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# Changes in Care and Support Needs Following Community-Based Intervention for Individuals With Acquired Brain Injury

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**O**bjective: To examine the care and support and participation outcomes for individuals with severe Acquired Brain Injury (ABI) provided with three consecutive years of Community Approach to Participation (CAP) intervention. *Method:* A case series study design was undertaken with a total of 43 participants from two private occupational therapy practices specialising in community-based, CAP rehabilitation for people with severe ABI. Data were collected at four time points: January 2004 (Baseline), January 2005 (T1), January 2006 (T2), and January 2007 (T3) and included rating on the Care and Needs Scale (CANS); number of hours of paid and gratuitous weekly support; FIM™ and Community Integration Questionnaire scores; and number of current life roles (as recorded on Part 1 of the Role Checklist). Participants were an average of 6.73 years post injury and were living in a range of community environments and residential facilities. *Results:* There was considerable change in participants' CANS rating across the intervention period, with statistically significant decreases occurring from Baseline to T1 and T1 to T2. Ninety-five per cent of participants received some level of weekly paid support throughout the intervention period, with the amount varying considerably. Paid care decreased by an average of 10.78 hours per week from 85.85 hours per week at Baseline to 75.06 at T3. Although not statistically significant, this equated to an average cost saving of AU\$324.84 per participant per week by the end of CAP intervention. There was an overall mean reduction of 4.96 hours of gratuitous care per week per participant over the intervention period, which was statistically significant. Increases in functional independence, community integration, and role participation were also found. On the FIM™, statistically significant improvement occurred between Baseline and T1 and on the CIQ between Baseline and T1 and T1 and T2. Significant increase on the Role Checklist occurred between Baseline and T1 and between T2 and T3. The number of life roles in which participants engaged increased by an average of 1.65 roles by the end of the intervention period. A reduction in care and support needs (measured by the CANS) was significantly associated with: (1) a reduction in total care hours, (2) and an increase in functional independence on the FIM™, and (3) an increase in community integration on the CIQ. *Conclusion:* With a long term approach and contextualised intervention targeted at skill development in the areas that underpin personally valued participation, increased role performance and community integration can be achieved by people with severe ABI, even many years post injury. This increased capacity has been found to be associated with a reduction in care and support needs, including paid and gratuitous care hours, over time.

**Keywords:** participation, community approach, rehabilitation, outcome measurement

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Long-term outcome studies indicate that many individuals with severe acquired brain injury (ABI) require ongoing care and support throughout their lifetime (Olver, Ponsford & Curran, 1996; Sloan, Winkler & Anson, 2007). This is due to an often complex array of underlying, residual impairments in multiple domains, such as physical, cognitive, communication and behavioural function. In order to receive support, some individuals live with family members, while others may require a specialised accommodation setting, such as a group home or residential aged care facility (Sloan et al., 2007; Winkler, Farnworth & Sloan, 2006; Winkler, Sloan & Callaway, 2007). Long-term mortality studies indicate that the life expectancy of people with ABI is comparable to the general population (less 3–7 years) (Baguley, Slewa-Younan, Lazarus, & Green, 2000; Brown et al., 2004; Colantonio et al., 2008; Harrison-Felix, Whiteneck, DiVivo, Hammond, & Jha, 2004; Ratcliff, Colantonio, Escobar, Chase, & Vernich, 2005). This, combined with the fact that the majority of ABI survivors are aged less than 30 years at the time of injury, highlights that the individual, their families and society as a whole will face many years of psychosocial and economic sequelae (Ponsford, 2003; Strettles, Bush, Simpson, & Gillet, 2005).

Following severe ABI, the nature and amount of support required will vary between individuals, although, as Tate (2004) has identified, people do not always receive the level or type of support they need. They may receive less support due to factors such as lack of service availability or unwillingness to accept services. Alternatively, they may receive higher levels of support than necessary, a situation that may reflect over-dependency or over-protectiveness. Tate's (2004) study, examining the outcomes of 67 people with severe brain injury 20 to 26 years post injury, found that almost three-quarters of the sample had ongoing care and support needs on a weekly (46%) or daily (25%) basis, and 4.5% required 24-hour support (Tate, 2004). Another study of 13 individuals with extremely severe TBI 8 years post injury reported that 6 of the 13 participants required 24-hour care (Sloan et al., 2007). The authors reported that at 8 years post injury, participants received an average of 61 hours of paid care per week and 41 hours of gratuitous care per week. When compared with total support hours for the same group at 2 years post injury, the number of care hours had remained stable. However, there was a shift in the proportion of paid and gratuitous care over time. So, although weekly hours of paid care decreased over the 6-year period, gratuitous care increased by an equiv-

alent number of hours. The high levels of gratuitous care identified in the study reflected the burden of care that often falls to family members.

