

Well-being of carers of injured individuals from a prospective cohort study in New Zealand

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Abstract

Background

Little is known about the effect on informal carers of caring for injured people. The aim of this paper is to identify characteristics of injured individuals and carers associated with poorer carer well-being.

Methods

This study was embedded within a New Zealand cohort study of injured individuals aged 18-64 years. Carers of injured people whose independence was affected 12 months after injury, were eligible. Information was collected about carer demographics, health and work before caring, Bakas Caregiving Outcomes Scale (BCOS), and Personal Well-being Index (PWI).

Results

Mean BCOS (53.5/105) and PWI (66.1/100) scores indicated low carer well-being. Anxiety or depression among the injured, and threat of long-term disability at the time of injury were associated with lower carer well-being. Female carers, and those with poor pre-caring health, had significantly lower well-being.

Conclusions

Early recognition of characteristics in the injured person, and their carer, may lead to interventions to improve well-being among carers.

Background

Long-term rehabilitation, and in some cases permanent disability following injury, bring major challenges for individuals and their families. Unexpected costs may arise^{1,2} and a family member may be required to change their employment situation to become an 'informal carer'³. In general, informal caring has been associated with poorer health, psychological distress and anxiety, and reduced employment, income and social contact³⁻⁶. The sudden nature of injury may bring special challenges, thrusting carers into their role with little time to prepare. Despite disability following injury being prevalent, investigation of the effects on carers of injured people has largely been restricted to carers of people with traumatic brain injury⁷ and spinal cord injury⁸.

The aim of this paper is to describe the well-being of informal carers of a population-based sample of injured people, and to identify characteristics of both the injured individual and the carer that contribute to reduced well-being for carers.

Methods

Study population and design

This study was embedded within the Prospective Outcomes of Injury Study (POIS), in which injured people aged 18-64 years living in one of five regions of New Zealand were recruited⁹. Participants were first interviewed three months after injury, and information was collected about age, gender, ethnicity, injury type and body region(s) affected, perceived threat to life and long term disability at the time of the injury, and EQ-5D general health status¹⁰. The EQ-5D comprises five dimensions – mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. We asked an extra question about cognitive functioning. Response options were categorised as 'no problems' or 'any problems' for analysis. Twelve-months after injury, those participants who indicated that their independence was still affected, and for whom the person caring for them lived in the same household, were eligible for inclusion in this study. Following their consent, a questionnaire was sent to their informal carer.

Information on carers' demographic characteristics, health and work status prior to caring, current Bakas Caregiving Outcomes Scale (BCOS)¹¹, and the Personal Well-being Index (PWI) was collected in the questionnaire¹². The BCOS is a 15-item scale that allows assessment of life changes as a result of caring. Responses to each item range from 1-7 (<4 = change for worse, 4 = no change, >4 = change for better). Summed scores range from 15 to 105; a score of 60 indicates 'no change'. If responses were missing for more than 50% of BCOS questions, participants were excluded from analysis; otherwise remaining responses were averaged and imputed¹¹. The PWI comprises eight domains – standard of living; personal health; achievement in life; personal relationships; personal safety; community connectedness; perceived future security; and spirituality/religion. Responses range from 0 (completely dissatisfied) to 10 (completely satisfied), and were converted to a 0-100 scale for analysis. If any response was missing, or if participants showed consistently maximum or minimum scores across all eight domains, they were excluded¹². The study was approved by the New Zealand Multi-Region Ethics Committee.

Statistical analyses

Comparison of characteristics was made using chi-square tests. Differences in carer BCOS and PWI according to carer characteristics were analysed using t-tests and one way ANOVA. STATA 11.0 (StataCorp LP, College Station, TX) was used to conduct analyses.

Results

A total of 2856 participants were recruited in the POIS study. Of these, 159 reported that their independence was affected 12 months after injury and that their main carer lived in the same household,

and so were eligible for inclusion in this analyses. Of these; 107 (67%) replied to a request to contact the carer. Responses were received from 65 (61%) carers (40.9% of eligible participants).

