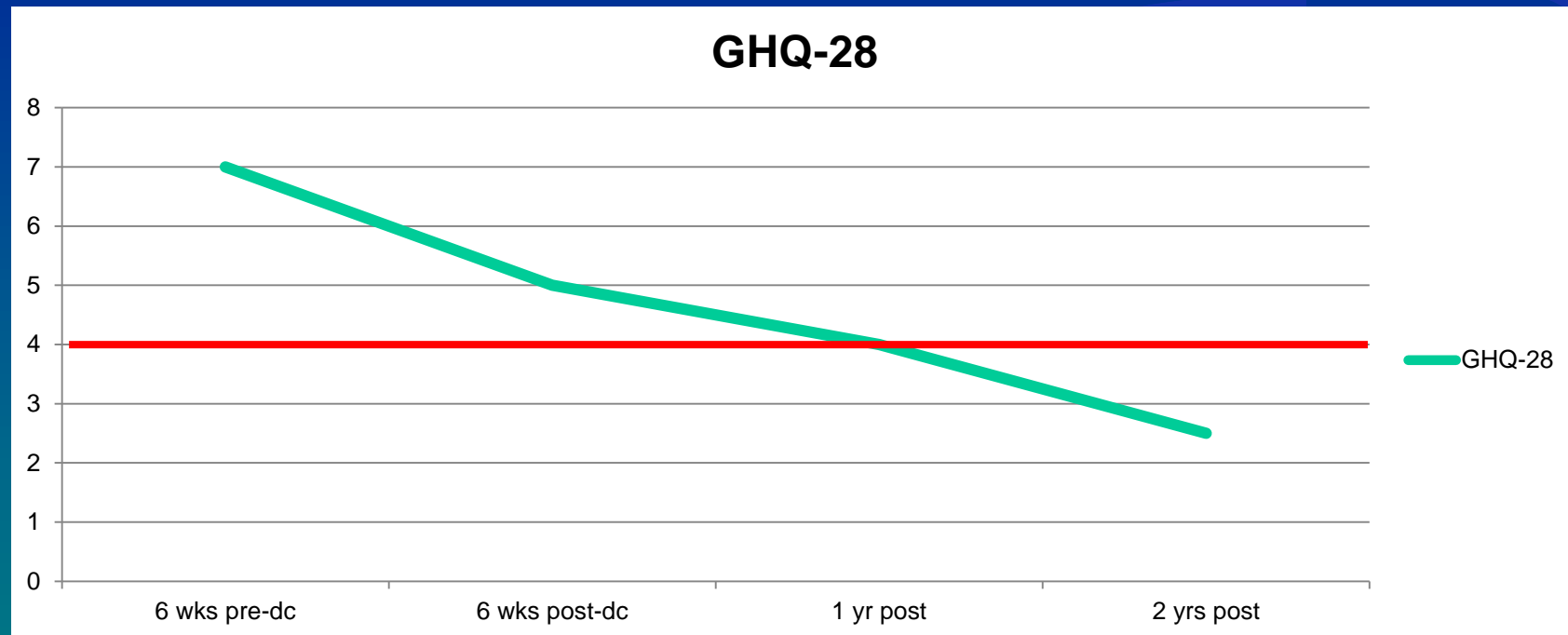
Note: * $p < .05$ (two-tailed); ** $p < .01$ (two-tailed); *** $p < .001$ (two-tailed). Guide to strength of the relationship: $r_2 = .10-.29$ small; $r_2 = .30-.49$ medium; $r_2 = .50-1.0$ large.

DO CARERS ADAPT OVER TIME OR JUST BURN OUT?

