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Community living after catastrophic brain injury in Victoria: preparedness, outcome and cost.

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Executive Summary

Purpose

This study aimed to determine the burden, cost and configuration of attendant care in Victoria for adults whose acquired brain injury occurred prior to 2014. The specific study aims were to:

- Describe the configuration of attendant care (paid and unpaid) provided early post discharge and >3 years after severe ABI
- Describe the equipment and home modifications in-situ, and other community services used post-discharge (recent and >3 years)
- Provide a per annum cost of attendant care received (inclusive of both paid and informal care costed at replacement valuation)
- Compare attendant care levels, caregiver preparedness, caregiver quality of life (QoL) and health-related QoL (HRQoL) among survivors of ABI (recent and >3 years; compensable and non-compensable).

Rationale

Following a severe acquired brain injury (ABI), whether as a result of traumatic brain injury (TBI) or stroke, people frequently require support and assistance. Frequently individuals require both paid and informal (unpaid) care in order to live in the community, and significant resources are invested in environmental adaptations, assistive equipment as well as attendant care.

Method

A prospective cross-sectional design which applied structured interviews, standardised assessment of function and ability, care-giver assessment and recall of care hours and tasks, and health economic projections.

Research findings

The key messages from this study are:

- i. Although all participants were deemed to have had an ABI severe enough to warrant continuous care (inclusive of supervision, passive and/or active care) at the time of discharge from inpatient hospital care, when assessed >1 year post-discharge they received an average of 92.93 hours of care per week (paid and informal combined). Reasons for the differences between discharge levels of support and support post-discharge requires further investigation.
- ii. On average, the sample was estimated to receive attendant care valued at a mean annual cost of \$208,399 p.a. (median \$163,025 p.a.). The long-term ABI group had a higher mean annual cost than the recent ABI group (\$257,762 vs. \$126,127) and a more stable estimate of care. The Transport Accident Commission (TAC) client group reported a higher mean annual cost than the non-TAC group (\$299,276 vs. \$147,814) inclusive of paid and informal (unpaid) care. This study did not, however, differentiate care need from the amount of care provided, and estimates should be taken as care provided.
- iii. Health related quality of life (HRQoL) was similar on all measures for TAC clients compared to non-TAC clients. Measures were also similar for the study group who were considered as having a long-term ABI (i.e. >3 years) and those who had a more recent injury. Findings suggest that HRQoL after severe ABI is complex and that relationships between HRQoL and variables such as adjustment over time, receiving

- case management, and support from compensation entities require further investigation.
- iv. FIM motor sub-scales were very similar between the group receiving TAC compensation funding and those who were not TAC clients. However, patient reported disability as reported on the Craig Handicap Assessment and Reporting Technique (CHART) suggests that those who received TAC compensation funding had a greater degree of physical *disability* than those who were not receiving TAC funding, and therefore required a greater degree of physical assistance to carry out daily activities. This is further reflected in the greater total weekly hours of care provided to the TAC compensation group, and raises the likelihood that FIM motor subscales alone are inadequate for determining physical disability after acquired brain injury.
 - v. Patient reported activity as measured by the three sub-scales of the Mayo-Portland Adaptability Inventory (MPAI-4) was similar for those who had long-term ABI (i.e. >3 years) and shorter term ABI, suggesting stability across time. Participants receiving compensation through TAC demonstrated greater problem severity on all subscales of the MPAI-4 ($p < 0.005$); these findings suggest the importance of interpreting costs based on measures of dependency, and may explain observed differences between the TAC and non-TAC participant mean and median annual cost estimates.
 - vi. Measures of carer experience, preparedness and burden revealed that, as a whole, informal caregivers report a lower quality of life than the general population. Measures to support the transition to the role of caregiver, and initiatives to support caregivers in the community are therefore of importance to investigate within the new Alfred Health severe ABI Rehabilitation Service.

Use of the research

This is the first Victorian study to gather cost-related data from individuals with severe ABI and all carers (paid and informal). The findings from the present study will be of key importance in providing a comparison data set for outcome data gathered following opening of the new Alfred Health severe ABI Rehabilitation Service in Victoria.

Potential impact of the research

The results of this study provoke important questions about the relationship between access to paid assistance and the amount of informal assistance provided, reasons that participants in this study were receiving an average of 92 hours/week of care, and whether the amount of care that people receive is reflective of actual care need. The findings from this study form an important baseline for the evaluative work that will be conducted in the new Alfred Health Severe ABI Rehabilitation Service over the next 3-5 years.

Background

A severe acquired brain injury (ABI) can have a major effect on an individual's cognitive, physical, and/or emotional functions. For some individuals, all three functional areas are involved, with serious effects on their ability to regain their previous level of independence [1, 2]. As a result, people with severe disabilities following ABI often require assistance to perform tasks they would normally complete themselves [3]. Environmental modification and support services, including attendant care, can enable such individuals to live more independently in the community. Some people only require care services for a limited period post-discharge. Others may require continuous attendant care and support services from at least one, and sometimes two, carers for the rest of their lives. The more severe a person's disability the more profound the limitations in their ability to live without support and thus, the greater their need for assistance to live in the community [4]. The incidence of severe ABI in Victoria each year is low [4, 5] but the liabilities represented by neurotrauma are disproportionately high compared to all other injury types [4]. Further, the cost of funding attendant care represents the greatest proportion of the total liabilities of compensable neurotrauma injuries [6]. Understanding attendant care configurations and their costs is, therefore, of importance.

Policy makers, funders and healthcare professionals alike accept that attendant care, inclusive of paid and informal care, enables a person with severe ABI to live in the community following discharge from hospitalisation. What remains unknown, however are robust costings of attendant care inclusive of both paid and informal care, an understanding of access to sufficient care, and the caregiver configurations within the home environment. While in some instances funds may be provided for paid attendant care (e.g. compensation), previously conducted studies in Australia suggest that the cost and availability of carers remain a challenge to many families and people with severe ABI [7]. Even when paid carers are involved, informal caregivers frequently provide a considerable amount of care to support the care situation, and these caregivers are likely to be family members [3, 8, 9]. Therefore, the aim of this study was to understand the amount of attendant care (inclusive of both paid and informal care) provided within Victoria to adults with severe ABI from stroke or traumatic brain injury (TBI).