A study of the perceptions of individuals with ABI regarding their care arrangements identified the need for more support in some areas and less in others (Ownsworth, Turpin, Carlson & Brennan, 2004). Overall, however, relative to the perceptions of family members and case managers, individuals with ABI tended to underestimate their support needs for a range of functional activities. The authors reported cases of individuals who were completely dissatisfied with the care arrangements, and also noted that natural support was preferred over paid care (Ownsworth et al., 2004). McColl et al. (1998) also identified that too much support can be a barrier to community integration, independence and autonomy. Structuring support to ensure it was acceptable to the individual and minimally intrusive was seen as important to the individual and their significant others (McColl et al., 1998). Haggstrom and Lund (2008) emphasise that adequate levels of support and flexible care arrangements assist individuals to make personal choices regarding activities and also to achieve a feeling of participation. McCluskey, Johnson and Tate's (2007) study of care management processes identified that in no instances was the person with the brain injury the decision-maker with regards to their care arrangements. Although this was likely to be due to the severity of cognitive deficits and impaired decision-making capacity in particular, the authors emphasised the importance of involving the person in decisions that affect their lives. The authors reported that reducing care hours involved acceptance, tolerance and management of associated risks, but the outcomes of this process could provide benefits for the individual, particularly their sense of autonomy and independence.

A number of research studies have found a relationship between family or caregiver burden and a range of negative psychosocial outcomes for caregivers, including increased anxiety and depression (Douglas & Spellacy, 2000; Hibbard et al., 2002; Marsh, Kersel, Havill, & Sleigh, 1998; Ponsford, Olver, Ponsford, & Nelms, 2003; Rivera, Elliott, Berry, & Grant, 2008), social isolation (Douglas & Spellacy, 2000), decreased coping ability (Chronister & Chan, 2006; Hibbard et al., 2002; Turner et al., 2007), increased family dysfunction or distress (Winstanley, Simpson, Tate, & Myles, 2006), decreased participation in work and leisure activities (Dixon, Walker, & Salek, 2006), increased financial burden (Turner et al., 2007), and decreased satisfaction and qual-

ity of life (Chronister & Chan, 2006). Ponsford and colleagues (2003) found that those family members responsible for providing care to their relatives displayed the highest levels of depression and anxiety. Marsh and colleagues (1998) found that the social isolation and negative emotional behaviours experienced by individuals with TBI were the greatest stressors for caregivers.

Importantly, Winstanley and colleagues (2006) found that family functioning and distress in relatives could not be predicted directly from the severity of residual neurobehavioural impairment. Rather, psychological distress was mediated by the degree of community participation achieved by their relative with brain injury, where participation comprised both occupational activities and independent living skills. The authors reported higher levels of distress in families when their relative with a brain injury was socially isolated, had few activities outside the family home, and had minimal leisure interests. The authors pointed to the need for increased community resources and a stronger rehabilitative emphasis on participation in order to promote family functioning.

There is some evidence that targeted intervention can impact on social role participation, support needs and costs of care. Worthington, Matthews, Melia, and Oddy (2006) reported that following a residential neurobehavioural rehabilitation program, their sample of 133 adults with severe brain injury showed a significant improvement in functional ability and role participation as well as a reduction in support needs. There was a corresponding saving in cost of care, even when treatment costs were considered.

The Community Approach to Participation (CAP) was developed by Sloan, Winkler, and Callaway (2004). The CAP is a community based, rehabilitation approach that aims to maximise an individual's level of participation in valued life roles through inclusion in home and community life by maintaining or developing social relationships, facilitating engagement in meaningful occupation, and focusing on skill development within activities that underpin role performance. An earlier study of CAP intervention revealed increases in functional independence, community integration, and role participation following 1 year of intervention (Sloan et al., 2009). Thus far, however, there is little research investigating the relationship between participation and lifetime care and support needs.

This study, a case series, aims to examine care and support outcomes for a group of 43 individuals with severe ABI who were living in community settings and received CAP Occupational

Therapy (OT) intervention over a 3-year timeframe. It also aims to examine whether the gains previously reported following 1 year of intervention (Sloan et al., 2009) are maintained or extended over a longer period of intervention. It was hypothesised that, despite considerable variability, there would be an overall decrease in paid care, with the likelihood of an increase in gratuitous care. It was also hypothesised that there would be a significant increase in functional independence, community integration and role participation, irrespective of time since injury. It was further hypothesised that there would be a relationship between change in care and support and outcomes in role participation, community integration, and functional independence.

