# HOURS AND COSTS OF FORMAL AND INFORMAL CARE FOLLOWING TRAUMATIC BRAIN INJURY AND SPINAL CORD INJURY SUSTAINED THROUGH MOTOR VEHICLE ACCIDENTS: A CROSS-SECTIONAL STUDY

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Objectives: To explore the weekly utilization of formal and informal care, and to calculate and compare the costs associated with these types of care after traumatic brain injury or spinal cord injury sustained through a motor vehicle accident in Australia. *Design:* Cross-sectional, quantitative design.

Subjects: A total of 81 people with traumatic brain injury and 30 people with spinal cord injury from 3 rehabilitation units in New South Wales, Australia. Methods: Data were collected using questionnaires administered through semi-structured interviews, and analysed using a series of Kruskal-Wallis tests. Results: Spinal cord injury (tetraplegia/ paraplegia) was significantly more expensive for both formal and informal care compared with traumatic brain injury. The costs of formal care were significantly greater for those in the traumatic brain injury group who had a more severe injury (post-traumatic amnesia >90 days) compared with the other traumatic brain injury groups (post-traumatic amnesia 7-28 days, 29-90 days). The costs of informal care were significantly higher for both traumatic brain injury and spinal cord injury compared with the costs of formal care.

*Conclusion:* This study highlights the complementary role of formal and informal care in supporting people with traumatic brain injury or spinal cord injury, particularly highlighting the significant role of informal care, which needs to be more explicitly acknowledged in policy and planning processes.

Key words: Traumatic Brain Injury; Spinal Cord Injury; Informal care; Health cost.

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In Australia, motor vehicle accidents (MVA) claim the lives of 1,100 individuals per year (1). The total cost of road trauma in Australia has been estimated as \$22.2 billion, with a cost of \$239,000 per hospitalization caused

### LAY ABSTRACT

This study explored the weekly utilization and annual costs of formal (paid support) and informal care (unpaid support) for 81 individuals with traumatic brain injury and 30 with spinal cord injury, sustained in motor vehicle accidents in Australia. Researchers conducted interviews with study participants, who were active clients of 3 separate rehabilitation units in New South Wales (NSW), Australia. Utilization of care differed across and within groups; however, the results showed significantly higher costs for spinal cord injury than for traumatic brain injury. Those with more severe traumatic brain injuries also had significantly higher costs. Finally, informal care was utilized significantly more than formal care services and contributed towards a greater annual "cost". Overall, these results demonstrate the significant role that informal care has following traumatic brain injury or spinal cord injury. This study highlights the overall importance and value of informal care being recognized more in policy and planning processes.

by road injury (2). It is estimated that half of people who survive a MVA in Australia have sustained a traumatic brain injury (TBI) (3) or spinal cord injury (SCI) (4).

TBI and SCI have long-term effects on physical, motor-sensory, cognitive, communication and behavioural domains (5, 6). The impairments associated with TBI or SCI often have a lifelong impact on an individual's ability to be independent and reintegrate into the community (7). This results in a range of health and disability services being heavily relied on following such injuries (8).

In Australia, people who sustain a TBI or SCI and are Australian citizens or permanent residents have the costs of their hospital care covered by Medicare, the Australian compulsory health insurance scheme. Following discharge from hospital, people with TBI and SCI often require a high level of care and assistance with activities of daily living, such as personal care, home support, and community participation, and overall care coordination (9, 10). This can be provided either formally by a service provider (formal care) or informally by a carer or family member (informal care).

While there is a range of formal support available to people with TBI or SCI caused by a MVA, in some circumstances the person's injury may render them dependent on caregivers (11, 12). Being able to place a monetary value on informal care is therefore important in understanding total cost structures (13, 14). Turner-Stokes (15, p. 254), in particular, noted that "simply costing (formal) care is not adequate, as it does not take into account care provided by the family, and generally reflects what the local social services are prepared to provide rather than what is actually needed".

The aim of this study was to explore the weekly hours of formal and informal care utilized following TBI and SCI, and to calculate and compare the costs associated with formal and informal care. It was hypothesized that, among people injured through a road traffic accident: (i) the costs of formal and informal care after sustaining a SCI will be greater over the longer term compared with those sustaining a TBI, due to the complexities of care required for SCI; (ii) formal and informal care costs will be greater for people with more severe (compared with less severe) TBI or SCI injuries; and (iii) informal care will make up a greater proportion of the "costs" of services, as calculated by placing a monetary value on the hours utilized in this type of care.