The opening of the new Statewide ABI Rehabilitation Service at Alfred Health will provide an opportunity to see family-centred rehabilitation offered to adults with severe ABI in Victoria. The model of care for this service has been developed to address caregiver preparedness, improve functional status and living situation, and ultimately lead to less caregiver hours being necessary post-rehabilitation. Therefore, a further aim of this study was to produce high quality baseline data pre-opening to permit the evaluation of the impact of introducing the new model of rehabilitation care in Victoria.

Definition of Severe ABI

Acquired brain injury (ABI) refers to injuries to the brain after birth, including injuries resulting from trauma (TBI), disease (stroke), substance abuse, lack of oxygen to the brain (hypoxic brain injury), or infection. Severity of ABI is usually classified based on an individual's level of consciousness following their injury. Methods used to determine level of consciousness for

those who present with a traumatic brain or hypoxic brain injury. include a score on the Glasgow Coma Scale (GCS) of between 3-8, duration of loss of consciousness of greater than 6 hours, or a period of post-traumatic amnesia (PTA) that extends for greater than 24 hours[2, 10]. For those who present with stroke, level of consciousness is usually assessed using the National Institutes of Health Stroke Scale (NIHSS) if the GCS is not recorded.

Broadly, this study aimed to determine the burden, cost and need for attendant care in Victoria for adults who experienced a severe ABI prior to 2014.

Specific study aims were to:

- Describe the configuration of attendant care (paid and unpaid) provided early post discharge and >3 years after severe ABI
- Describe the equipment and home modifications that are provided and other community services used post-discharge (recent and >3 years)
- Commence costing of attendant care provided (inclusive of both paid and informal care)
- Compare attendant care levels, caregiver preparedness, caregiver quality of life (QoL) and health-related QoL (HRQoL) among survivors of ABI (recent and >3 years; compensable and non-compensable).

Methodology

Design

Prospective cross-sectional design.

A range of methodologies were used in this study, including structured interviews, standardised assessments, surveys of care-givers, and health economic modelling.

Ethics

Ethical approval was gained for this project through the Alfred Hospital Ethics Committee (404/12), Melbourne Health Ethics Committee (2014.092) and the La Trobe University Human Research Ethics Committee.

Participant Recruitment

People were included in the study if they:

- Had sustained a severe, catastrophic ABI[11]. As participants were not recruited at the time of injury, severe ABI was classified as being a GCS of between 3-8, reported duration of loss of consciousness of greater than 6 hours, or reported a period of post-traumatic amnesia (PTA) that extended for greater than 24 hours
- And, reported having received continual care and/or supervision for 24-hours or more per day at the time of their discharge from hospital (acute or subacute). As participants were not recruited at time of injury, the medical record was used to retrospectively calculate a Care and Needs Scale (CANS) score as able (Section 2: Support Levels, Level 6 or 7). This information was then checked using a subjective interview with potential participants and/or their caregivers that at discharge the participant met the CANS support levels 6 or 7.

- Were aged over 18, and
- Were living either in private housing or a community group home in Victoria at the time of assessment.

A combination of diagnostic criteria and limitation of activity and participation measures were used to define a severe ABI to select a sample population. Diagnostic criteria may inform treatment and rehabilitation decisions in clinical settings but are not always a good stand-alone measure of long term function and disability (Walsh et al, 2005). Therefore, diagnostic measures recorded in the medical record were used to assess the severity of ABI (including Glasgow Coma Scale score at scene and length of time in post-traumatic amnesia) and these were further informed by the clinical judgement of the researcher. Measures used by the researcher included the Care and Needs Scale (CANS) applied retrospectively to discharge functional levels based on hospital reports and/or caregiver recall, and Functional Independence Measure scores at time of discharge.

Two cohorts of people with ABI and their caregivers were included in this study. Participants in one cohort had been discharged in the 12 months prior to interview, and participants in the other cohort had been discharged more than 3 years ago.

People were not included in the study if they:

- were living in a supported living facility (e.g. nursing home) at the time of interview, or
- required interpreters* (due to budgetary constraints).

** Minimally conscious participants were included in this study provided that their caregiver/s were able to participate in the interviews*

Potential participants were identified from three sources – two major neurotrauma primary care facilities in Victoria (The Alfred and Melbourne Health) and the Transport Accident Commission (TAC) claimant database. A retrospective approach was utilised by each of the three sources to identify potential participants. Methods varied slightly across source, based on available data.

Alfred Health Emergency & Trauma Centre participants

The research team obtained Emergency and Trauma Centre admission lists from Alfred Health for the time periods corresponding to the required cohort groups. Information contained within the admission lists was supplemented through screening of the patient's medical records to identify the individuals who met the study inclusion criteria (ie. low GCS and length of PTA greater than 24 hours). The research team then contacted potential participants via phone to confirm that they met the inclusion criteria (ie. level of support and supervision on discharge from hospital).

Melbourne Health Emergency and Trauma Centre participants

Research partners at Melbourne Health provided the study inclusion criteria to their Health Information Services department who then completed the screening procedure. The resultant nine names were provided to the research team for further screening. Further screening by the research team revealed that one person was suitable to contact regarding the study, while the other eight did not meet the inclusion criteria (six were high functioning, one lived interstate and the other was aged under 18 years). The Melbourne Health research partners also provided the contact details for the coordinator at Villa Maria's purpose built home which supports the needs of young people with high support needs as a result of significant ABI. The coordinator at Villa Maria identified one suitable resident who agreed, along with their family, to participate in the study.

TAC claimant participants

The TAC Client research team used the study inclusion criteria to screen their claimant database for potential participants. They then excluded the individuals who had indicated that they did not want to be contacted regarding research activities. Members of the TAC Client Research Team contacted each of the potential participants by mail and follow up phone call to determine their interest in being contacted by the research team. The names of 8 of interested TAC claimants were provided to the research team for follow up. All 8 participants were contacted and 6 claimants participated in the study, with the remaining 2 participants declining to participate. All participants (people with an ABI, informal carers and / or paid carers) completed a written consent form prior to participation.