## Method

### *Participants*

Participants were recruited from the caseloads of two Victorian private practices specialising in community rehabilitation for people with severe ABI. Individuals were generally referred for intervention to increase community integration and independent living skills, develop a community support program, or because they required a review of their accommodation and support. Inclusion criteria for the study were that the person had a diagnosis of ABI and was over 18 years of age. Forty-five potential participants were identified, who were consecutive admissions and received 3 years of OT intervention between January 2004 and January 2007. Two individuals with degenerative neurological conditions were excluded. Participants were not excluded based on challenging behaviour, or comorbidities, including substance abuse or dual diagnoses. These complexities are often present in this population and reflect a true representation of clients seen in the two practices. A sample of 43 individuals was identified, all of whom consented to intervention. Family members provided consent for those individuals unable to do so by reason of profound cognitive impairment.

The 43 participants were a subgroup of a larger sample of 85 who received 1 year of CAP OT intervention. The results of this larger group have previously been reported (Sloan et al., 2009). The 43 participants received extended intervention over a 3-year timeframe. Some participants had also received community rehabilitation input prior to January 2004, which is not reported on in this study.

Demographic data for the group is presented in Table 1. Twenty-five (58%) participants were

male and 18 (42%) were female. Sixty-seven per cent of the sample had sustained a traumatic brain injury, 21% a hypoxic brain injury, and the remainder had experienced a cerebrovascular accident or infection. There was a mix of non-compensable and compensable clients. These funding sources have previously been described by the authors (Sloan et al., 2009).

Living situation prior to the commencement of intervention (Baseline) included living with parents and/or siblings (34.9%), with partner and/or children (18.6%), in a group home or supported accommodation setting with 24-hour staffing (18.7%), in residential aged care (9.3%), alone with carer support (7%), in a locked neuropsychiatric unit (7%), with friends (2.3%), and living with others but in a separate area such as a bungalow (2.3%). None of the participants was living independently of caregiver support at Baseline.

Over 95% of participants were receiving at least one other type of therapy at some point during the intervention period. Many participants received three or more therapies. However, there was considerable fluctuation in the frequency and length of other therapy input and its examination is beyond the scope of this study. At some time during the 3-year intervention period, 69.8% of the sample received physiotherapy, 48.8% received case management, 46.5% received psychology, 51.2% received speech therapy, 11.6% received recreation input, and 11.6% received other therapies such as dietetics and vocational rehabilitation.

## Measures

### Care and Needs Scale (CANS)

The CANS is a clinician rating scale, designed to measure support needs for everyday activities and community living. It was developed for people with traumatic brain injury, and aims to capture the full range of potential support needs, from very high to minimal requirements (Tate, 2004). It measures the type and extent of support required

(as opposed to the amount of care the individual is receiving) and the duration of time an individual can be left alone. Individuals are placed in one of five groups depending on type of support, and then a Support Level is assigned depending on the length of time an individual can be left alone. Support Levels are hierarchically arranged as follows: 0 (*equivalent of does not need contact*), 1 (*needs intermittent contact, less than weekly*), 2 (*needs weekly contact*), 3 (*needs contact every few days*), 4 (*needs daily contact*), 5 (*can be left alone during the day, but not at night*), 6 (*can be left alone for a few hours*), 7 (*cannot be left alone*). Although the CANS has remained an eight-category scale since its development, scoring of the levels has changed from one to eight in 2004 to zero to seven in 2007 (Soo et al., 2007), with the items remaining the same. In this study the CANS Research Edition (Tate, 2004) was used, with levels ranging from 1 to 8; however, the participants' scores were converted to comply with the 2007 (Soo et al.) revised edition.

**Hours of care (paid and gratuitous).** The total amount of care and support provided to each participant was recorded in hours per week, as suggested by Tate (2004). Total hours comprised both paid and gratuitous support and these hours were noted separately. The number of paid care hours was identified from the approval letters of funding bodies or initial occupational therapy reports and cross-referenced with participants' timetables. The number of gratuitous hours of support per week provided by family members or significant others were calculated via interview, occupational therapy progress notes, and clinical knowledge of the client.