- 46 carers of people with SCI
- Consecutive series
- Assessed at 6 wks pre-discharge, 6 wks post-discharge, 1 and 2 years post-discharge
- Completed measures for psychological distress (GHQ-28) and health-related quality of life (SF-36)
- Are scores consistent with adaptation vs wear and tear hypothesis



WEAR AND TEAR vs ADAPTATION AMONG SCI CARERS



Psychological distress (General Health Questionnaire-28) significantly decreased across the four time points

FURTHER QUESTIONS ABOUT RESILIENCE

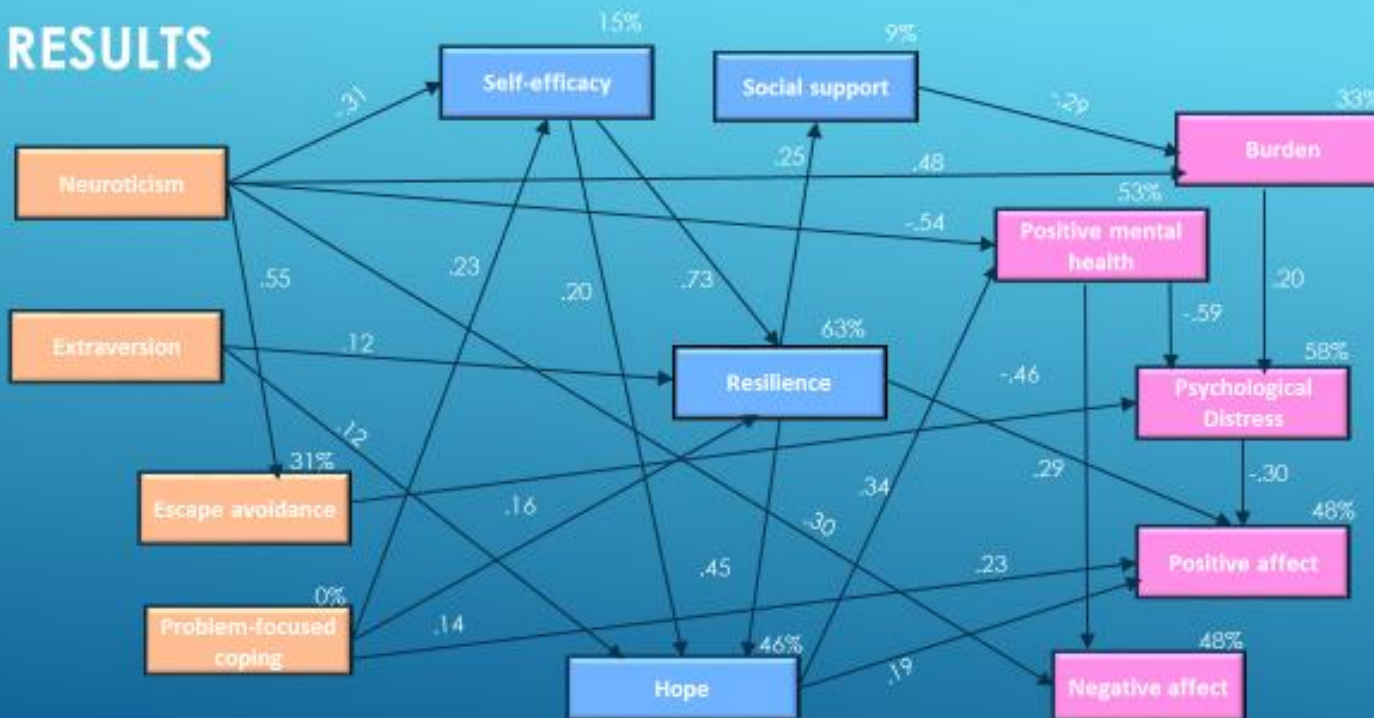
- Is resilience simply a personality trait that one is 'born with'?
- Is self-efficacy the 'effective' ingredient in 'black-box' of resilience?
- Is resilience associated with capacity to mobilise social support?
- Is there a link between resilience, hope and caregiver outcomes?