As shown in Figure 1: Recruitment flowchart, following screening of the Alfred Health medical records and TAC claimant database, 163 people were deemed potentially eligible for inclusion in the study. Sixty individuals were able to be contacted using the details provided and forty of those individuals participated in the interviews.

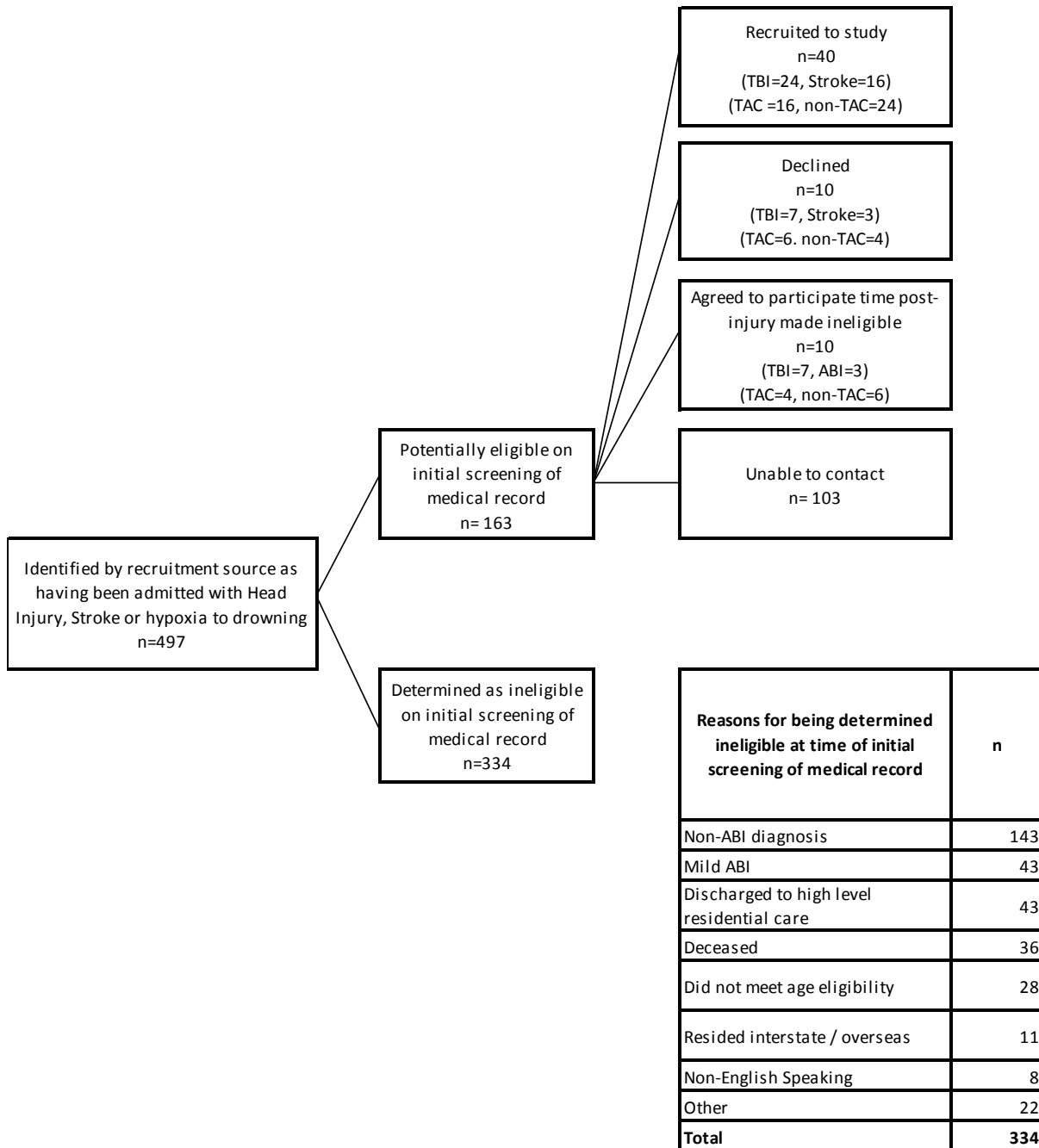
Data Collection

Data were collected by a registered occupational therapist at a location identified by the person with an ABI and/or their caregivers (paid and informal), most often their own home. All participants were encouraged to have a caregiver present during the data collection session; sessions took between one hour and four hours. Participants were offered the opportunity to cease the session and schedule a second session if required.

In addition to collecting demographic details from each participant, a range of measurement tools were used during the data collection session and completed in conjunction with person with an ABI and/or their carer:

- Mayo Portland Adaptability Index, Version 4 (MPAI-4) [12, 13]
- Functional Independence Measure (FIM) [14]
- Short Form-12 (SF-12) [15]
- Hospital Anxiety and Depression Scale (HADS) [16]
- Care and Needs Scale (CANS) [17]
- Paid and/or unpaid care recall questionnaire [18]
- List of current disability-specific equipment and housing modifications
- List of current services received by the participant
- List of current medications
- Craig Handicap Assessment and Reporting Technique (CHART): Physical and Cognitive independence scales [19]
- EQ-5D Health Questionnaire [20]
- Nottingham Extended ADL Scale [21]
- Carer Experience Scale (ICECAP-A) [22]
- Caregiving Burden Scale [23]
- Carer Preparedness Scale [24]

Figure 1: Recruitment flowchart



Health Economic Evaluation

Paid and informal care was valued using a proxy good (or market cost) method[25]. In this way, the time invested by caregivers is recorded and valued using a price of a close market substitute. The proxy good method thus requires a list of the care tasks performed, the time spent on these tasks and proxy values for each task. Carer costs of both formal (paid) and informal (unpaid) carers were estimated based on the Craig Handicap Assessment and

Reporting Technique (CHART) questionnaire. For each respondent, the number of hours provided daily (inclusive of physical assistance and passive supervision) as well as and the number of hours of occasional assistance provided per month were recorded. To assist participants recall care received, researchers sought to understand care provided daily (such as physical assistance, prompting, passive supervision and inactive overnight care) as well as care regularly provided on an occasional basis (such as nail care, gardening).