**Functional independence, community integration, and role participation.** The FIM™ (UDS Data Management Service, 1990), Community Integration Questionnaire (CIQ; Willer, Rosenthal, Kreutzer, Gordon, & Rempel, 1993), and Role Checklist (RC; Oakley, Kielhofner, Barris, & Reichler, 1986) were used to measure functional independence, community integration, and role participation respectively. FIM™ scores

TABLE 1

Demographic Data for Age at Injury, Injury Severity, and Time Post Injury at Baseline

	N	M (SD)	Range
Age at injury (years)	43	28.42 (12.74)	3–58
Length of PTA (days) <sup>a</sup>	25	117.48 (60.81)	25–180
Time post injury	43	6.73 (5.14) years	2 months–20.63 years

Note: <sup>a</sup>PTA not applicable for 14 participants. Missing PTA data for 4 participants with TBI.

range from 18 to 126, CIQ scores range from zero to 29, and there are 11 possible roles on the RC (student, worker, volunteer, caregiver, home maintainer, friend, family member, religious participant, hobbyist and participant in organisations and 'other'). On each measure, higher scores indicated greater levels of ability and participation. These measures have been discussed in more detail previously (Hall, Bushnik, Lakusic-Kazazic, Wright, & Cantagallo, 2001; Hall et al., 1996; Kielhofner, Mallinson, & de las Heras, 1995; Willer, Ottenbacher & Coad, 1994).

**CAP OT hours.** The number of CAP OT hours each participant received in each of the 3 years was gathered from the practices' computerised accounting systems.

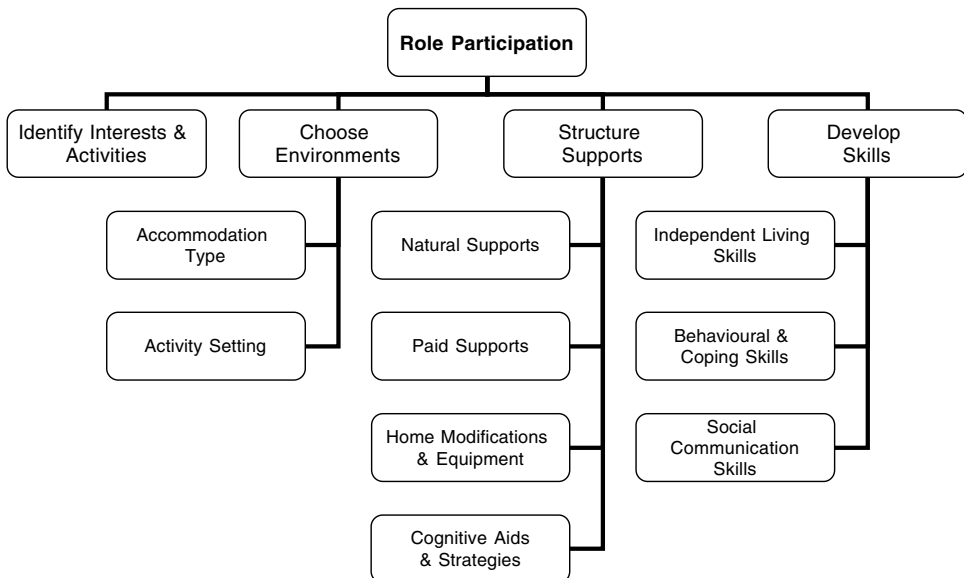
### Procedure

Potential participants were identified in January 2005. Data for participants who had received CAP OT intervention between January 2004 and January 2005 was collected retrospectively from client files and the treating clinician's knowledge of the individual and their program of activities and support. All other data were collected prospectively via assessment by the treating therapist. Data were collected at four time points: January 2004 (Baseline), January 2005 (T1), January 2006 (T2), and January 2007 (T3).

### Intervention

The CAP is a model of community-based rehabilitation that has been described previously (Sloan et al., 2009; Sloan et al., 2004). CAP intervention was provided by seven occupational therapists across the two practices. All therapists were trained in the CAP and received regular clinical supervision from the principal therapists who developed the approach. As depicted in Figure 1, there are four key areas of focus for CAP intervention, with the overarching aim to promote meaningful and valued role participation for the individual. An outline of the application of the CAP, as it relates to developing support structures to promote role participation, is provided below.