Table 1 presents characteristics of injured people three months after injury, according to whether or not their carer participated. A higher proportion of Māori and 'Other' ethnic groups' carers were non-participants. The age of carers ranged from 27-71 years (mean = 49 years).

Table 1 – Characteristics of injured participants according to whether their nominated carer participated in the Carers Study

Characteristics of eligible POIS participants three months after injury	Carer Study Participant (n=65)		Carer Study Non-participant (n=94)		p-value
	N	%	N	%	
Sex					
Male	39	60.0	52	55.0	
Female	26	40.0	42	45.0	0.55
Ethnicity					
European	43	66.1	40	42.5	
Māori	10	15.4	27	28.7	
Other	12	18.5	27	28.7	0.01
Injury nature					
Fractures	8	12.3	12	12.8	
Sprains & strains	21	32.3	26	27.7	
Concussion	1	1.5	1	1.1	
Contusions/superficial	1	1.5	4	4.3	
Other single injury types	5	7.7	11	11.7	
Multiple injury types	29	44.6	40	42.5	0.86
Body region					
Lower extremities	23	35.4	29	30.8	
Upper extremities	11	16.9	14	14.9	
Head & neck	2	3.1	5	5.3	
Spine & back	10	15.4	17	18.1	
Multiple regions	19	29.2	29	30.8	0.91

The mean BCOS score was 53.5 (SD 12.6) for 62 of the carers who completed the BCOS. Greatest 'change for the worse' was reported for: level of energy (65%), financial well-being (64%), time for family activities (53%), and emotional well-being (53%). 'Change for the better' was greatest in: relationship with the care recipient (34%), roles in life (16%) and self-esteem (14%).

The mean PWI total score was 66.1 (SD 19.2) for 60 of the carers who completed the PWI. The lowest mean scores were in the domains of satisfaction with health (62.8) and feeling part of

their community (62.5). The highest mean scores were in satisfaction with safety (75.8) and personal relationships (74.5).

Carers of injured people who reported anxiety or depression as measured through the EQ-5D, and those who perceived a threat to long-term disability at the time of the injury had significantly lower BCOS scores. Significantly lower PWI scores were also found among carers of injured people who perceived a threat to life, threat of disability, and carers of injured males (Table 2).

Table 2 – Bakas Caregiving Outcomes Scale (BCOS) and Personal Well-being Index (PWI) responses from Carers' (after 12 months in the carer role) according to characteristics of POIS participants