The cost for formal care was estimated by multiplying the total number of hours provided and the carer wage rate. To calculate the cost for informal care, we adopted a single cost replacement valuation method, i.e. the cost of buying a similar amount of service from the formal care sector. In this analysis, the carer wage rate was set as \$36.50 per hour, a standard hourly payment rate for attendant care from the Transport Accident Commission.

Cost for equipment and home modification was calculated based on an audit of equipment use and home modification conducted during the interview session. The audit collected detailed information regarding bathroom (24 items), manual handling (6 items), bedroom (11 items), continence (8 items), daily living aids (28 items), pressure care (3 items), community living (5 items), mobility (19 items), home modifications (20 items), and other equipment (53 items). Participants also had opportunity to report any additional equipment or home modification that were not included in the original audit questionnaire. For each listed item of equipment, the recommended replacement schedule was used to assist the calculation of annual cost. In case an item should be replaced less than once a year (e.g. a scooter is limited of 1 per person every 5 years), we specify the full cost to be incurred in the first year. The cost for a particular equipment or home modification was calculated by multiplying the average item cost and the number of items required per person (derived based on the recommended frequency of replacement). The total equipment and home modification cost was the summary of all item costs recorded.

Analysis

Descriptive statistics were used to describe the study population and their outcomes. Data are presented as proportions. The distribution of each outcome measure was firstly tested by the Shapiro-Francia normality test. For continuous variables with a normal distribution data were summarised using the mean and standard deviation (SD); where data were not normally distributed, the data were summarised using the median and interquartile (IQR) range or were categorised for analysis. Depending on the distribution of each outcome score, the t test (for normal distribution) and Mann-Whitney test (for non-normal distribution) were used to assess sub-group differences. The significance level was set at 5%.

Results

Participant characteristics

As shown in Table 1, 40 participants with a severe ABI agreed to participate in the study. The majority of our sample sustained their severe ABI from a traumatic cause (60%) rather than disease (Table 3 outlines cause of ABI). The gender ratio (male:female) was 1.35:1, with 23 (57.5%) males recruited to the study. To understand potential impact of time on attendant care patterns and costs, we recruited participants with either a recent ABI (as defined as being less than three years (or the care situation had not yet settled) or a long-term ABI, defined as being greater than 3 years at time of assessment.

Table 1: Number of participants recruited

	Whole Sample	Injured >3 years participants	Recently injured participants
Whole sample	n=40	25	15
Traumatic Brain Injury participants	24 (60%)	14 (56%)	10 (67%)
Stroke participants	16 (40%)	11 (44%)	5 (33%)

Figure 2: Compensability status of participants

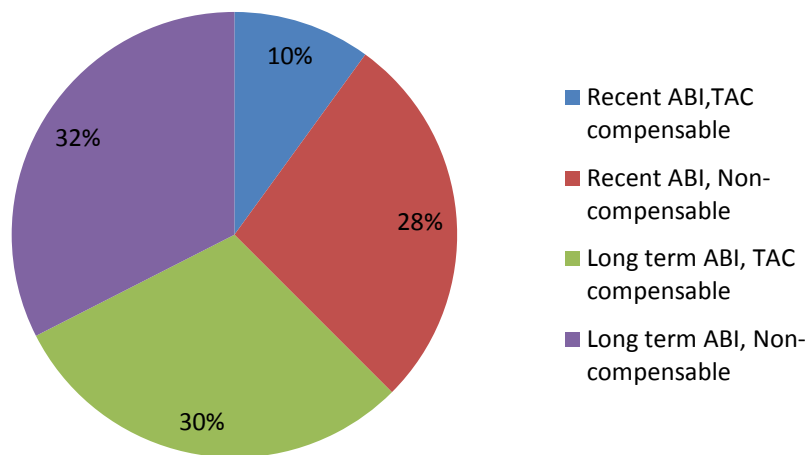


Table 3: Cause of Injury

	n (%)
Stroke	16 (40)
Incidental fall	3 (7.5)
Road traffic accident: Motor Vehicle*	15 (37.5)
Road traffic accident: Pedestrian	1 (2.5)
Road traffic accident: Cyclist	1 (2.5)
Sport / recreational related injury	2 (5)
Other	2 (5)
Total participants	40 (100)

*Note: One of the individuals who reportedly sustained a motor vehicle accident was injured when riding a trail bike and therefore was ineligible for TAC compensation funding.

Table 4: Time since injury (months)

	All	Study Group		Compensation Group	
		Injured >3 years	Recent injury	TAC	Non-TAC
Average	37.82	52.57	13.24	45.39	32.77
SD	23.84	17.77	2.46	25.08	22.06
Range	8 - 98	33-98	8-17	13-98	8-74

A variety of living situations were encountered in our study, despite all participants requiring continual attendant care support at the time of discharge from the incident hospital (Table 5 below). The most common living situation was to live with family member/s plus receive paid attendant care support (n=20, 50%).

Table 5: Living / care circumstances

	Whole sample n=40	Study Group		Compensation Group	
		Recent injury n=15	Injured >3 years n=25	TAC n=16	Non-TAC n=24
Alone, without support	1 (2.5%)	0	1 (4%)	0	1 (4%)
With family who support them	8 (20%)	6 (40%)	2 (8%)	0	8 (33%)
With family plus paid carers	20 (50%)	6 (40%)	14 (56%)	8 (50%)	12 (50%)
Alone, with support from paid carers	1 (2.5%)	1 (7%)	0	1 (6%)	0
Alone, with support from unpaid carers	3 (7.5%)	1 (7%)	2 (8%)	2 (12.5%)	1 (4%)
Alone, with both paid and unpaid carers	3 (7.5%)	1 (7%)	2 (8%)	2 (12.5%)	1 (4%)
Shared accommodation, with support of paid carers	4 (10%)	0	4 (40%)	3 (19%)	1 (4%)

The carers of 36 participants with ABI participated in the study. Of these, 34 were informal (unpaid) carers and 2 were paid carers. Twenty-seven (79.4%) informal carers lived with the person with an ABI. The gender ratio (female:male) of informal carers was 3.25:1, with 26 (76.5%) female carers participating in the study. The relationship of the informal carers to the participants are shown in Table 6.