A predictive model of resilience among family caregivers supporting relatives with traumatic brain injury (TBI): A structural equation modelling approach

Malcolm I. Anderson, Maysaa Daher & Grahame K. Simpson

DOES RESILIENCE MEDIATE FAMILY OUTCOME AFTER TBI? (n=131)

RESULTS



Final model of resilience in caregivers of family members with TBI

Significant proportions of variance explained

R - Direct pathway to Positive affect

Buffer for burden mediated by SI support
Contribute to good MH mediated by Hope

Hope direct pathways to positive affect and good MH

RESULTS: FAMILY PARTICIPANTS

	TBI (n=131)	SCI (n=50)
Sex (n, %)		
Male	25 (19.1)	7 (14.0)
Female	106 (80.9)	43 (86.0)
Age, years (mean, SD)	53.5 ±11.7	49.5 ±13.2
Marital status (n, %)		
Married/De facto	103 (78.6)	43 (86.0)
Single	9 (6.9)	4 (8.0)
Separated/divorced/widowed	19 (14.5)	3 (6.0)
Relationship to person with injury (n, %)		
Parent	58 (44.3)	13 (26.0)
Spouse	59 (45.0)	31 (62.0)
Other*	14 (10.7)	6 (12.0)
Current employment status (n, %)		
Employed full time	44 (33.6)	17 (34.0)
Employed part time	31 (23.7)	10 (20.0)
Not employed	56 (42.7)	23 (46.0)
Living with person with injury at time of injury (n, %)		
Yes	98 (74.8)	36 (72.0)
No	33 (25.2)	14 (28.0)
Living with person with injury now		
Yes	109 (83.2)	41 (82.0)
No	22 (16.8)	9 (18.0)

RESULTS: RELATIVES WITH TBI or SCI

	TBI (n=131)	SCI (n=50)
Sex (n, %)		
Male	98 (74.8)	40 (80.0)
Female	33 (25.2)	10 (20.0)
Age, years (mean, SD)	41.2 ±14.3	45.4±15.7
Time since injury, months (mean, SD)	36.3 ±46.9	18.3±49.0
Injury Circumstance		
Road related	59 (45.4)	11 (22.0)
Pushbike	11 (8.5)	4 (8.0)
Fall	40 (30.8)	15 (30.0)
Struck by object	17 (13.1)	1 (2.0)
Water-related injuries	-	6 (12.0)
Non-traumatic	-	9 (18.0)
Other**	3 (2.3)	4 (8.0)
SCI Level		
Paraplegia	-	18 (36.0)
Quadriplegia	-	32 (64.0)
SCI Lesion		
Complete	-	12 (24.0)
Incomplete	-	38 (76.0)
Posttraumatic amnesia		
Severe	4 (3.1)	-
Very severe	42 (32.6)	-
Extremely severe	83 (64.3)	-

SEM FIT STATISTICS FOR TOTAL GROUP, VARIANT GROUP, AND INVARIANT GROUP MODEL FOR FAMILY MEMBERS OF INDIVIDUALS WITH TBI OR SCI

Model	χ^2	df	P	NFI	IFI	TLI	CFI	RMSEA
Total group	47.42	39	.167	0.962	0.993	0.985	0.993	0.035
Invariant-group	126.37	107	.097	0.905	0.984	0.976	0.983	0.032
Variant-group	93.81	78	.107	0.927	0.987	0.973	0.987	0.034

RESILIENCE AND HOPE in FAMILIES: A MULTIGROUP ANALYSIS OF TBI vs SCI (n=181)

The model fits equally well for families supporting relatives with SCI

- Additional pathways
- Neuroticism to resilience
- Extraversion to social support
- Good MH as a buffer to burden
- Escape avoidance additional pathways

