

BUILDING RESILIENCE AMONG FAMILY MEMBERS SUPPORTING RELATIVES WITH ACQUIRED BRAIN INJURY IN RURAL NEW SOUTH WALES:

TESTING THE FEASIBILITY OF A PHONE-BASED DELIVERY OF THE STRENGTH 2 STRENGTH PROGRAM



Denise Young¹

Grahame K Simpson²

Jerre Weaver¹

Michelle Genders²

¹ Mid Western Brain Injury Rehabilitation Program, Bathurst Health Service, Bathurst, Australia

² Brain Injury Rehabilitation Research Group, Ingham Institute of Applied Medical Research, Sydney Australia



AUTHORS MIA/ THERAPISTS



DENISE YOUNG

JERRE WEAVER

ACKNOWLEDGEMENTS

Thanks to Daniella Pfeiffer for assistance in co-facilitating the initial pilot group in 2010.

Thanks to Josephine Wyborn for assistance with data collection and presentation.

FAMILY MEMBERS OF PEOPLE WITH ABI

- **Make pivotal contribution to QoL, health and community participation of people with ABI over the long term**
- **Reduce overall cost of care to the national economy**
- **Individual family members and family system affected in many ways by their relative's permanent neurobehavioural impairments**
- **Helping to sustain family members will benefit their own wellbeing, the person with ABI and the national good**

FAMILY MEMBERS OF PEOPLE WITH ABI

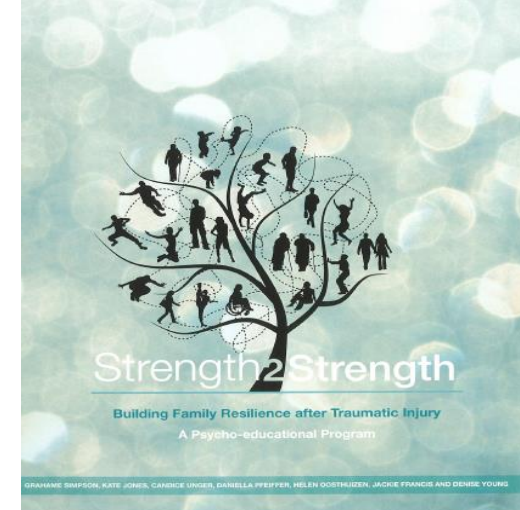
- Increased resilience and positive wellbeing associated with reduced burden, depression and anxiety for family members

HOWEVER

- Family members can be isolated due to demands of their family responsibilities
- People living in rural areas face significant geographical barriers that may limit their opportunity to participate in rehabilitation services and support interventions.

STRENGTH 2 STRENGTH PROGRAM (S2S)

- 10 hour group-based, manualized psycho-educational program to build resilience among family members supporting relatives with ABI
- S2S defines resilience as a “*dynamic* process encompassing positive adaptation within the context of significant adversity” (Luthar et al., 2000)
- Face to face version of S2S evaluated in a non-randomised controlled clinical trial which provided initial evidence of the efficacy of the program (Simpson et al., 2012)
- Abbreviated 5 hour version of the program was developed and piloted (but not tested)



STUDY AIMS

To test the

- i) Feasibility – ease or convenience of execution
- ii) Acceptability - suitability of the program material as judged by participants
- iii) Outcomes

of a telephone-based delivery of the Abbreviated S2S

WHY AN ABBREVIATED S2S PROGRAM?

- To increase access - less time demand
- To improve flexibility of delivery options – 1 short day or weekly by phone delivery
- Phone delivery of group programs is cognitively demanding and requires:
 - > reduced session length
 - > fewer participants
 - > program resource material received before sessions
 - > good audio
 - > guidelines for interaction

TABLE 1: CONTENT OF ABBREVIATED STRENGTH2STRENGTH PROGRAM

Session	Resilience Themes
1. Telling Your Story	Acquiring resilience is a process of self discovery Making meaning Valuing open emotional expression
2. Active Participation	Active coping – being more in control of circumstances Personal organisation
3. Staying On Top	Awareness of strength Positive appraisal
4. Regaining Some Balance	Balance the injury and other personal and family needs Flexibility of roles in meeting needs of all family members
5. Staying Connected	Connectedness Family cohesion Mobilising social and economic resources

TELEPHONE DELIVERY

“Comparison studies involving face to face groups and telephone mediated groups consistently demonstrate that none of the therapeutic factors of group participation is lost in the transition from traditional support groups to telephone groups.” Hyde (2013)

Previous research has found no evidence to suggest telephone groups are less effective than face to face groups when delivering programs. (Brown 1999, Waller 2017)

PROGRAM SETTING

Rural Area: Mid-west of New South Wales:

4 hours' drive from east to west, popn 147,000

2 regional centres (approx. 40,000 each)