Table 6: Relationship of informal carers to participant

	Female n (%)	Male n (%)	Total carer group n (%)
Spouse / defacto	9 (34.6)	4 (50)	13 (38.2)
Child	1 (3.9)	1 (12.5)	2 (5.9)
Parent	12 (46.2)	1 (12.5)	13 (38.2)
Sibling	3 (11.5)	2 (25)	5 (14.7)
Other relative	1 (3.9)	0	1 (2.9)
Total number of informal carers	26	8	34

Patient-Reported Quality of Life (QoL) and Capability Outcomes

Table 7 presents the health-related QoL and capability scores derived from the application of three generic preference based instruments – the EQ-5D-3L, SF-6D (health-related QoL) and ICECAP-A (capability). The EQ-5D and SF-6D utility scores were found to be normally distributed whilst the EQ VAS and ICECAP-A values were not normally distributed. The mean EQ-5D utility was 0.62 for the whole sample, and the long-term injury group exhibited very similar utilities as the recent injury group (0.62 vs. 0.61). Grouped by compensation status, the non-TAC group had slightly higher mean utility than the TAC group (0.64 vs. 0.58); however, none of the sub-group differences were found to be statistically significant (all $p > .05$). Similar conclusions hold when the EQ-VAS (mean score 74.26), SF-6D (mean score 0.68) and ICECAP-A (mean score 0.74) were compared. Importantly, ICECAP-A scores for the sample of caregivers is more than 2SD below the published mean index of 0.848, indicating that caregivers of adults with severe ABI in Victoria report lower HRQoL than other Australian caregivers[26].

Table 7 Health-related Quality of Life and Capability

	All		Study Group				Compensation Group			
	N	Mean (SD)	Injured >3 years		Recent Injury		TAC		Non-TAC	
			N	Mean (SD)	N	Mean (SD)	N	Mean (SD)	N	Mean (SD)
<i>Person with ABI Quality of Life</i>										
EQ-5D	38	0.62 (0.27)	23	0.62 (0.29)	15	0.61 (0.26)	14	0.58 (0.25)	24	0.64 (0.29)
EQ VAS	35	71.97 (19.94)	21	73.33 (20.94)	14	69.93 (18.90)	13	67.31 (18.49)	22	74.73 (20.66)
SF-6D	36	0.68 (0.14)	21	0.71 (0.15)	15	0.64 (0.13)	14	0.65 (0.16)	22	0.71 (0.12)
<i>Caregiver Quality of Life</i>										
ICECAP-A	32	0.74 (0.22)	19	0.76 (0.23)	13	0.72 (0.20)	11	0.74 (0.25)	21	0.74 (0.20)

Note: all sub-group differences were statistically insignificant.

Patient-Reported Activity Outcome: Mayo-Portland Adaptability Inventory – 4 (MPAI-4)

The MPAI-4 and its three subscale scores are presented in Table 8. The null hypothesis of normally distributed scores could not be rejected (all $p > .05$). The whole sample had a mean score of 50.66 on the MPAI-4 total score. Based on the t test statistics, the differences in mean scores between the two study groups were insignificant, whilst the differences between two compensation groups were found to be highly statistically significant (all $p < .005$). TAC patients had significantly higher MPAI-4 scores than non-TAC patients, indicating greater problem severity.

Table 8 Mayo-Portland Adaptability Inventory – 4

	All		Study Group				Compensation Group			
	N	Mean (SD)	Injured >3 years		Recent Injury		TAC		Non-TAC	
			N	Mean (SD)	N	Mean (SD)	N	Mean (SD)	N	Mean (SD)
Ability T Score	39	51.90 (12.78)	24	52.67 (13.25)	15	50.67 (12.34)	15	57.33 (12.46)	24	48.50 (12.00)
Adjustment T Score	39	51.49 (15.87)	24	53.46 (17.06)	15	48.33 (13.71)	15	60.13 (16.43)	24	46.08 (13.13)
Participation T Score	39	54.87 (11.21)	24	56.08 (13.14)	15	52.93 (7.14)	15	60.67 (10.32)	24	51.25 (10.36)
Total T Score	39	55.21 (15.45)	24	56.46 (16.20)	15	53.20 (14.48)	15	63.47 (13.48)	24	50.04 (14.53)

Note: the difference between MPAI-4 (ability/adjustment/participation/full) T Scores on two compensation group was statistically significant (all $P < 0.005$, t test); all else were insignificant.

Patient-Reported Activity Outcome: Nottingham Extended Activities of Daily Living (NEADL) Scale

The NEADL and its four subscale scores are presented in Table 9. The null hypothesis of normally distributed scores could not be rejected (all $p > .05$). The total sample had a mean NEADL score of 10.59. None of the sub-group differences were statistically significant.

Table 9 Nottingham Extended Activities of Daily Living Scale

	All		Study Group				Compensation Group			
	N	Mean (SD)	Injured >3 years		Recent Injury		TAC		Non-TAC	
			N	Mean (SD)	N	Mean (SD)	N	Mean (SD)	N	Mean (SD)
Mobility	39	3.13 (2.23)	24	3.08 (2.21)	15	3.20 (2.34)	15	3.13 (1.88)	24	3.13 (2.46)
Kitchen	39	3.31 (1.84)	24	3.33 (1.86)	15	3.27 (1.87)	15	3.67 (1.59)	24	3.08 (1.98)
Domestic	39	1.90 (1.71)	24	1.75 (1.73)	15	2.13 (1.73)	15	1.53 (1.41)	24	2.13 (1.87)
Leisure	39	2.26 (1.39)	24	2.08 (1.47)	15	2.53 (1.25)	15	2.07 (1.22)	24	2.38 (1.50)
Total	39	10.59 (6.28)	24	10.25 (6.22)	15	11.13 (6.56)	15	10.40 (5.12)	24	10.71 (7.01)

Note: all sub-group differences were statistically insignificant.