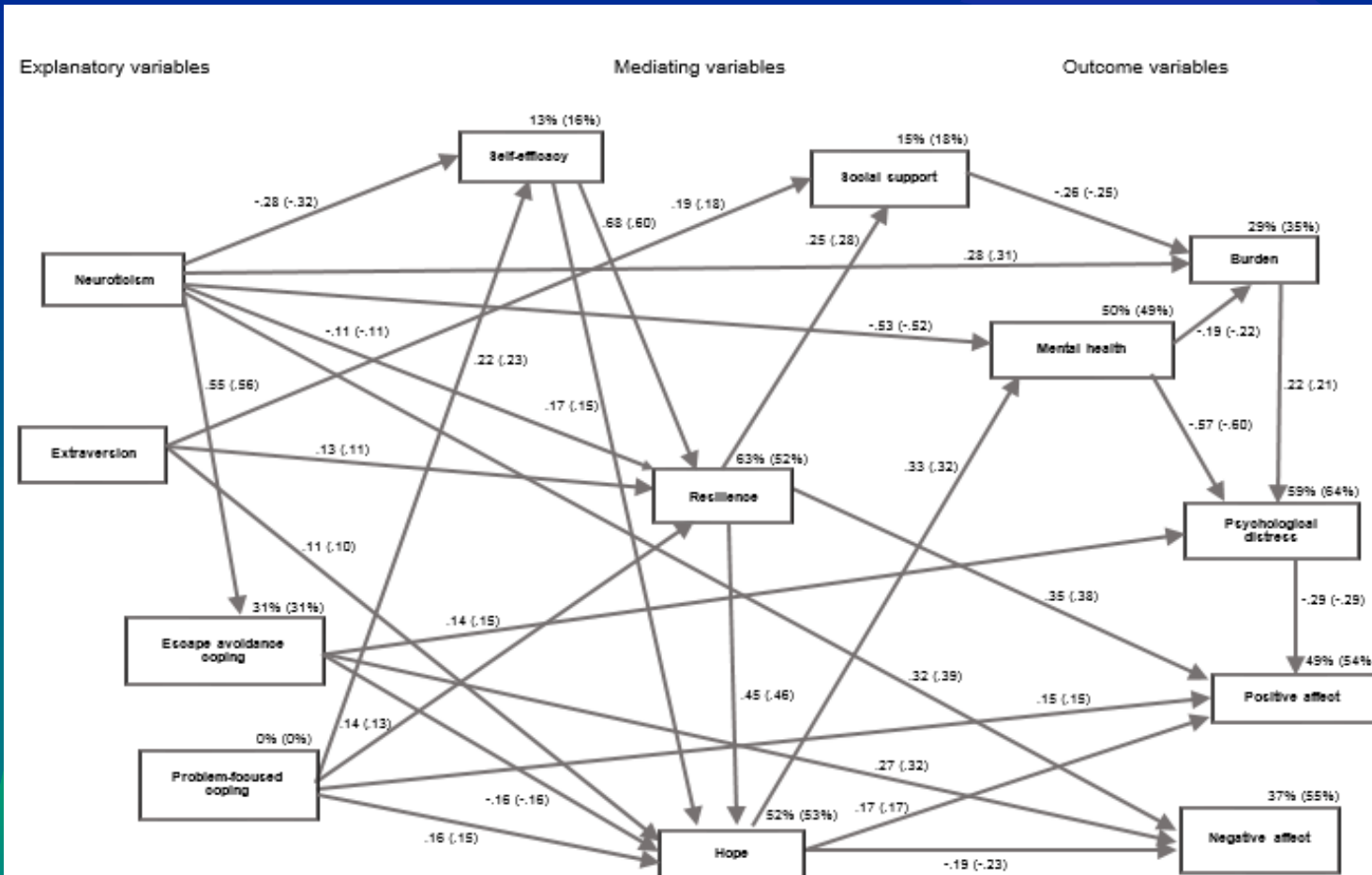


Figure 2. Model of resilience in caregivers of family members with TBI versus (SCI)