# **METHODS**

# Study design

This study has a cross-sectional design, consisting of 4 cohorts comprising individuals at different time-points post-injury: a 2-year cohort, a 5-year cohort, a 10-year cohort, and a >15-year cohort. The year in which the study commenced (2006) was used as the base year to determine the corresponding year for each cohort (cohort 1: 2003, cohort 2: 2000, cohort 3: 1995 and cohort 4: prior to 1990).

### Ethics

Ethics approval was granted by the University of Wollongong/South East Sydney and Illawarra Area Health Service Ethics Committee and the individual ethics committees of each of the 5 participating specialist TBI and SCI units in New South Wales (NSW), Australia.

### Sampling

A stratified random sampling approach was applied to select the study sample. Injury type (TBI or SCI) and cohort (4 cohorts) were used as stratification variables, which produced a sample frame comprising 8 strata. Potential study participants were initially identified through an analysis of admission data held at 5 specialist units. No information about the person's current utilization of services was known during the sampling process.

# Participants

The study was conducted between 2006 and 2009 and included 111 individuals with TBI or SCI who were clients of 1 of 3 specialist brain injury (Liverpool and Westmead Brain Injury Rehabilitation Units, Royal Rehab) and 2 specialist spinal cord injury rehabilitation units (Royal North Shore Hospital, Prince of Wales Hospital) in NSW, Sydney, NSW, Australia. These sites were chosen as they provided the majority of specialist inpatient rehabilitation service for adults with severe TBI or SCI in NSW. Referral to the specialist units is based on the patient's geographical residence and each unit has standardized referral protocols.

### Inclusion criteria

The inclusion criteria were: individuals who had sustained a TBI or SCI as a result of a MVA, age 18 years or older, a minimum of 2 years post-injury (to ensure that injuries had stabilized to a point at which long-term patterns of service utilization could be examined). No maximum time post-injury was applied, in order to capture service utilization patterns over the very-long-term. Those with previous TBI or SCI were still included in the study. For TBI, inclusion criteria of post-traumatic amnesia (PTA) > 7 days and a score of 5 or less on any item on the Functional Independence Measure (FIM) were applied. A score of 5 on a FIM item indicates that an individual requires assistance (physical, supervision or verbal prompting) from another person to complete a task and is therefore classified as having modified independence. Scores lower than 5 indicate higher levels of assistance being required (16). Overall, the inclusion criteria reflected people within a severe TBI range. For SCI, inclusion criteria resulted in acute traumatic lesion on the spinal canal (spinal cord or cauda equina) resulting in permanent sensory deficit, motor deficit or bladder/bowel dysfunction assessed after spinal stability. These inclusion criteria reflected the eligibility requirements of many compensation schemes in Australia at the time of the study (2006).

## Recruitment

Individuals were initially contacted in writing and invited to participate in the study. A follow-up telephone call was made 2 weeks later if required. When a person agreed to participate in the study, a suitable time and place for the interview was arranged. If no response was received to either the invitation letter or the follow-up telephone call, the next person in the relevant sample stratum was selected and the recruitment process re-commenced.

### Measures

*Demographic/injury details.* Demographic and injury details were collected using a 28-item data protocol. Items included in the protocol were: accident, sex, indigenous status, accommodation and living arrangements, carer arrangements, employment situation, government benefit or pension status, geographical area of residence, country of birth, main language spoken at home, health insurance and injury-compensation details.

Purpose-designed service utilization measure. Detailed service utilization of formal and informal care was collected using a purpose-designed instrument that captured the full spectrum of services that may have been utilized by study participants. The content validity of the questionnaire was established with reference to previous studies that have examined service utilization patterns associated with TBI or SCI (17, 18). In addition, clinical input was obtained from experienced TBI and SCI clinicians to ensure that a comprehensive range of long-term services was identified. It consisted of 12 questions measuring utilization of personal care, health and community-based services. The unit of measure was the number of hours of formal care and informal care utilized during the previous 4-week period. The categories were sub-divided into personal care (eating, grooming, bathing, dressing, toileting, transferring, communication, equipment maintenance, other personal care) home support (telephone, shopping, food preparation, housekeeping, laundry, transportation, medication, finances, other home support) and participation support (leisure and recreation, advocacy and information, ethnic health, legal advice, financial advice, vocation/ education support, other participation support).