Patient-Reported Disabilities Outcome: Craig Handicap Assessment and Reporting Technique (CHART)

The two CHART subscales were non-normally distributed. The mean scores on physical and cognitive independence scales were 63.27 and 53.95, respectively. Sub-group analyses suggests that the non-TAC group had a significantly higher score (greater degree) on physical independence than the TAC group (i.e. the compensation group displayed a greater degree of physical disability than the non-compensation group).

Table 10 Craig Handicap Assessment and Reporting Technique

	All		Study Group				Compensation Group			
	N	Mean (SD)	Injured >3 years		Recent Injury		TAC		Non-TAC	
			N	Mean (SD)	N	Mean (SD)	N	Mean (SD)	N	Mean (SD)
Physical independence	40	63.27 (42.94)	25	52.84 (45.46)	15	80.66 (32.80)	16	46.48 (44.96)	24	74.47 (38.49)
Cognitive independence	40	53.95 (29.68)	25	50.32 (32.25)	15	60.00 (24.65)	16	43.50 (28.72)	24	60.92 (28.79)

Note: the difference between physical independence value on two compensation group was statistically significant ($p=0.016$, Mann-Whitney test); all else were insignificant.

Clinician-rated Outcome: Functional Status of Patients

The FIM and its two subscales are reported in Table 11. The null hypothesis of normally distributed scores was rejected for FIM (Motor/Cognitive) scores (all $p<.05$). The mean FIM motor, cognitive and total scores were 69.35, 26.53 and 95.88, respectively. Based on Mann-Whitney test statistics, sub-group analyses found that recent injury/non-TAC group had statistically significant higher cognitive scores (higher cognitive function) than the long-term/TAC group ($p<.05$). All other sub-group differences were insignificant.

Table 11: Functional Independence Measure

	All		Study Group				Compensation Group			
	N	Mean (SD)	Injured >3 years		Recent Injury		TAC		Non-TAC	
			N	Mean (SD)	N	Mean (SD)	N	Mean (SD)	N	Mean (SD)
Motor	40	69.35 (23.87)	25	67.36 (26.00)	15	72.67 (20.25)	16	69.69 (23.17)	24	69.13 (24.82)
Cognitive	40	26.53 (7.18)	25	24.64 (7.98)	15	29.67 (4.17)	16	23.44 (7.67)	24	28.58 (6.16)
Total	40	95.88 (28.06)	25	92.00 (31.12)	15	102.33 (21.47)	16	93.13 (29.55)	24	97.71 (27.50)

Note: the difference between cognitive values on two study/compensation group was statistically significant ($p<.05$, Mann-Whitney test); all else were insignificant.

Carers Quality of Life, Preparedness, and Burden

The Carer Experience Scale (CES), Preparedness for Caregiving Scale (PCS) and two caregiver burden scale (CBS) domain scores were all normally distributed based on the Shapiro-Francia normality test. The mean CES/PCS score was 66.66/2.70 for the whole sample. The mean caregiving demand and difficulty scores measured by CBS were 0.44 and 1.24, respectively. The sub-group differences were insignificant.

Table 12 Carers Quality of Life, Preparedness, and Burden

	All		Study Group				Compensation Group			
	N	Mean (SD)	Injured >3 years		Recent Injury		TAC		Non-TAC	
	N	Mean (SD)	N	Mean (SD)	N	Mean (SD)	N	Mean (SD)	N	Mean (SD)
CES	33	66.66 (14.74)	20	69.30 (15.38)	13	62.60 (13.23)	11	64.67 (17.69)	22	67.66 (13.37)
CPS	33	2.70 (0.80)	21	2.82 (0.77)	12	2.49 (0.84)	11	2.53 (0.75)	22	2.78 (0.83)
CBS - Demand	38	0.44 (0.24)	23	0.45 (0.23)	15	0.43 (0.27)	14	0.40 (0.25)	24	0.47 (0.24)
CBS - Difficulty	38	1.24 (0.88)	23	1.19 (0.90)	15	1.33 (0.88)	14	1.25 (0.92)	24	1.24 (0.88)

Note: all sub-group differences were statistically insignificant.

Cost of Care

The average hours of care provided per week is presented in Table 13. The long-term ABI and TAC sub-groups received more hours of paid physical assistance and occasional assistance, whilst recent ABI and non-TAC sub-groups received more hours of unpaid physical assistance.

Table 13 Hours of care provided per week, mean (SD)

	N	Physical Assistance (Paid)	Physical Assistance (Unpaid)	Occasional Assistance (Paid)	Occasional Assistance (Unpaid)	Total
All	40	22.95 (52.34)	29.31 (57.27)	15.26 (38.91)	25.41 (45.39)	92.93 (95.52)
Long-term ABI	25	35.91 (63.07)	18.90 (46.30)	22.37 (47.80)	35.64 (53.99)	112.82 (105.56)
Recent ABI	15	1.35 (3.67)	46.67 (70.33)	3.42 (7.80)	8.35 (15.67)	59.79 (66.57)
TAC	16	54.69 (72.88)	4.59 (9.37)	35.06 (56.39)	32.53 (49.72)	126.88 (116.83)
Non-TAC	24	1.79 (3.76)	45.79 (69.26)	2.06 (6.26)	20.66 (42.69)	70.30 (72.34)

SD - standard deviation.