The CAP framework proposes a flexible and individualised approach when considering a person's care and support needs. Support was tailored to the individual's needs and preferences, as well as the possibilities within each accommodation type and activity setting. For some individuals or in some environments, naturally occurring supports were sufficient, particularly if they were enhanced by education about brain injury and the individual's support needs and skills. For others, paid support was required, provided either by attendant care workers trained in acquired brain injury, or experts skilled in a particular activity area (e.g., computers, woodwork), who received



**FIGURE 1**  
Areas of focus of the community approach to participation.

additional training to assist them to understand how to support the individual with the brain injury. The development of a therapeutic relationship with the individual and their primary support network, in combination with the continuity of CAP OT input, allowed support models to be adapted over time. Where possible, as skills and confidence increased, paid supports were replaced by natural supports. Achieving an effective and, for the individual, acceptable model of support was seen as crucial for the development of new life roles, with an important byproduct being increased social contact. The use of flexible, embedded support models within living situations and community settings to facilitate role participation allowed individuals to develop a heightened sense of belonging, in more naturally occurring ways.

### *Data Analysis*

The score distributions of each variable at each time point were examined with a series of Kolmogorov-Smirnov tests, and because a large number of variables were not normally distributed, nonparametric statistics were conducted. A series of repeated measures Friedman analyses of variance (ANOVA) were conducted to investigate changes in outcome measures over the 3-year period of intervention. Statistically significant results were further explored with Wilcoxon Signed Ranks Tests to examine the time periods that accounted for the improvements. Spearman correlations were also calculated to investigate relationships between changes in care and support and other outcome variables. Cost of care and support was derived using the published hourly attendant care rate of AU\$30.12 per hour set by the Transport Accident Commission of Victoria, Australia, in July 2008 (Transport Accident Commission, 2008b). The Transport Accident Commission hourly rate of AU\$75.70 was also used to cost OT services (excluding travel costs) (2008a).

## **Results**

### *CANS*

A summary of the CANS levels and total care hours over the four time points is presented in Table 2. Friedman's ANOVA indicated there was significant change across the intervention period for the CANS total score. Contrasts were undertaken to investigate where the differences occurred. Significant decreases occurred between Baseline and T1 ( $z = -2.80, p = .005$ ) and between T1 and T2 ( $z = -2.33, p = .02$ ). There was no significant change in the CANS from T2 to T3.

### *Total Care Hours*

Friedman's ANOVA indicated there was significant change across the intervention period for total care hours. As depicted in Table 2, total care hours decreased by an average of 15.64 hours per week per person over the 3 years of intervention. Wilcoxon tests were conducted to explore where the decrease occurred. There was a significant decrease in total care hours per week between T1 and T2, ( $z = -2.73, p = .006$ ). There was no significant change between baseline to T1, or between T2 to T3. Significant decreases also occurred over the extended period of consecutive years of intervention, with statistically significant decreases revealed between baseline and T2 ( $z = -2.95, p = .003$ ) and between Baseline and T3 ( $z = -2.97, p = .003$ ).

Total care hours comprised hours of paid care and hours of gratuitous care, which were examined separately.

### *Paid Care*

Ninety-five per cent of participants received some level of weekly paid support throughout the intervention period. As shown in Table 3, the level of paid support varied considerably among participants, ranging from no support to 210 hours of care per week. This maximum refers to participants with 24-hour support who were receiving the assistance of two caregivers at particular times, for example, for hoist transfers or community access. Friedman's ANOVA showed the reduction in paid care hours per week was not statistically significant. However, paid care hours did decrease by an average of 10.78 hours per week from 85.85 ( $SD = 75.00$ ) at Baseline to 75.06 ( $SD = 72.60$ ) at T3. This amounted to an average cost saving of AU\$324.84 per participant per week by the end of the 3-year intervention period.

### *Gratuitous Care*

As shown in Table 3 there was a statistically significant overall mean reduction of 4.96 hours of gratuitous care per week per participant over the intervention period. There was a mean increase in gratuitous care from Baseline to T1 (3.61 hrs), followed by a significant decrease between T1 and T2 (5.82 hrs;  $z = -2.41, p = .02$ ). A further decrease of 2.75 hours occurred from T2 to T3; however, this was not statistically significant.