Characteristics of eligible POIS participants three months after injury	BCOS*				PWI*			
	n	%	Mean (SD) n=62	p value	n	%	Mean (SD) n=60	p value
Injury nature								
Single injuries only	35	56.5	53.3 (13.8)		32	53.3	63.1 (20.9)	
Multiple injury types	27	43.5	53.8 (12.0)	0.89	28	46.7	69.5 (41.2)	0.20
Body region								
Lower extremities	22	35.5	50.3 (14.6)		21	35.0	62.1 (19.2)	
Upper extremities	11	17.7	57.0 (18.2)		11	18.3	73.7 (21.0)	
Head & neck	2	3.2	46.0 (11.3)		2	3.3	56.8 (16.8)	
Spine & back	10	16.1	55.5 (7.5)		9	15.0	65.4 (20.9)	
Multiple regions	17	27.4	55.2 (6.8)	0.49	17	28.3	67.5 (17.7)	0.53
EQ-5D								
Mobility no problems	22	35.5	53.7 (10.3)		22	36.7	68.8 (21.1)	
Mobility any problems	40	64.5	53.4 (13.9)	0.93	38	63.3	64.5 (18.2)	0.41
Self-care no problems	30	48.4	52.3 (13.9)		29	48.3	65.3 (19.7)	
Self-care any problems	32	51.6	54.7 (14.8)	0.46	31	51.7	66.8 (19.0)	0.77
Usual activities no problems	4	6.5	58.2 (7.7)		4	6.7	67.8 (19.5)	
Usual activities any problems	57	91.9	53.1 (13.0)	0.44	55	91.7	65.8 (19.5)	0.84
Pain/discomfort no problems	4	6.4	55.0 (6.8)		4	6.7	68.7 (12.5)	
Pain/discomfort any problems	58	93.5	53.4 (12.9)	0.81	56	93.3	65.9 (19.7)	0.77
Anxiety/depression no problems	34	54.8	56.7 (12.1)		33	55.0	70.8 (16.2)	
Anxiety/depression any problems	27	43.5	49.4 (12.6)	0.02	26	43.3	59.6 (21.4)	0.02
Cognitive no problems	44	70.9	54.6 (12.9)		41	68.3	67.0 (19.2)	
Cognitive any problems	16	25.8	49.7 (12.0)	0.19	17	28.3	61.8 (19.3)	0.30
Threat to life								
Yes	11	17.7	47.2 (12.7)		11	18.3	53.3 (28.9)	
No	48	77.4	55.0 (12.7)	0.07	46	76.7	68.6 (17.7)	0.01
Threat to long term disability								
Yes	29	46.8	49.4 (11.6)		30	50.0	59.6 (19.7)	
No	29	46.8	57.7 (13.2)	0.01	26	43.3	71.2 (16.6)	0.02
Sex								
Male	37	59.7	52.0 (12.2)		36	60.0	61.4 (18.2)	
Female	25	40.3	55.8 (13.2)	0.24	24	40.0	73.1 (18.9)	0.02

*Lower scores show more burden and less personal well-being.

When considering pre-caring characteristics of carers (Table 3), females had lower PWI compared to males. Carers whose pre-caring health state was fair or poor had lower scores on both the BCOS and PWI, and carers receiving a benefit had a lower PWI score than those who were working. No significant associations were found between the age of the injured person or carer, and BCOS or PWI outcomes.

Table 3 – Bakas Caregiving Outcomes Scale (BCOS) and Personal Well-being Index (PWI) responses from Carers' (after 12 months in the carer role) according to their characteristics before taking on caring role

Carers' characteristics before taking on caring role	n	%	BCOS* Mean (SD) n=62	p value	PWI* Mean (SD) n=60	p value
Sex						
Male	26	60.0	55.8 (13.2)		73.1 (18.9)	
Female	39	40.0	52.0 (12.2)	0.24	61.4 (18.2)	0.02
Health state						
Excellent	18	27.7	57.9 (11.9)		69.1 (15.8)	
Very good	30	46.1	53.6 (7.7)		68.6 (17.9)	
Good	11	16.9	51.8 (9.2)		67.2 (16.4)	
Fair	3	4.6	29.7 (17.8)		25.8 (14.6)	
Poor	2	3.1	41.5 (19.1)	<0.001	49.4 (7.9)	0.002
Work status						
Full-time	48	73.8	54.1 (11.3)		68.9 (18.2)	
Part-time	9	13.8	57.2 (14.3)		66.2 (10.1)	
Benefit	5	7.7	40.8 (19.8)		37.0 (18.5)	
Other	3	4.6	55.7 (4.9)	0.11	73.3 (18.8)	0.003
Job security						
Very secure	19	33.3	54.8 (12.6)		72.0 (18.0)	
Secure	23	40.3	55.5 (9.8)		64.8 (19.0)	
Insecure	3	5.3	69.7 (18.9)		67.5 (6.6)	
Very insecure	12	21.1	52.1 (10.9)	0.13	71.0 (13.9)	0.59

*Lower scores show more burden and less personal well-being.

Discussion

This group of carers of injured people reported an overall change for the worse and a lower level of well-being 12 months after the injury event. Energy levels, financial well-being, time for family activities, and emotional well-being were negatively affected.