Service: Multidisciplinary community brain injury rehabilitation service for adults of working age – outreach from eastern regional centre

Facilitators: Senior social worker & clinical psychologist

Facilities: Health service paid for all telephone conference calls using commercial provider



RESEARCH MEASURES

DEMOGRAPHIC DATA PROTOCOL

- i) Information about family member / caregiver
- ii) Information about family member with ABI

FEASIBILITY

- i) **Data sheets completed weekly by facilitators:**
Attendance, audio quality, program materials received, preparation time
- ii) **User Feedback Survey – Modified (USF-M):** feedback by therapists about program implementation (Webster et al, 2009)

RESEARCH MEASURES

ACCEPTABILITY

- i) Participant-completed session satisfaction sheet: 5 closed questions and 2 open - completed weekly**
- ii) Narrative Evaluation of Intervention Interview (NEII): Participant semi-structured interview – following completion of the group program (Hasson-Ohayon et al, 2006)**

RESEARCH MEASURES

OUTCOMES

Data collected at Baseline, Post Program and Follow Up at 3 months after group completion

PRIMARY MEASURES

- i) Connor Davidson Resilience Scale (CD-RISC) *
(Connor and Davidson 1993)**
- ii) Resilience Scale (RS) (Wagnild and Young 1993)**

RESEARCH MEASURES

SECONDARY OUTCOME MEASURES

- i) Carer Assessment of Managing Index (CAMI)
(Nolan et al, 1998)**
- ii) Caregiver Burden Scale (CBS) (Elmstahl, 1996)**
- iii) Positive and Negative Affect Scale (PANAS)
(Watson and Clark 1994)**
- iv) Depression, Anxiety & Stress Scale-21 (DASS-21)
(Lovibond and Lovibond 1995) ***