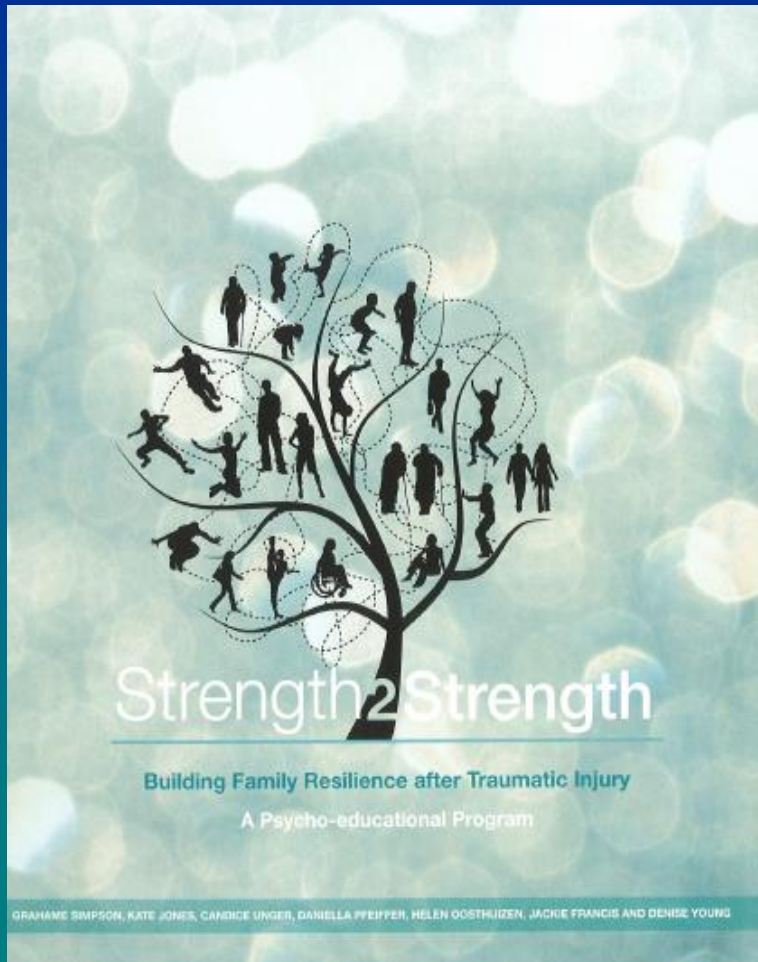
KEY POINTS

- **Similarities between TBI and SCI families**
- **Extraversion and resilience (Campbell-Sills et al 2006); Neuroticism and caregiver burden (Norup & Mortensen, 2015)**
- **Among studies of Ways of Coping (Folkman & Lazarus, 1988) among families after TBI, Problem solving has been a key mediating factor between neurobehavioural impairments and caregiver outcomes (Anderson et al 2015)**
- **Escape-Avoidance has been identified as a transdiagnostic symptom, and we found evidence of its role in this model.**
- **Strong association between self-efficacy and resilience, however self-efficacy appeared to be a more narrowly defined and individualistic psychological construct**
- **Resilience was associated with social support (Windle et al 2010) which acted as a protective factor against caregiver burden**

FINAL CONCLUSIONS

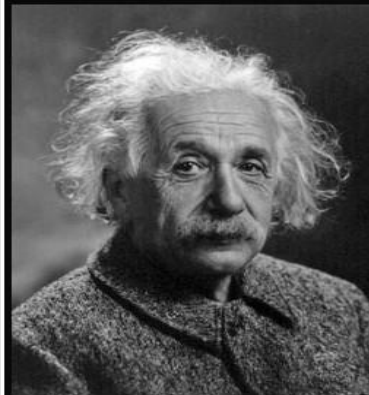
- Initial studies show promise; resilience does seem to mediate family morbidity
- Important to continue to refine and develop broad consensus about the construct
- Longitudinal studies needed to understand more about the contribution of resilience to the sustainability of informal care
- Further work on developing key skills/coping mechanisms associated with resilience
- Further work on how to build resilience
- Focus not just on resilient individuals but fostering resilient systems

THANK YOU



Prof Grahame Simpson
Director, Brain Injury Rehabilitation Research Group

Social Worker-Clinical Specialist
Liverpool Brain Injury Rehabilitation Unit, Australia
grahame.simpson@sswahs.nsw.gov.au



If we knew what it was we were doing, it would not be called research, would it?

(Albert Einstein)

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