A greater proportion of carers reported a change for the better in their relationship with the injured person. Anxiety or depression experienced by the injured person three months after injury, and threat of severe long-term disability at the time of injury related to significantly lower well-being for carers. For the carers themselves, significantly lower well-being was evident amongst females, those with fair or poor health before commencing the caring role, and those receiving a government benefit.

The Auckland Regional Community Stroke Study (ARCOS) is the only other New Zealand study to our knowledge for which there are published data using the BCOS instrument¹³. Despite the ARCOS involving carers of older people who had suffered a stroke, the mean BCOS score for carers was similar (51.7; SD 12.0) to carers in our study (53.5; SD 12.6). Moreover, the proportion of carers who reported an improved relationship with the care recipient (32%) was similar to our study (34%). This high proportion was unexpected given that other studies have indicated increased stress on relationships^{3,14}. However, these previous studies refer to relationships in general rather than the relationship with the person being cared for.

The PWI has not previously been used in any study of carers in New Zealand to our knowledge. It was used in a large study of carers in Australia¹⁵, in which the overall score of those living in the same household as the care recipient (58.5) was lower than that observed in our study (66.1). The wide range of ages and length of time in the carer role in the Australian study, or the support available through the existence of New Zealand's no-fault ACC scheme, may account for greater well-being among carers in our study.

Studies have reported that carers of people with cognitive and intellectual difficulties^{16,17}, or anxiety and depression¹⁸ have greater levels of burden and stress than carers of people with physical disabilities. Our study showed a tendency for carers of people with cognitive problems to have poorer BCOS and PWI outcomes than those without; however this difference was not statistically significant, perhaps due to our small sample size. We found that anxiety and/or depression were related to poorer BCOS and PWI outcomes. Threat to life has been found to relate to longer term psychosocial outcomes for injured people themselves¹⁹. Our finding that such perceived threats also affect outcomes for carers suggests further research examining these relationships is warranted. Our study also supports previous findings that carers who themselves have a medical or psychological condition have lower well-being than carers without a condition¹⁵.

The main strengths of this study are, firstly, the inclusion of people of all injury types selected from a population-based cohort study. Secondly, we have been able to link carers' characteristics to that of the injured person. Lastly, we have been able to show both positive and negative aspects of caring using measures of well-being rather than the more commonly-used measures of burden.

A limitation of our study is that only 67% of eligible injured participants consented to our contacting their carer, and only 41% of carers of eligible injured participants consented. However, apart from ethnicity, no significant differences were found between the characteristics of injured participants and non-participants in relation to age, gender and injury characteristics. Unfortunately, no information is available on the characteristics of the carers who did not respond. Anecdotal evidence provided during the telephone tracking of non-responding carers suggests that they may be more burdened and have less time to participate. Therefore, the data presented here may be an under-estimate of the negative consequences of caring. Further research using a larger number of study participants would also enable adjustment for various pre-injury characteristics to help determine those that contribute to lower well-being.

Conclusions

This study suggests that it is possible to identify characteristics of injured individuals in the early stages after injury that have an effect on those caring for them. Specifically, health and social support personnel need to be alert for anxiety or depression, or threat at the time of the injury, and to be aware of the possible effect on well-being of the carer.

Implications for rehabilitation:

- Informal carers have poorer health, more psychological distress, and lower work force participation, income and social contacts.
- Anxiety or depression, or a perception of threat of long-term disability, in an injured individual soon after injury can impact on the well-being of their carer.
- Carers themselves who have poorer health before taking on the caring role are more likely to have lower levels of well-being.
- Health and social support personnel need to be alert for these factors in the injured individual and be aware of the possible effect on well-being of the carer.

Competing interests

The authors declare that they have no competing interests.