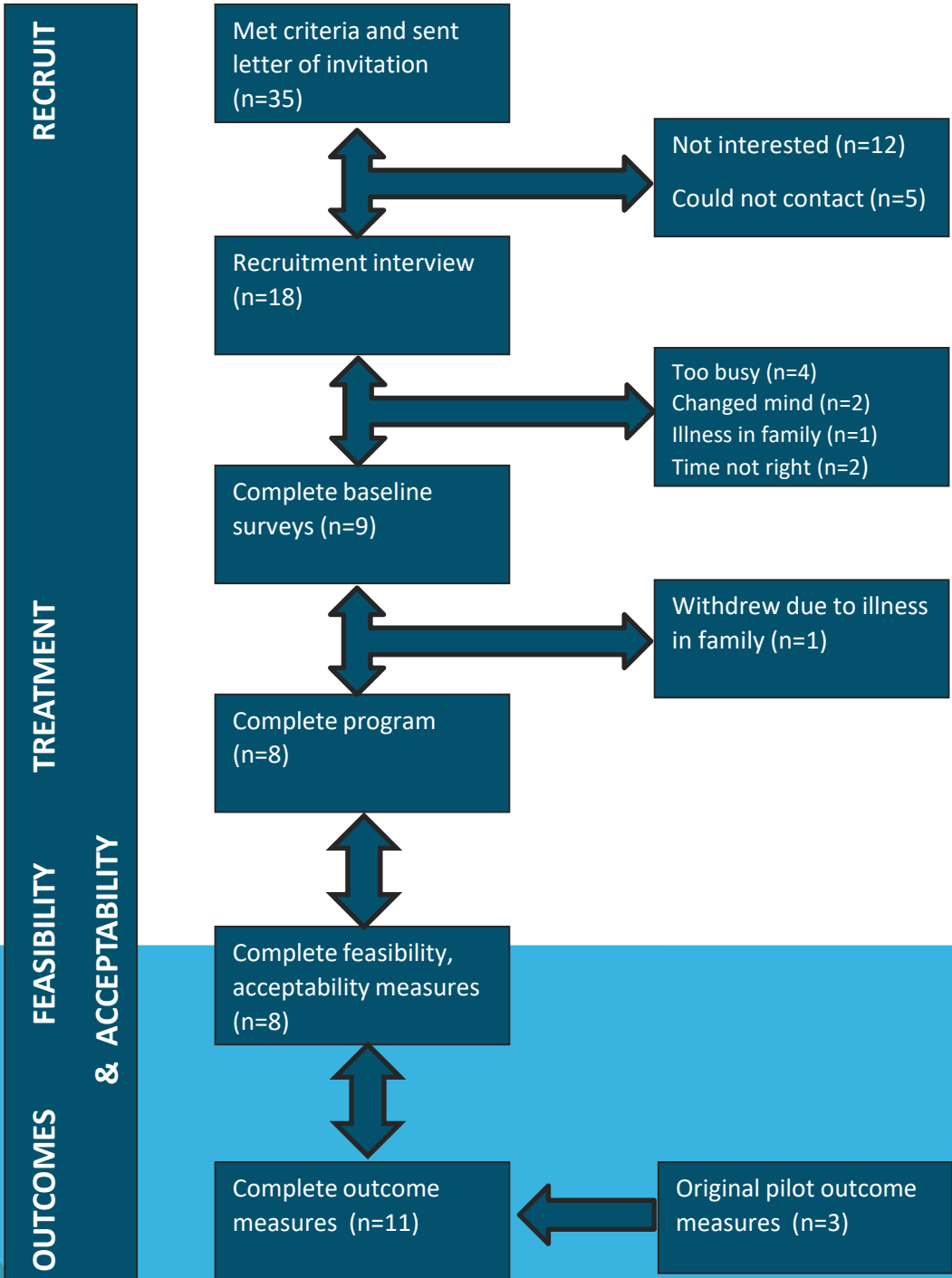
PARTICIPANTS

CRITERIA FOR RECRUITMENT

Family member of adult client of Mid Western Brain Injury Rehabilitation Program at least 6 months after acquiring brain injury

- **Aged 18 years or older**
- **Primary person providing support to person with ABI**
- **No severe co-morbid psychiatric condition**
- **Adequate English fluency and English literacy**

RECRUITMENT PROCESS



DEMOGRAPHICS

	Family member n (%) / mean (SD)	Person with ABI n (%) / mean (SD)
Age (yrs)	58.6 (8.1)	37.0 (13.0)
Sex		
Female	8 (100.0)	-
Male	-	8 (100.0)
Marital status		
Separated/divorced	3 (37.5)	-
Married/defacto	5 (62.5)	1 (12.5)
Single	-	7 (87.5)
Years of education	11.5 (2.6)	11.12 (1.0)
Employment status		
Not currently employed	4 (50.0)	8 (100.0)
Employed part-time/casual	4 (50.0)	-
Relationship to person with TBI		
Parent	6 (75)	n/a
Spouse	1 (12.5)	n/a
Sibling	1 (12.5)	n/a
Living with person with TBI at time of injury		
Yes	3 (37.5)	n/a
No	5 (62.5)	n/a
Living with person with TBI now		
Yes	4 (50)	n/a
No	4 (50)	n/a
Current living situation of person with TBI		
Own home	n/a	1 (12.5)
Parent's home	n/a	3 (37.5)
Rental	n/a	2 (25.0)
Nursing home	n/a	1 (12.5)
Other	n/a	1 (12.5)
Injury circumstances		
MVA driver	n/a	1 (12.5)
MVA passenger	n/a	1 (12.5)
Fall	n/a	2 (25.0)
Struck by object	n/a	2 (25.0)
Other TBI	n/a	1 (12.5)
Length of PTA (days)	n/a	52.8 (40.1)

(I) FEASIBILITY DATA (N=8)

	Session 1 n=8	Session 2 n=8	Session 3 n=8	Session 4 n=8	Session 5 n=8
Attendance	100%	100%	100%	83%	100%
Materials Received	100%	100%	100%	100%	100%
Audio Quality (Mean) (1-5; very poor to very good)	4.3	4.1	4.3	4.3	4.4
Staff (n=2) hours of Preparation over the 3 groups run	7 hrs	4.5 hrs	2.5 hrs	3 hrs	2 hrs

(I) FEASIBILITY – USF-M

Key points:

Pre-delivery of all group resource material was effective (not all had email, postal service delivery times unreliable for weekly delivery)

Telephone delivery enables very flexible approach to timing of weekly sessions – able to alter times to suit participants and therapists if something unexpected occurs or people take leave

Took slightly more time for most weekly sessions (1.25hrs vs 1 hr) but the amount of content in the abbreviated program is suitable

Program probably more suited to earlier period after injury and soon after people return home

Relevance of some session content was questioned – needs to be reviewed and updated

Is the program content as relevant to people with high resilience

Review wording in manual for section on “growth through adversity”

Enable facilitators to select which specific skills to focus on in sessions 2 and 4 dependent upon group

(II) ACCEPTABILITY - SATISFACTION

	Session 1 (n=8)	Session 2 (n=8)	Session 3 (n=8)	Session 4 (n=7)	Session 5 (n=8)
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
The information and content discussed today was relevant to me	3.6 (0.5)	3.4 (0.5)	3.3 (0.4)	3.0 (0.8)	3.3 (0.7)
The information discussed today was clear and easy to understand	3.8 (0.3)	3.6 (0.5)	3.6 (0.5)	3.4 (0.5)	3.5 (0.7)
The session covered the aims and objectives adequately	3.8 (0.4)	3.4 (0.5)	3.6 (0.5)	3.3 (0.5)	3.4 (0.7)
I liked the mix of activities and discussion	3.6 (0.5)	3.3 (0.4)	3.6 (0.5)	3.3 (0.5)	3.4 (0.7)
The session ran for the right amount of time	3.5 (0.5)	3.4 (0.5)	3.5 (0.5)	3.3 (0.5)	3.5 (0.5)