### *Variability in Care Hours*

While there was an overall decline in total care hours over the three year period for the 43 participants, there were three distinct groups identified:

**TABLE 2**Summary of CANS and Total Care Hours Outcomes ( $n = 43$ )

Outcome measure	Time point	M	SD	Median	Min	Max	IQR	Repeated measures ANOVA
CANS score (0–7)	Baseline	5.56	1.80	7	1	7	3	$\chi^2(3) = 19.58, p < .001$
	T1	5.19	1.82	6	1	7	3	
	T2	5.02	1.90	5	1	7	4	
	T3	5.07	1.93	4	1	7	3	
Total care hours (per week)	Baseline	118.95	70.80	168	0	230.50	135	$\chi^2(3) = 12.38, p = .006$
	T1	115.81	72.38	168	6	230.50	143	
	T2	107.76	73.61	168	0	210	145.75	
	T3	103.31	75.95	168	0	210	150	

Note: IQR = Interquartile Range

CANS = Care and Needs Scale

those individuals whose care hours reduced, those whose hours increased and those whose hours remained constant. Total care hours reduced for 41.86% ( $n = 18$ ) of the sample by an average of 40.14 ( $SD = 46.62$ ) hours per week. Total care hours for 16.28% ( $n = 7$ ) of the sample increased by an average of 7.14 ( $SD = 3.89$ ) hours per week, whilst the hours of care remained constant for 41.86% ( $n = 18$ ) of participants. Figure 2 depicts the change in care hours for these three groups over the 3-year period of intervention. For the 18 participants whose care hours reduced, this was achieved with a reduction of 19.29 paid hours and 20.85 gratuitous hours per week. Figure 2 shows that the 18 participants who had no change in care hours over the 3-year period had the greatest care needs with all but one of the participants in this group requiring 24-hour care. For this group, how-

ever, there was a redistribution of support with a reduction of 9.14 hours of paid care and an equivalent increase in hours of gratuitous support.

#### *Functional Independence, Community Integration, and Role Participation*

Statistically significant increases in functional independence, community integration, and role participation were observed across the 3-year intervention period, as shown in Table 4.

Wilcoxon Tests were conducted to investigate the time periods that accounted for the improvements. On the FIM™ the greatest improvement occurred between Baseline and T1, ( $z = -3.73, p < .001$ ) Significant increases on the CIQ occurred between Baseline and T1 ( $z = .440, p < .001$ ) and between T1 and T2 ( $z = -2.85, p = .004$ ). Highly significant increases on the RC occurred

**TABLE 3**Paid and Gratuitous Hours and Costs of Care Over the 3-Year Period of Intervention ( $n = 43$ )

Type of care	Time point	M	SD	Median	IQR	Min	Max	Friedman ANOVA	Mean cost per week per participant
Paid care hours	Baseline	85.85	75.00	58.00	156.00	0.00	202.00	$\chi^2(3) = 3.78, p = .27$	\$2585.77
	T1	78.99	73.02	44.00	160.00	0.00	202.00		\$2379.30
	T2	76.77	73.18	44.00	160.00	0.00	210.00		\$2312.41
	T3	75.06	72.60	44.00	160.00	0.00	210.00		\$2260.93
Gratuitous care hours	Baseline	33.10	45.74	8.00	54.50	0.00	130.00	$\chi^2(3) = 11.21, p = .01$	
	T1	36.81	49.36	14.00	87.00	0.00	156.00		
	T2	30.99	43.98	10.00	45.00	0.00	126.00		
	T3	28.24	44.30	7.00	28.00	0.00	134.00		

Note: IQR = Interquartile Range

between Baseline and T1 ( $z = -3.77, p < .001$ ) and between T2 and T3 ( $z = -2.36, p < .02$ ). The number of life roles in which participants engaged, increased by an average of 1.65 roles by the end of the intervention period.

**Care and Support Needs Correlations**

Spearman correlations were performed to investigate relationships with changes in care and support from Baseline to T3. A reduction in care and support needs as measured by the CANS was significantly associated with a reduction in total care hours ( $r_s = .45, p < .003$ ) and an increase in functional independence on the FIM™ ( $r_s = -.33, p = .03$ ) and community integration on the CIQ ( $r_s = -.49, p = .001$ ). There was no association between change on the CANS and severity of injury ( $r_s = .05, p = .83$ ). No significant relationships between change in paid care and change in gratuitous care were found ( $r_s = -.25, p = .10$ ). There was no association between the change in total care and role participation.