Figure 3: hours per week of care as a total proportion of available hours (total sample)

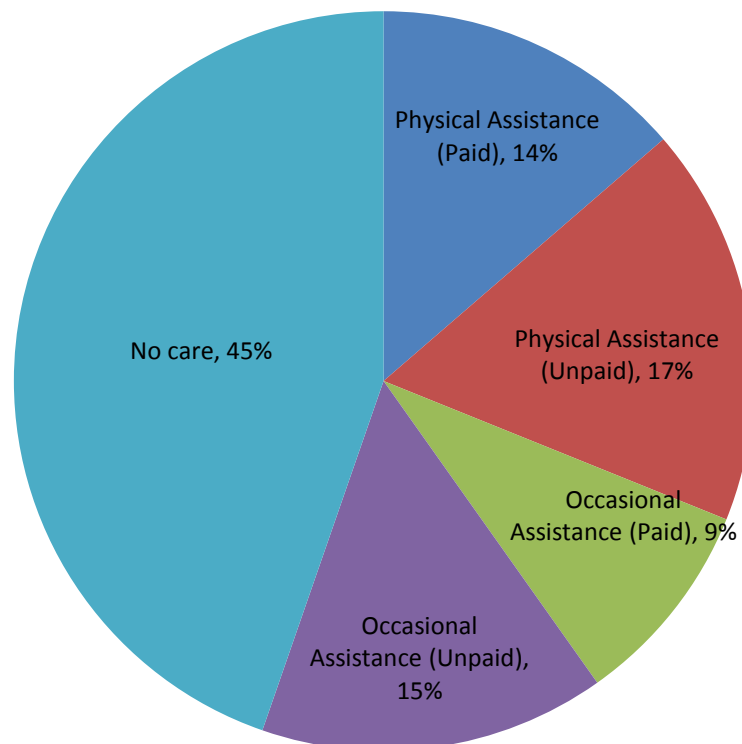
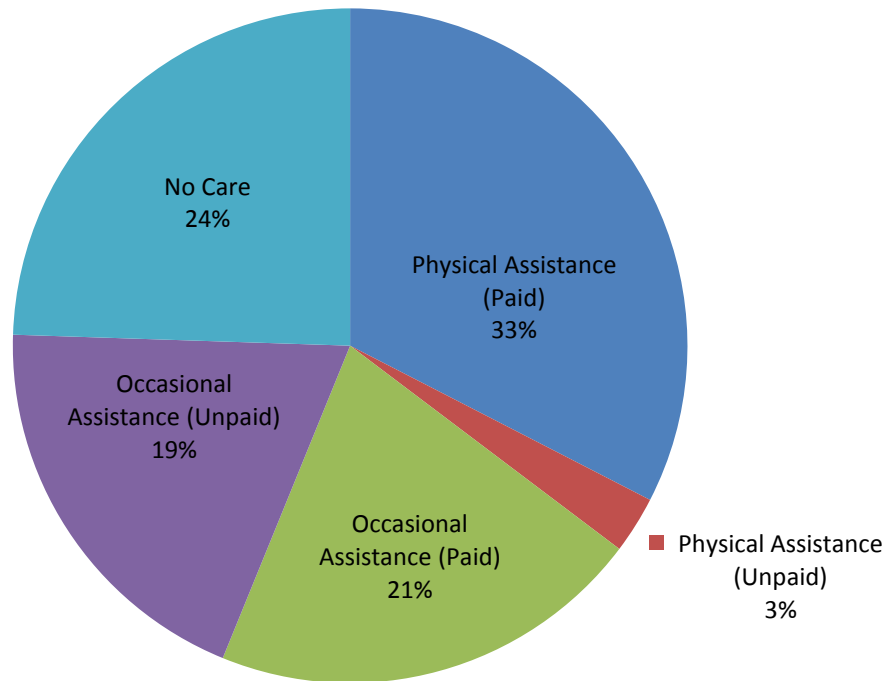


Figure 4: hours per week of care as a total proportion of available hours (TAC sub-group)



The detailed estimated annual cost is presented in Table 14. The first three columns present the cost of care calculated based on hours of care provided. The total carer cost (Column 3) suggests that the long-term ABI and TAC sub-groups had higher annual mean costs than the recent ABI and Non-TAC sub-groups. The equipment and home modification cost is reported in Column 4. Similarly, long-term ABI and TAC sub-groups had a higher mean cost than the recent ABI and the Non-TAC sub-groups. The annual total cost is reported in Column 5. On average, the total sample had a mean annual cost of \$208,399. The long-term ABI group had a higher mean annual cost than the recent ABI group (\$257,762 vs. \$126,127), whilst TAC group had a higher mean annual cost than the Non-TAC group (\$299,276 vs. \$147,814).

Table 14 Total Cost (annual)

Statistics		Carer (based on everyday tasks questionnaire)			Equipment & Home Modification	Annual total cost
		Physical Assistance	Occasional Assistance	Total		
		(1)	(2)	(3)=(1)+(2)	(4)	(5)=(3)+(4)
All (N=40)	Mean	\$99,469	\$71,252	\$170,721	\$37,678	\$208,399
	Median	\$13,323	\$15,330	\$88,549	\$3,382	\$163,025
	SD	\$138,489	\$128,126	\$174,726	\$70,714	\$218,558
	Min	\$0	\$0	\$0	\$0	\$0
	Max	\$386,353	\$527,352	\$660,577	\$372,242	\$1,032,819
	Lower 95% CI	\$0	\$3,743	\$45,672	\$1,255	\$52,512
	Upper 95% CI	\$99,919	\$41,887	\$294,336	\$21,735	\$295,081
Long-term Injury (N=25)	Mean	\$104,315	\$101,634	\$205,949	\$51,813	\$257,762
	Median	\$19,984	\$32,412	\$143,719	\$18,167	\$251,737
	SD	\$143,316	\$152,351	\$191,783	\$85,049	\$245,544
	Min	\$0	\$0	\$0	\$0	\$0
	Max	\$386,353	\$527,352	\$660,577	\$372,242	\$1,032,819
	Lower 95% CI	\$0	\$5,201	\$49,603	\$1,202	\$72,643
	Upper 95% CI	\$129,756	\$68,830	\$329,476	\$54,235	\$352,024
Recent Injury (N=15)	Mean	\$91,392	\$20,615	\$112,008	\$14,120	\$126,127
	Median	\$0	\$6,570	\$45,990	\$1,885	\$50,941
	SD	\$134,556	\$39,308	\$126,823	\$24,047	\$134,558
	Min	\$0	\$0	\$0	\$0	\$32
	Max	\$326,401	\$150,672	\$333,409	\$79,255	\$346,941
	Lower 95% CI	\$0	\$156	\$15,360	\$55	\$15,532
	Upper 95% CI	\$237,966	\$17,052	\$245,822	\$23,794	\$260,286