#### Analysis

Data were analysed using SPSS version 17 (IBM Corp. IBM SPSS statistics for windows. 26.0 ed. Armonk, NY). Units of service for formal care and informal care were based on the number of hours of service reported in the previous 4-week period. Formal care was calculated as the total of personal care, home support and participation support where the service provider was paid. Informal care was calculated as the total of these variables where the service provider was not paid.

Injury severity is recognized as a strong predictor of long-term outcomes (19) and cost (20) following TBI. PTA duration is widely used as a measure of injury severity (21).Various classifications of PTA duration have emerged based on the original system devised by Russell & Smith (22). For this study, 3 injury groupings were applied (7–28 days, 29–90 days, and >90 days). The categories 7–28 and 29–90 days follow Teasdale (23).The >90 days category was included to measure costs for the relatively small number of study participants with extremely long duration of PTA.

Quantifying supervision can be difficult where passive supervision occurs concurrently with other services (such as providing assistance with activities of daily living (ADL) or instrumental activities of daily living (IADL)), particularly where an individual is receiving full-time (24 h) supervision due to severe cognitive impairment of behavioural issues. In these situations, the number of hours of care provided in a day can appear to exceed 24 h. This phenomenon has been referred to in other clinical areas as the "36 h" day (24). This issue has been addressed in previous TBI studies by applying a cap of 168 h per week (24 h per day) on the total number of hours of care that can be recorded by a carer (13).

Estimated costs were calculated by multiplying the number of units utilized by a dollar rate specific to each service. The cost of formal and informal care was calculated at a rate of \$70.00 an hour. This rate is the 2022 hourly rate charged by the Lifetime Care and Support Scheme (LTCS) (an insurance scheme that aims to provide care for people who have been severely injured in a MVA in NSW, Australia). Univariate analyses were conducted to explore the cost of long-term services, including the relative cost of formal and informal care. Costs were produced for all study participants and across 3 sub-groups: (i) injury group (TBI vs SCI); (ii) injury severity (PTA days 7–28, 29–90, and > 90 days for the TBI group; and paraplegic/tetraplegic for the SCI group); (iii) time since injury with: (the 2-year and 5-year cohorts were combined into one group and the 10-years and >15 years cohorts were combined into a second group for this analysis. Within each sub-group, Mann-Whitney U tests or Kruskal–Wallis tests were performed to assess statistical differences in cost between major cost categories.

### RESULTS

### Demographic and injury characteristics

Demographic and injury characteristics of the sample are shown in Table I. The proportion of participants

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Table II. Social characteristics

Table I. Demographic and injury characteristics

	TBI and	TBI sample	CCI comple
Variable	(n = 111) n (%)	(n = 81) n (%)	(n = 30) n (%)
Age			
18-29 years	30 (27.0)	25 (30.9)	5 (16.7)
30-45 years	42 (37.8)	31 (38.3)	11 (36.7)
45-64 years	32 (28.8)	22 (27.2)	10 (33.3)
>65 years	7 (6.3)	3 (3.7)	4 (13.3)
Sex			
Male	85 (76.6)	60 (74.1)	25 (83.3)
Female	26 (23.4)	21 (25.9)	5 (16.7)
Age at accident			
<18 years	8 (7.2)	8 (9.9)	0 (0.0)
18–29 years	57 (51.4)	42 (51.9)	15 (50.0)
30-45 years	30 (27)	22 (27.2)	8 (26.7)
45-64 years	13 (11.7)	8 (9.9)	5 (16.7)
>65 years	3 (2.7)	1 (1.2)	2 (6.7)
Geographical area			
Urban	79 (71.0)	61 (75.0)	18 (60.0)
Regional/rural	32 (29.0)	20 (25.0)	12 (40.0)
Main language			
English	104 (93.6)	74 (91.4)	30 (100.0)
Other than English	7 (6.3)	7 (8.6)	0(0)
Cohort			
Cohort 1 (2 years)	25 (22.5)	18 (22.2)	7 (23.3)
Cohort 2 (5 years)	26 (23.4)	18 (22.2)	8 (26.6)
Cohort 2 (10 years)	19 (17.1)	16 (19.8)	3 (10.0)
Cohort 4 (>15 years)	41 (36.9)	29 (35.8)	12 (40.0)
SCI completeness			
Complete tetraplegia	na	na	6 (20.0)
Incomplete tetraplegia	na	na	5 (17.0)
Complete paraplegia	na	na	13 (43.0)
Incomplete paraplegia	na	na	6 (20.0)
SCI level			
C1-C4	na	na	7 (23.0)
C5-C8	na	na	6 (20.0)
T1-T6	na	na	10 (33.0)
T7-L1+	na	na	7 (23.0)
PTA days			
7–14 days	na	4 (4.9)	na
15-28 days	na	18 (22.2)	na
29-90 days	na	27 (33.3)	na
>90 days	na	19 (23.5)	Na