(II) PROCESS THEMES FROM NEII

Themes	Specific Aspects	Frequency (n=5)
Timing of participation in S2S program	<ul style="list-style-type: none"> • Would have been more useful earlier in experience of supporting a person with brain injury – even during inpatient rehabilitation as could have helped counteract some feelings of fragility and uncertainty 	5
	<ul style="list-style-type: none"> • Recommend time to focus more on the “next stage” of supporting a person with brain injury – when having to manage the more complex issues that become more obvious over time 	3
Reflecting on lived experience over time	<ul style="list-style-type: none"> • Was reminded of the value of reflection 	5
	<ul style="list-style-type: none"> • Participation helped the process of reflecting on what had happened over time for family members and the person with brain injury and helped identify a future direction 	5
	<ul style="list-style-type: none"> • Helped identify personal strengths and life learnings and how these were useful in dealing with life challenges 	3
	<ul style="list-style-type: none"> • Acknowledgement of strengths was empowering 	3

(II) PROCESS THEMES FROM NEII

Themes	Specific aspects	Frequency (N=5)
Importance of recognition and understanding from others (development of a supportive environment)	• Connecting with people in similar situations (mutual support)	4
	• Listening to others' experiences and reflecting on the differences in the ways people think and respond	3
	• Gaining ideas about other ways to do things	3
Importance of a structured group program with skilled facilitators	• Being specific to brain injury helped with structure and focus	2
	• The structure enabled reflection and skills development	5
	• Having the session resource material before the group facilitated preparation	2
	• The facilitators helped the interaction and connection with others, clarified what was said and ensured we were "heard"	5

(III) OUTCOMES DATA (N=11)

	N	Pre m (SD)	Post m (SD)	F/up m (SD)	Pre vs Post t stat	Pre vs F/up t stat	Post vs F/up t stat
Resilience	11	133.5 (31.6)	138.6 (22.7)	146.8 (18.6)	-.559	-1.682	-2.767**
CBS	10	52.4 (10.3)	51.5 (10.4)	47.3 (12.1)	-.133	2.243**	2.930**
CAMI	11	68.2 (19.5)	76.0 (14.2)	79.9 (13.2)	-2.086*	-2.672**	-1.247
PANAS – Positive	11	33.4 (7.9)	35.5 (5.3)	37.4 (6.1)	-1.040	-1.819*	-1.274
PANAS – Negative	11	20.3 (9.0)	16.3 (6.9)	18.0 (6.6)	1.245	.687	-1.042
CD-RISC	8	67.0 (14.3)	72.1 (17.1)	77.8 (10.9)	-.814	-2.093*	-1.137
DASS – Depression	8	4.5 (2.8)	4.4 (3.5)	1.8 (2.0)	.096	2.868**	3.111**
DASS – Anxiety	8	3.5 (3.3)	2.9 (2.9)	2.4 (2.7)	.568	1.116	1.528
DASS – Stress	8	4.6 (3.5)	4.3 (3.3)	2.8 (2.0)	.444	1.594	1.110

Note * <0.10 ** <0.05

DISCUSSION

Despite small sample size, a number of valuable findings identified

Feasibility: Telephone delivery of the abbreviated S2S Program is feasible:

All participants and facilitators commented positively about the cost, ease of use and quality of the teleconference facility as well as being able to participate from a range of locations

Acceptability: The telephone delivery of the abbreviated S2S Program is acceptable:

All commented on the experience of being part of a mutually supportive group and of taking time to reflect as well commenting on the benefits of exploring skills found to be useful in enhancing resilience

Specific aspects of program content would benefit from review and participants and therapists reported these

Easier to recruit participants for the delivery of the S2S Program by telephone if program offered more regularly

DISCUSSION

Outcomes:

Findings suggestive of the efficacy of the Abbreviated S2S Outcome data compared favourably to previously evaluated full (10 hour, face to face) version of S2S Program

All trends heading in right direction and results relatively strong for a small sample

Presence of positive emotion has significance in terms of people's overall wellbeing

Resilience identified as a protective factor against depression – experimental support for the findings from observational studies

Delayed benefits identified at the follow-up time-point – suggesting that practical skills and reappraisal techniques are gradually being embedded, no evidence of gains being lost

THANK YOU

Prof Grahame Simpson PhD
Director, Brain Injury Rehabilitation Research Group
Ingham Institute for Applied Medical Research

Professor, School of Human Services and Social Work
Griffith University Queensland Australia

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