(Table 14 cont.)	Statistics	Carer (based on everyday tasks questionnaire)			Equipment & Home Modification	Annual total cost
		Physical Assistance	Occasional Assistance	Total		
		(1)	(2)	(3)=(1)+(2)		
TAC (N=16)	Mean	\$112,825	\$118,424	\$231,249	\$68,026	\$299,276
	Median	\$26,645	\$27,156	\$226,473	\$23,766	\$280,732
	SD	\$147,523	\$169,206	\$211,584	\$100,451	\$281,849
	Min	\$0	\$0	\$1,752	\$0	\$1,752
	Max	\$386,353	\$527,352	\$660,577	\$372,242	\$1,032,819
	Lower 95% CI	\$0	\$9,817	\$26,950	\$193	\$46,056
	Upper 95% CI	\$223,265	\$175,622	\$357,914	\$104,606	\$413,236
Non-TAC (N=24)	Mean	\$90,565	\$39,803	\$130,369	\$17,446	\$147,814
	Median	\$3,331	\$6,789	\$56,247	\$2,243	\$77,422
	SD	\$134,615	\$81,142	\$135,362	\$28,818	\$140,050
	Min	\$0	\$0	\$0	\$0	\$0
	Max	\$339,724	\$294,336	\$351,988	\$108,018	\$368,391
	Lower 95% CI	\$0	\$876	\$30,285	\$1,078	\$41,948
	Upper 95% CI	\$102,165	\$39,155	\$275,855	\$17,722	\$282,466

CI - confidence intervals for the median; Min - minimum cost; Max - maximum cost; SD - standard deviation.

Discussion / Implications

The primary focus of this study was economic, identifying the actual cost of care being provided to catastrophically injured people with ABI in Victoria, taking into account the value of paid care and informal (unpaid) care. The key economic finding of the study is the annual costs of care per incident case for ABI was a mean \$170,721 p.a. (95% CI \$45,672 to \$294,336) exclusive of equipment/home modification costs, and \$208,399 p.a. (95% CI \$52,512 to \$295,081) inclusive of equipment/home modification costs.

As expected, increasing severity of injury and decreasing functional status (as measured by FIM and by SF-6D) caused a significant increase in the mean cost of care (inclusive of paid and informal care and equipment). Perhaps unexpectedly, the TAC sub-group had a higher mean annual cost than the Non-TAC sub-group (\$299,276 vs. \$147,814). In general, this finding confirms a significant inverse relationship between formal and informal care being received by participants; such that the more paid care a severely injured participant received, the less informal care they received and vice versa.

Initial review of the data suggests that provision of equipment did not significantly influence costs. The more severely disabled participants (as defined by their lower SF-6D scores) required greater amounts of equipment, however they also continue to receive high levels of care - confirming that within the severe ABI group, attendant care represents the greatest contributor to long-term community costs incurred. Further research conducted with a sample of persons with moderate ABI rather than severe may determine whether equipment is able to decrease the number of care hours required in a less disabled group of participants.

In the current study, people with an ABI deemed severe enough to warrant continuous care at the time of discharge (i.e. at least 168 hours of care per week) were in fact only receiving an average of 92 hours of care per week at the time of assessment. Possible reasons for this discrepancy and lower care hours may include limited availability of care services (i.e. that the current care arrangements are insufficient), or it may be that some participants were not receiving continuous care because they no longer required it. So, while they required significant amounts of care at time of hospital discharge, it is possible that there is a portion of survivors of severe ABI who no longer need continuous care at the study time points (1 year and 3 years post-injury). All potential reasons warrant further investigation in a larger study. Objective assessment of care at the time of discharge would also seem to warrant further investigation. Whilst FIM scores and CANS measures were valid indicators of the level of incapacity, a broader range of factors may need to be taken into consideration when assessing the actual amount of care needed by an individual with a severe ABI.

Costs presented in the current study indicate an estimate of lifetime care costs as being significantly higher than the previous estimate published by Access Economics (June 2009). This variation is hypothesised to be because the published Access Economics' estimate is exclusive of informal care hour estimates. While the financial and time burden of care have been accurately assessed in the present study by valuing the care that is currently received (both formal and informal), what has not been assessed is whether the current level of care provided is "enough". Therefore, care estimates produced in our study can only reflect the care received, and do not necessarily reflect care needs of participants.

The reality of care in Victoria for people with severe ABI injury is that, through either need and/or by choice, care is configured to incorporate both informal and formal care provision. In valuing both we have captured a true reflection of the total value of care being provided in Victoria, while raising further questions in relation to care configurations and service delivery models. Beyond the financial information outlined above, study findings also showed that women were more likely to fulfil the role of informal carer than men, and that informal care was more likely to be provided by a mother or wife than any other role.

There were, however, limitations inherent in using self-reported data and not randomly selecting participants from the true population of Victorians living with severe ABI in the community. The lack of a registry of all ABI diagnoses in Victoria, and the incomplete coverage of the Australian Stroke Clinical Registry, prevents drawing a random sample at the current time. A second limitation in study design is the use of a pragmatic assessment of current care arrangements. Participants inherently choose their own care arrangements. Thus, this study cannot determine sufficiency of care nor whether one care pattern was more effective than another. However participants who chose one care arrangement over another (with greater or lower amounts of paid care) may have other health-behaviour attributes which influence variables that this study did not assess. For example, informal care may be used when paid care is unavailable. It is important, therefore, to consider the total costs of care both paid and informal care in future studies. Finally, it must be acknowledged that care hours were collected using subjective recall methodology.

Conclusions

Findings from the present study will be of key importance in providing a comparison data set for outcome data from the new statewide severe ABI Rehabilitation Service to be based at Alfred Health, since the study is the first in Victoria to specifically collect cost data prospectively from individuals with severe ABI to determine cost of care inclusive of informal care. Our cohort was not selected using the same set of inclusion and exclusion criteria typically used in population cohort trials from which international data has been derived, because we were observing a naturally occurring phenomena rather than assigning treatment arms. These results, therefore, are likely to have greater validity and future application than previous estimates.

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