TBI: traumatic brain injury; SCI: spinal cord injury; PTA: post-traumatic amnesia.

with TBI (77%) relative to SCI (23%) reflects the sampling methodology. The high proportion of males relative to females (10:3) is consistent with previously reported incidence rates of TBI and SCI in Australia (25, 26). The mean age for the study participants was 41.7 years (standard deviation (SD) 14.3 years) with the majority of participants located in the great Sydney metropolitan area.

### Social characteristics

Social characteristics of the sample are shown in Table II. For both SCI and TBI most people reported living with others (70.3%). A greater percentage of people with SCI reported having a carer living with them (60.0%) compared with those with TBI. For those with carers, the most common carer relation for TBI was spouse, while people with SCI reported a greater percentage of their carers to be a parent. A greater number of people with SCI were com-

Variable	SCI sample $(n = 111) n (\%)$	( <i>n</i> =81) <i>n</i> (%)	( <i>n</i> = 30) <i>n</i> (%)
lives alone			
Lives alone	33 (29.7)	24 (29.6)	9 (30)
Lives with others	78 (70.3)	57 (70.4)	21 (70)
Carer availability			
Has carer	62 (55.8)	44 (54.3)	18 (60)
Does not have carer	49 (44.1)	37 (45.7)	12 (40)
Carer resident			
Lives with carer	40 (36.0)	22 (27.2)	18 (60)
Does not live with carer	71 (63.9)	59 (72.8)	12 (40)
Carer relation			
Spouse	25 (22.5)	21 (25.9)	4 (13.3)
arent	24 (21.6)	16 (19.8)	8 (26.7)
Other (son, daughter, other relative, friend)	13 (11.7)	13 (16.0)	0(0)
Not applicable (no carer)	) 49 (44.1)	31 (38.3)	18 (60)
In workforce			
In workforce	56 (50.5)	44 (54.3)	12 (40)
Not in workforce	55 (49.5)	37 (45.7)	18 (60)
Government pension			
Government pension not major income source	50 (45)	39 (38.1)	11 (36.7)
Government pension or benefit major income source	57 (51.4)	40 (49.4)	17 (56.7)
Unknown	4 (3.6)	2 (2.5)	2 (6.7)
Compensable			
Compensable	62 (55.9)	43 (53.1)	19 (63.3)
Not compensable	49 (44.1)	38 (46.9)	11 (36.7)
Private health insurance			
Private health insurance	33 (29.7)	24 (29.6)	9 (30)
No private health insurance	78 (70.3)	57 (70.4)	21 (70)

TBI: traumatic brain injury; SCI: spinal cord injury.

pensable compared with people who had sustained a TBI. More people with TBI reported being in the workforce at the time of the study than people with SCI.

### Hours/utilization of formal and informal care

Hours of formal and informal care were collected during the previous 4-week period. In total, 74% of individuals with TBI and 96% of individuals with SCI utilized both formal and informal care services. The TBI group (n = 81) reported a mean of  $12.3 \pm 30.7$  h of formal care (median; interquartile range (IQR) 0.0, 7.1; range 0.0–168.0 h) with 47% (38/81) of the group using formal care services. For informal care and those with TBI a mean of  $15.4 \pm 30.8$  h was reported (2.0, 19. range 0.0–168 h) with 74% (60/81) of the group using informal care services. For people with SCI a mean of  $13.9 \pm 20.2$ h of formal care was reported (4.0, 25.2; range 0.0-82.6 h) with 73% (22/30) of people using formal care services. For informal care and those with SCI a mean of  $33.9 \pm 27.8$  h was reported (26.7, 36.9; range 0.0-99.4) with 96% (29/30) of people using informal care services.