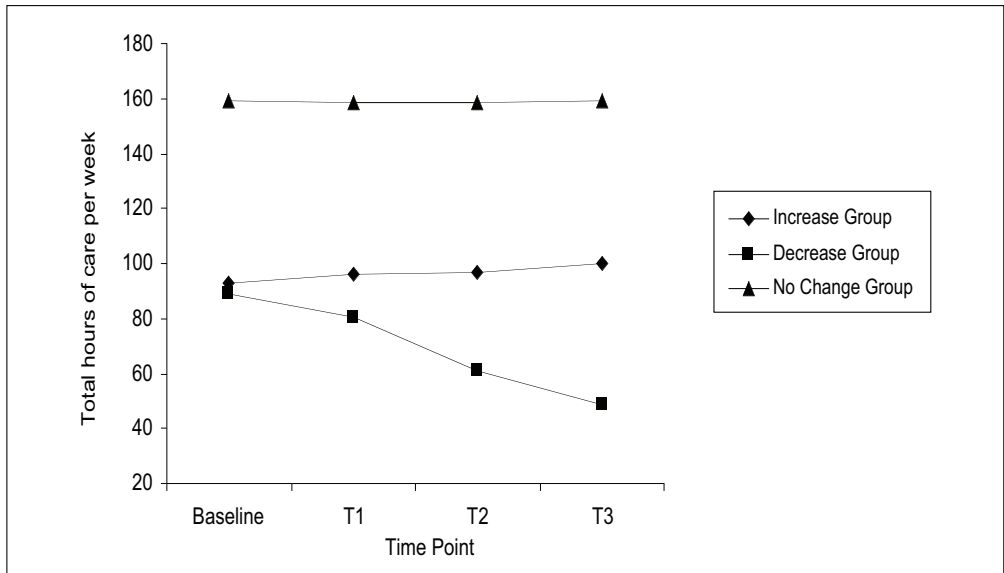
**CAP OT Intervention**

As shown in Table 5, there was a statistically significant reduction in CAP OT hours over the intervention period. The hours of CAP OT intervention were relatively stable between Baseline and T2,

and the significant reduction occurred between T2 and T3, ( $z = -3.62, p = .001$ ). The average number of hours of OT input provided between Baseline and T1 was 62.12 ( $SD = 58.06$ ), 63.09 ( $SD = 59.27$ ) between T1 and T2, and 35.46 ( $SD = 35.70$ ) between T2 and T3. The hours of OT equated to an average cost of AU\$4,054.17 per participant per annum.

**Discussion**

The results of this study show that the care and support needs of participants who had sustained a severe ABI, significantly reduced over three years of CAP OT intervention. Total care hours comprised paid and gratuitous support and, despite considerable variability, both were found to decline overall. There was no evidence for the hypothesis that gratuitous care would increase as paid care decreased. The results also highlight that the level of gratuitous care provided by family members to the person with brain injury remains high. This reflects both the profound level of disability in this group as well as the intensive nature of family input often necessary to sustain community living following severe ABI. The findings also support the hypothesis predicting a significant increase in functional independence, commu-



**FIGURE 2**  
Variability in care hours for total care, paid care, and gratuitous care.

**TABLE 4**Summary of Outcomes on the FIM™, CIQ, and RC (*n* = 43)

Outcome measure	Time point	M	SD	Median	Min	Max	IQR	Friedman's ANOVA
FIM™ score (18–126)	Baseline	84.28	33.56	95	18	124	59	$\chi^2(3) = 16.92, p = .001$
	T1	87.49	33.07	101	18	125	41	
	T2	87.91	32.76	100	18	124	40	
	T3	88.70	32.14	96	18	126	29	
CIQ score (0–29)	Baseline	7.60	4.35	8.00	0	17.25	5	$\chi^2(3) = 48.49, p < .001$
	T1	10.42	4.77	11.25	0	19.25	6	
	T2	11.69	4.99	11.75	1	20.75	7	
	T3	11.88	5.86	12	1	23	9	
RC score (0–11)	Baseline	2.98	1.73	3	0	7	2	$\chi^2(3) = 40.15, p < .001$
	T1	3.88	1.92	4	0	7	4	
	T2	4.12	1.87	5	0	7	2	
	T3	4.63	1.48	5	1	7	2	

Note: IQR = Interquartile Range  
 FIM™ = Functional Independence Measure  
 CIQ = Community Integration Measure  
 RC = Role Checklist

nity integration and role participation, irrespective of time since, or severity of, injury.

The study design limits the ability to draw a causal relationship between CAP intervention, reduction in hours of care and increase in functional independence, community integration and role participation. However, previous research findings, showing total hours of care to be relatively stable many years post injury (Sloan et al., 2007), suggest intervention did influence a reduction in support needs. Although the participants were quite heterogeneous, the CAP principles allowed therapists to work individually with each participant to tailor an appropriate support structure. It is extremely difficult to conduct more rigorous, group-based research in this area due to the heterogeneity of the participants as well as the variation in each individual's life situation and goals. While a diverse group is more reflective of

clinical practice, it limits the generalisability of findings.