Authors' contributions

SM designed and implemented this research within her PhD research. SD, CP and RA are her PhD research supervisors and contributed to the design and implementation accordingly. SM and SD developed the idea for the paper and drafted the manuscript. SM led the analysis with advice from all authors. RA and CP critically revised the manuscript. All authors read and approved the final document.

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References

1. Jorgensen D, Parsons M, Jacobs S. *The experiences of informal caregivers in New Zealand*. Auckland: University of Auckland;2009.
2. Holland K. *Carers' perspectives on caring: A qualitative analysis of open-ended responses to the Carer Health and Wellbeing Index Survey*. Canberra: University of Canberra;2007.
3. Goodhead A, McDonald J. *Informal caregivers literature review*. Wellington: Health Services Research Centre, Victoria University;2007.
4. Bittman M, Hill T, Thomson C. The impact of caring on informal carers' employment, income and earnings: a longitudinal approach. *Australian Journal of Social Issues*. 2007;42(2):255-272.
5. Edwards B, Higgins D, Zmijewski N. The families caring for a person with a disability study and the social lives of carers. *Family Matters*. 2007;76:8-17.
6. Pinquart M, Sorensen S. Correlates of physical health of informal caregivers: A meta-analysis. *The Journals of Gerontology. Series B, Psychological and Social Sciences*. 2007;62(2):126-137.
7. Perleaz A, Kinsella G, Crowe S. Impact of traumatic brain injury on the family: A Critical Review. *Rehabilitation Psychology*. 1999;44(1):6-35.
8. Post M, Bloemen J, De Witte L. Burden of support for partners of persons with spinal cord injuries. *Spinal Cord*. 2005;43(5):311-319.
9. Derrett S, Davie G, Ameratunga S, et al. Prospective Outcomes of Injury Study: recruitment, and participant characteristics, health and disability status. *Injury Prevention*. 2011;17(6):415-418.
10. Brooks R. EuroQol: the current state of play. *Health Policy*. 1996;37(1):53-72.
11. Bakas T, Champion V, Perkins S, Farran C, Williams L. Psychometric testing of the revised 15-Item Bakas Caregiving Outcomes Scale. *Nursing Research*. 2006;55(5):346-355.
12. International Wellbeing Group. *Personal Wellbeing Index - Adult (PWI-A)*. 4th ed. Melbourne: Australian Centre on Quality of Life, Deakin University; 2006: http://www.deakin.edu.au/research/acqol/instruments/wellbeing_index.htm.
13. Parag V, Hackett M, Yapa C, et al. The impact of stroke on unpaid caregivers: Results from the Auckland Regional Community Stroke Study, 2002-2003. *Cerebrovascular Disease*. 2008;25(6):548-554.
14. Edwards B, Higgins D, Gray M, Zmijewski N, Kingston M. *The Nature and Impact of Caring for Family Members with a Disability in Australia*. Australian Institute of Family Studies: Melbourne; 2008.
15. Cummins R, Hughes J, Tomyn A, Gibson A, Woerner J, Lai L. *The Wellbeing of Australians - Carer health and wellbeing*. Melbourne: Deakin University;2007.
16. Magliano L, Fiorillo A, De Rosa C, Malangone C, Maj M. Family burden in long-term diseases: a comparative study in schizophrenia vs. physical disorders. *Social Science & Medicine*. 2005;61(2):313-322.
17. Schofield H, Murphy B, Herrman H, Bloch S, Singh B. Carers of people aged over 50 with physical impairment, memory loss and dementia: a comparative study. *Ageing and Society*. 1998;18(3):355-369.
18. Knight R, Devereux R, Godfrey H. Caring for a family member with a traumatic brain injury. *Brain Injury*. 1998;12(6):467-481.
19. Holbrook T, Hoyt D, Stein M, Sieber W. Perceived threat to life predicts posttraumatic stress disorder after major trauma: risk factors and functional outcome. *The Journal of Trauma*. 2001;51(2):287-292.