*Traumatic brain injury*. Formal care and informal care were then subdivided and examined at the level of

Tab	le II	. Wee	kly	hours:	personal	care,	home	support	and	participatio	n support
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		ТВ	I			SC	Ĩ	
Service category	Mean (SD)	Median (IQR)	Maximum	Used (n, %)	Mean (SD)	Median (IQR)	Maximum	Used (n, %)
Personal care formal	6.8 (24.5)	0.0 (0.0)	168	17 (21)	6.3 (10.0)	0.0 (10.0)	34	13 (43)
Personal care informal	6.3 (24.8)	0.0 (0.8)	168	24 (30)	3.0 (6.3)	0.0 (1.8)	21	11 (37)
Total personal care	12.9 (34.1)	0.0 (6.0)	168	34 (42)	9.3 (12.7)	1.8 (15.8)	45	16 (53)
Home support formal	3.4 (7.7)	0.0 (1.5)	42	30 (37)	6.5 (12.5)	2.3 (5.9)	61	20 (67)
Home support informal	7.8 (12.8)	1.0 (9.5)	55	48 (59)	15.8 (16.7)	13.0 (24.7)	56	22 (73)
Total home support	11.2 (15.1)	4.0 (21.3)	68	55 (68)	22.2 (18.4)	20.5 (27.9)	61	29 (97)
Participation support formal	2.5 (6.2)	0.0 (0.8)	38	27 (33)	1.1 (4.6)	0.0 (0.0)	25	6 (20)
Participation support informal	2.3 (5.4)	0.0 (0.8)	23	25 (31)	0.7 (1.5)	0.0 (0.8)	6	9 (30)
Total participation support	4.8 (8.3)	0.0 (6.0)	40	40 (49)	1.8 (5.2)	0.0 (1.6)	28	12 (40)

TBI: traumatic brain injury; SCI: spinal cord injury; SD: standard deviation; IQR: interquartile range.

Table IV. Annual cost by injury type (spinal cord injury (SCI)/traumatic brain injury (TBI))

		TBI (n=81)			SCI (n=30)		Mann-W	hitney U
Service category	Mean, \$ (SD)	Range, \$	Used n (%)	Mean, \$ (SD)	Range, \$	Used n (%)	Z score	<i>p</i> -value
Personal care formal	24,146 (86,297)	0-575,120	17 (21)	22,944 (36,523)	0-124,063	13 (43)	-	-
Home support formal	12,514 (27,898)	0-151,060	30 (37)	23,700 (45,311)	0-222,040	20 (66)	-	-
Participation support formal	9,094 (22,718)	0-139,230	27 (33)	3,917 (16,593)	0-91,000	6 (20)	-	-
Formal care sub-total	44,901 (111,688)	0-611,520	38 (46)	50,561 (73,358)	0-300,603	22 (73)	-2.36	0.02
Personal care informal	22,727 (88,098)	0-586.040	24 (29)	10,810 (22,931)	0-76,440	11 (36)	-	-
Informal care-home support	28,317 (46,714)	0-200,200	48 (59)	59,605 (59,756)	0-203,840	22 (73)	-	-
Informal care-participation support	8,433 (19,545)	0-83,720	25 (30)	2,557 (5,297)	0-21,840	9 (30)	-	-
Informal care sub-total	56,115 (111,957)	0-611,520	53 (65)	72,973 (72,539)	0-214,760	24 (80)	-2.12	0.03
Formal care and informal care total	101,016 (157,445)	0-655,200	60 (74)	123,535 (101,459)	0-361,694	29 (96)	-2.60	0.01

SD: standard deviation; range begins at \$0.00 as not all supports were utilized and therefore did not have a cost.

personal care, home support and participation support (Table III). For those with TBI, formal and informal home support was the most commonly utilized service (68%), followed by formal and informal participation support (49%) then personal care (42%). While personal care was the least utilized service for people with TBI, it was reported to account for the most number of hours used (mean (SD)) (12.9 (34.1) h), followed by home support (11.2 (15.1) h), then participation support (4.8 (8.3) h). When breaking down the service categories (personal care, home support and participation support) into formal and informal types of care, home support was the only service category where there was an hourly difference between formal (3.4 (7.7)) and informal care (7.8, 12.8)).

*Spinal cord injury.* Similarly for the SCI group, home support was the most utilized service (97%), followed by personal care (53%) and participation support (40%). The mean (SD) total hours of home support reported for the SCI group, 22 (18.4) h, was double that reported for the TBI group. The mean (SD) reported hours for personal care, 9.2 (12.7) h, and participation support, 1.8 (5.2) h, were similar to the TBI group's reported hours of care utilized. While home support was the most utilized form of

care, this was mostly provided informally, 15.8 (16.7) h, compared with formally, 6.5 (12.5) h. Personal care was also provided more often on a formal care basis, 6.3 (10.0) h, than informally, 3.0 (6.3) h, for people with SCI.