Although changes in care hours were often seen in the first year of intervention, the results caution against limiting examination of outcomes to such short timeframes, as many participants continued to show a substantial decline in total care hours over an extended time frame. For the 18 participants who showed a reduction in total care, the greatest decrease occurred between T1 and T2. The decrease between T2 and T3 was also greater than that between baseline and T1. These findings are particularly relevant for lifetime care planning and costing. They are also relevant for funding bodies who may evaluate outcomes at 3-, 6- or 12-monthly intervals and, on the basis of short-term change, determine if funding for therapy input will continue. The eventual decrease in paid care hours resulted in a marked reduction in

**TABLE 5**

Occupational Therapy Hours and Costs over the 3-Year Period of Intervention

Time point	M	SD	Median	Min	Max	IQR	Friedman's ANOVA	Mean cost per participant per annum
Year 1	62.12	58.06	54.50	1	225	90	$\chi^2(2) = 7.45, p = .02$	\$4702.20
Year 2	63.09	59.27	44.75	3.50	233.50	87.50		\$4776.05
Year 3	35.45	35.70	22	1	138.50	46.75		\$2684.27

Note: IQR = Interquartile Range

the ongoing financial cost of care provision, with an overall saving in paid care of AU\$324.69 per participant per week, or a potential ongoing annual saving of AU\$16,929.34 per participant. Over the 3-year period of intervention the average amount spent on CAP OT was AU\$4,054.17 per participant per annum. These figures should be treated with caution due to the wide variation in the changes experienced by participants. Further, a causal relationship was not established between the reduction in care and the intervention. Also, the costs of other therapy input were not analysed. Despite this, it appears that there may be a potential cost benefit of providing CAP intervention, even many years post injury.

Changes in gratuitous care are more difficult to attribute a cost to, particularly as these changes relate, either positively or negatively, to caregiver stress and the impact on the time available for carer's own valued role participation. An area of further investigation relevant to the current study is suggested by Ponsford and colleagues (2003), who postulated that it is likely that as the individual's skills develop, the burden of care reduces and this may flow on to moderate levels of emotional distress in the caregiver. This relationship was not specifically examined in this study, and more detailed analysis of the nature of the care and the impact of gains in independence and participation in relation to caregiver burden would be beneficial.

The hypothesised relationships between outcomes in care and support needs and role participation, community integration, and functional independence were, in general, not found. That is, changes in participation levels were independent of changes in support hours and, importantly, achieved without an increase in these hours. There was however a statistically significant relationship between improvement on the CIQ and decrease in CANS level. This is consistent with an association between reduced need for support and increased engagement in activities that underpin role performance, independent of injury severity. Given that the CANS measures *required* hours of support, not *received* hours of support, it is possible that gains reflected in change on the CANS take some time to be actualised. So, a longer timeframe may be required to translate gains in independence and role participation into reductions in hours of weekly support. A limitation in examining this relationship was selection of a gross measure of support (i.e., number of hours). Such a measure failed to capture the nuances of a support structure that can also vary in the *nature* of the support (e.g., manual handling support in transfers or prompting

to provide cues for memory); the *intensity* of support (e.g., 1:1 hands on assistance or distant supervision); the *focus* of support (e.g., domestic or recreational activity); the *provider* of the support (e.g., parent, paid worker or taxi driver) as well as the *frequency* of support (e.g., daily or weekly). To achieve an increase in participation and to promote skill development, the therapist may act to change any of these support variables, but only change in the *hours* of support was captured in the current data. Clinical experience suggests that the relationship between support and participation may be bi-directional. That is, a change in care hours may expand an individual's opportunities for engaging in daily activities and valued roles and, conversely, engagement in activities and roles provides a platform for developing skills and routines that impact on the nature and level of ongoing support required by the individual.

It is noted that there was significant variability amongst participants, with 41.86% of participants' total care hours reducing and 16.28% of participants' support hours increasing. Such variability makes it difficult to generalise findings, even within this study group. This variability does however highlight the need for flexible models of support over the individual's lifespan, tailored to their participation goals and in line with key CAP principles. The relationship between care and functional independence, community integration, and role participation requires greater exploration and will be further analysed and reported separately in relation to living situation in a sub-group of participants, who changed accommodation during the 3-year intervention period.

In summary, this study reinforces the authors' clinical observations that individuals with severe ABI can achieve a significant reduction in support hours as well as improvements in levels of participation, even many years post injury. Significant variability within the study group however points to the need for individualised support models and targeted programs of community-based intervention provided over an extended timeframe.

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