# Costs

Differences in annual costs were analysed for formal and informal care between the TBI group (n = 81) and the SCI group (n=30) (Table IV).

The mean (SD) overall annual costs of both formal and informal care were greater for the SCI group (\$123,535 (\$101,459)) compared with the TBI group (\$101,016 (\$157,445)). However, when the types of care were subdivided and compared, the TBI group was more expensive than the SCI for formal (\$9,094 (\$22,718)) and informal (\$8,433 (\$19,545)) participation support. The TBI group was also more expensive than the SCI group in terms of informal personal care \$22,727 (\$88,098).

A larger proportion of the SCI group utilized personal care and home support on a formal and informal basis. While the SCI group was significantly more expensive than the TBI group, the range of costs was much greater

Table V. Annual cost	according to post-t	traumatic amne	esia (PTA) c	ays						
	PTA day:	s 7-28 (n=22)		PTA day	ys 29–90 ( <i>n</i> =27)		PTA	days > 90 days ( <i>n</i> =	= 19)	Kruskal-W
Service category	Mean, \$ (SD)	Range, \$	Used n (%)	Mean, \$ (SD)	Range, \$	Used <i>n</i> (%)	Mean, \$ (SD)	Range, \$	Used n (%)	×
Personal care formal	330 (1,552)	0-7,280	1 (4)	10,807 (37,784)	0-185,640	4 (14)	48,022 (107,089)	0-458,640	8 (42)	I
Home support formal	1,778 (6,824)	0-31,850	3 (13)	8,088 (29.447)	0-151,060	7 (25)	28,784 (35,436)	0-101,010	13 (68)	I
Participation support formal	2,316 (10,864)	0-50,960	1 (4)	7,201 (18,885)	0-72,800	9 (33)	21,670 (35,543)	0-139,230	12 (63)	I
Formal care sub-total	4,425 (19,171)	0-90,090	3 (13)	26,097 (80,844)	0-402,220	11 (40)	98,477 (141,852)	0-458,640	15 (78)	22.1
Personal care informal	9,761 (27,775)	0-109,200	4 (18)	1,786 (4,461)	0-14,560	6 (22)	71,746 (171,552)	0-586,040	9 (47)	ı
Home support informal	18,985 (47,839)	0-200,200	8 (36)	24,145 (41,959)	0-171,080	17 (63)	52,831 (56,031)	0-187,460	15 (78)	I
Participation support informal	2,647 (9,675)	0-43,680	2 (9)	2,797 (6,289)	0-21,840	5 (18)	20,770 (30,198)	0-83,720	13 (68)	I
Informal care sub-total	31,395 (84,029)	0-353,080	9 (40)	28,729 (46,314)	0-171,080	17 (63)	131,011 (185,699)	0-611,520	17 (89)	12.4
Formal care and informal care total	35,820 (84,591)	0-352,080	10 (45)	54,826 (105,388)	0-508,690	18 (66)	229,489 (190,637)	13,650-637,970	19 (100)	I
SD: standard deviation.										

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for the TBI group than the SCI group. The maximum cost of TBI participants for both formal and informal care (\$655,200) was more than double the maximum cost of any SCI participant (\$361,694).

# *Costs: injury severity traumatic brain injury group* (PTA days)

Differences in costs were then analysed within the TBI group based on PTA duration (Table V). For this analysis, 3 injury-severity groups were created (PTA days 7–28 days, n = 22; PTA days 29–90 days, n = 27; and PTA days >90 days, n = 19). A Kruskal–Wallis test indicated a statistically significant difference in the cost of services across all 7 cost categories with the PTA days >90 days group being significantly more expensive than the other 2 groups in each cost category.

For formal care, the PTA 28-90 days group (mean (SD) \$26,097 (\$80,844)) was 5 times more expensive than the 7–28 days group (\$4,425 (\$19,171)) while the >90 days group (\$98,477 (\$141,852)) was almost 4 times more expensive than the 7–28 days group. The very substantial difference in cost between each group clearly suggests that injury severity (as measured by PTA duration) is the major driver of the cost of formal care.

A different pattern emerged regarding informal care. Here, the mean (SD) PTA >90 days group \$131,011 (\$185,699) was more than 4 times as expensive as both the 28–90 days group \$28,729 (\$46,314) and the 7-28 days group \$31,395 (\$84, 029). The very high cost associated with providing both formal care and informal care to participants with PTA duration of >90days is particularly notable.

# Costs: spinal cord injury group (paraplegia/ *tetraplegia*)

Costs were compared within the SCI group based on the injury level resulting in tetraplegia (n = 11)vs paraplegia (n=19) (Table VI). Participants with tetraplegia were significantly more expensive (mean (SD) \$165,979 (\$92,790)) than those with paraplegia (\$91,078 (\$83,028)). This large difference in cost was not reflected in the informal care, where participants with paraplegia \$77,546 (\$83,028) were more expensive than participants with tetraplegia \$66,994 (\$58,793), although the difference was not statistically significant.

# DISCUSSION

The aim of the current study was to use empirical data to explore and breakdown the utilization and cost components of formal and informal care provided to individuals following TBI and SCI sustained through

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	Parapl	egic ( <i>n</i> = 17)		Tet	raplegic ( $n = 1$	3)	Mann-W	hitney U
Service category	Mean, \$ (SD)	Range, \$	Used n (%)	Mean, \$ (SD)	Range, \$	Used n (%)	Z score	<i>p</i> -value
Personal care formal	2,016 (5,764)	0-19,717	2 (11)	50,311 (41,804)	0-124,063	11 (84)	-	-
Home support formal	5,317 (7,187)	0-21,233	9 (52)	47,740 (61,547)	0-222,040	11 (84)	-	-
Participation support formal	6,198 (21,981)	0-91,000	3 (17)	933 (2,036)	0-5,460	3 (23)	-	-
Formal care sub-total	13,532 (31,233)	0-130,737	10 (58)	98,984 (84,981)	0-300,603	12 (92)	-3.68	0.00
Personal care informal	8,850 (23,662)	0-76,440	4 (23)	13,374 (22,621)	0-74,620	7 (53)	-	-
Home support informal	67,857 (70,754)	0-203,840	11 (64)	48,813 (41,617)	0-105,257	11 (84)	-	-
Participation support informal	838 (2,892)	0-11,830	2 (11)	4,806 (6,855)	0-21,840	7 (53)	-	-
Informal care sub-total	77,546 (83,028)	0-214,760	11 (64)	66,994 (58,793)	2,123- 167,440	13 (100)	-	-
Formal care and informal care total	91,078 (98,067)	0-345,496	16 (94)	165,979 (92,790)	58,240- 361,694	13 (100)	-2.28	0.02

Table VI. Mean annual cost by paraplegic/tetraplegic

SD: standard deviation

MVAs in NSW, Australia. Previous research has explored the utilization (6, 27) and costs of care and services following TBI and SCI (28, 29). However, to the best of our knowledge, this is one of the first studies to quantify both formal and informal care of long-term service utilization across 27 individual personal care, home support and participation support activities.

The results support all 3 study hypotheses. Firstly, the overall hours of care (and annual cost) of formal and informal care were significantly greater for those who had sustained a SCI compared with those with a TBI. This difference was greater for home support, which incorporates care tasks, such as shopping, food preparation, housekeeping and transportation. The level of assistance that people with SCI require in the home has been well documented in previous research (30, 31). For example, a study conducted by Nott, Baguley (32) found that people with SCI required higher levels of care and support, including support with housework, shopping, hygiene bathing and feeding compared with those with TBI or a dual diagnosis of SCI and TBI (32).

There were also differences in care and costs within the SCI injury group, not just between those with SCI and TBI. For example, the annual costs of those with tetraplegia were almost double the costs of those with paraplegia. Previous studies have also found that injury severity is a key factor in determining costs of care (33, 34). There were also considerable differences between the 2 SCI groups when it came to formal care, with the tetraplegia group being approximately 7 times more expensive compared with those with paraplegia. However, this was not the case for informal care, which was slightly higher for those with paraplegia. The utilization and costs differences in types of care within the SCI injury group may reflect the differing levels of disability faced by these individuals (35). People with tetraplegia have a greater level of disability, and therefore may receive formal care on a regular basis (daily) from disability support agencies rather than informally from friends or family on a sporadic basis (36, 37). These differences become increasingly apparent when comparing formal personal care and formal home support between the 2 SCI groups; people with tetraplegia report significantly more hours of these types of care compared with people with paraplegia.

The second hypothesis in this study was also supported, with results indicating significant differences in hours of formal and informal care between the TBI injury severity groups. People with more severe TBI injuries (PTA>90 days) reported more hours of formal and informal care compared with those who experienced PTA for fewer days (7-28, 29-90), which resulted in greater annual costs of these types of care across all the care domains (personal care, home support, participation support) for people with greater TBI severity. This difference was apparent across all types of formal and informal care, with personal informal care being the greatest contributor towards annual costs for the more severely injured TBI group. Similar results have been found in previous research exploring service utilization and costs following brain injury (38). Similar to the differences mentioned between the types of SCI injuries, this high utilization (and cost) of informal personal care may be a reflection of the high level of disability and incapacities people face as their severity of injury increases (39).

The hours associated with participation support (both formal and informal) for those with more severe TBIs was fairly low compared with other types of care utilized. This may indicate that, as a person's level of disability increases, they are less likely to utilize participation services, due to the nature of their disabilities, and more likely to utilize home and personal care support. Individuals with less severe TBI injuries (PTA 7–28 days) reported that their use of home support was minimal compared with the other 2 PTA injury severity groups, with the most significant contributor to annual costs being reflected in the informal home support category. This finding is also reflective of previous research (40). The results of the current study support the role that severity of TBI injury has on the utilization (and costs) of formal and informal care, as well as the types of care being utilized by these injury groups.

Finally, the third hypothesis in this study was supported, with informal care making up a significant proportion of the total costs of care, despite injury type (SCI, TBI) or severity. The annual cost of informal care for both the SCI and TBI group made up a significantly higher proportion of the total annual costs compared with formal care. These results reflect previous research in the area of informal care utilization following these types of injuries (41).

In the current study, the majority of hours attributed to home support were provided on an informal care basis. This is a crucial finding, as previous research has reported that, despite the significant hours of informal care people with SCI receive, carers are often left feeling as though the role they play in the injured person's life is not recognized or supported by health professionals (42). The high level of informal care people with TBI and SCI receive has been shown to have a clear impact on the overall quality of life of the carer, resulting in common negative outcomes, such as depression, anxiety and isolation, for informal carers (43).

A recent Australian report, by Deloitte (44), estimated the economic value of Australia's informal carers and provided a forecast of supply and demand for this type of care in Australian over the next 10 years. The report concluded that there is an increasing gap between supply and demand for informal care, and the need for greater recognition of the needs of informal carers. Recognition of informal care is imperative in social policy in order to ensure the sustainability of Australia's disability systems (44).

There are a number of key findings from this study that ultimately add to the field of TBI and SCI rehabilitation medicine. These findings include: (i) the significantly greater utilization and cost of informal care compared with formal care for both people with SCI and TBI; (ii) the role that injury severity has in terms of formal and informal care utilization and costs for TBI and SCI; and, finally, (iii) the significantly greater utilization and cost of formal and informal care for people with SCI compared with people with TBI. The current study has made an original contribution to understanding the hours utilized of formal and informal care following TBI and SCI sustained through a MVA, as well as the significant costs associated with care following these types of injuries. This study not only highlights the complementary role of both care types, but also reinforces the position that informal care needs to be more explicitly acknowledged in policy and planning processes, together with increased and strengthened long-term support for individuals with the injury and their families This view has been increasingly expressed by other TBI and SCI researchers in previous years (45). This is a critical issue for Australia, since, as carer burden increases, quality of life is potentially adversely affected, and carers generally become less able to sustain the levels of care currently being provided, as shown in previous studies (46).

This study has several limitations, including its relatively small sample size. As service utilization details were collected using participant (and carer) recall, some under- or over-estimation may have occurred. It is also important to note that the most disabled group of people with SCI (ventilator-dependant quadriplegic subjects) were not included in the current study, who it would be anticipated would have a greater number of hours of care, and thus a higher annual cost of care associated with the nature of their disability due to the intensity of care they require.

The challenges associated with informal family care provided to people with TBI or SCI have been documented across Europe (47), South East Asia (48), and North and South America (49). However, the hours of informal care have been recorded in only a small number of countries (47, 50, 51) and it is likely that the hours (and associated costing) will vary from country to country, depending on the nature of public and private health/social service systems and the means to access such service systems. In addition, informal caregivers from lower income groups are also at higher risk of strain, and this may, in part, be due to a reduced access to services (48). There is a need for further research in this area, as increasing hours of care are strongly correlated with higher burden of care (51, 52), which increases the risk of family breakdown. Furthermore, within the Australian context, as these data were collected before the introduction of specific compensation schemes, such as Lifetime Care and Support Scheme (LTCS) and the National Disability Insurance Scheme (NDIS), future research should consider examining the utilization of formal and informal care after the implementation of these schemes, which would make for a useful comparison.

The authors have no conflicts of interest to declare.

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