

Evaluation of quality of life outcomes for TAC and WorkSafe claimants with severe traumatic brain injury living in shared supported accommodation

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Executive Summary

Key messages

- This pilot study offers an insight into the physical and mental health, choice, social networks, community integration and participation outcomes of a group of 40 people with severe traumatic brain injury living in shared supported accommodation funded by the Transport Accident Commission or WorkSafe Victoria (WSV).
- The outcomes of the group were varied, and some people with TBI had forged a range of valued home and community based life roles and social connections, whilst others were social isolated, experiencing limited opportunities for choice making in their daily lives, and restricted participation in activities that offered community access or social interaction.
- Regardless of participation outcome, the support needs of this pilot group were complex, with a range of physical and mental health issues and behaviours of concern identified and most often necessitating high levels of daily support.
- For the TAC and WSV, this pilot study points to a range of areas within supported housing, as well as the design and implementation of models of paid support, that requires further examination and may be influenced to impact client experience and outcomes and scheme viability. These include the management of physical and mental health conditions, as well as behaviours of concern, in community settings; strategies to build environments of choice and opportunities for social and community integration; and broadening of the supported living options available to people with TBI over time, as well as opportunities to review people's satisfaction with the model of supported housing within which they live.
- Further research is required to increase participant numbers and understand the outcomes of this group over time, compare these outcomes with those of TAC and WSV clients living in other models of housing and support (e.g., in their own homes; in new models of housing developed through TAC's housing trust, Residential Independence Pty Ltd), and to test and evaluate targeted interventions that may impact the impairments and activity limitations, and participant restrictions, experienced by this group. These next stages of research are being implemented by this project group in collaboration with ISCRR, TAC and WorkSafe Victoria.

Purpose

This project had four key aims:

1. Evaluate health, activity, participation and quality of life outcomes of Transport Accident Commission (TAC) and WorkSafe Victoria (WSV) clients with traumatic brain injury (TBI) living in shared supported accommodation (SSA)
2. Compare findings with an existing data set of DHS clients with acquired brain injury (ABI) living in Residential Aged Care (RAC)
3. Identify factors that may contribute to health, participation and quality of life outcomes of participants
4. Provide recommendations for service planning and implementation to improve outcomes of TAC and WSV clients.

Rationale

To date there have been few studies that have examined the experience and outcomes of people with TBI who live in SSA. Each year in Victoria, 12-15 people sustain a catastrophic

brain injury in a transport accident, whilst approximately 8-10 sustain workplace-related catastrophic injury. Both of these groups require long term paid support to live in the community. Currently in Victoria, there more than 170 people in receipt of compensation from TAC or WorkSafe who lived in SSA funded by the Schemes. The TAC has been proactive in working with service providers to develop models of accommodation and support for people with TBI. Most of these services are owned and run by corporations or private companies. People accessing these services generally receive additional funding for rehabilitation and individualised disability supports to access the community. However, little is known about the health, activity or quality of life outcomes of this population, how the funded supports provided impact upon these outcomes, or the perspective of the person with TBI regarding their circumstance. This information is important to work to identify key factors that impact the quality of care, life and outcomes of this group. Such research will also inform new models of housing and support the TAC are developing through their housing trust, Residential Independence Pty Ltd. This pilot research project offers an indepth understanding of the health, participation and quality of life outcomes of a group of TAC and WSV clients with severe TBI living in SSA which has previously been lacking.

Methods

A total of six accommodation providers who deliver SSA to TAC and WSV clients were approached regarding this study. Participants were recruited from a total 14 SSA settings delivered by four providers.

Forty participants with TBI, in receipt of TAC or WSV funding and living in SSA funded by the Schemes, were recruited for participation in this research. The authors' existing evaluation framework used in previous research with people with brain injury was utilised. In a face to face interview participants completed a range of standardised measures including the Community Integration Questionnaire, the Lubben Social Network Scale, the Resident Choice Scale, the Personal Wellbeing Index, the Impact on Participation and Autonomy Scale and part one of the Role Checklist.

A paid support worker and/or family member nominated by the person with TBI also completed a dedicated survey package that included the standardised measures: Health of a National Outcome Scale-ABI, designed to indicate the status of mental health, the Care and Needs Scale (a measure of the level and type of support need) and the Overt Behaviour Scale (a measure of behaviours of concern following TBI). Less than half of the participants (45%) nominated a next of kin for this study, being more likely to nominate a paid support worker as the other key informant (100%).

All data collected was entered into SPSS statistical program for storage and subsequent analysis. Descriptive statistics were utilised which was most appropriate given the project sample size.

Research findings & implications

Research findings

Seventy five per cent of the participant group were male, and average age was 43.8 years ($R = 24-69$ years). The group were on average 16 years post injury ($R = 1-32$ years). The majority of the group were single (72.5%), almost a quarter of the group were divorced (22.5%), one person was separated and one person was married. Thirty-eight participants were in receipt of TAC funding, one participant was in receipt of WSV funding and one participant was in receipt of both TAC and WSV funding. On average, participants had been living in the current SSA for 7.5 years ($R = <1$ year-24 years). Most (87.5%) were living as

one of a number of residents in a traditional community group home or hostel model, 7.5% were living in their own unit in a cluster of units for people with disability, and 5% were live in a shared unit with one other person with TBI, at the rear of a traditional group home. Almost half (47.5%) of the group were fully aware of their circumstances and surroundings, 42.5% were partially aware and 1 person was minimally aware, with 3 people unable to be fully assessed.

Having collected the above data for each of the research participants, analysis of a range of factors contributing to the health, activity, participation and quality of life outcomes was undertaken using descriptive statistics, and is summarised below. Findings, however, must be interpreted with caution, given this is an observational study with limitations that include small sample size, reliance on the person with brain injury and a paid support workers as the primary informants, and the heterogeneity of the participant characteristics.

Physical health – This group had complex physical health care needs:

- 62.5% experiencing continence issues
- 45% experiencing difficulty communicating basic daily needs
- 42.5% requiring assistance with transfers and mobility,
- 32.5% having epilepsy
- 22.5% requiring assistance with bed mobility and
- 10% requiring PEG feeding.

These secondary health conditions require proactive management in community settings and pose risk of complications that may lead to further health issues.

Thirty-five percent of the group had a non-elective admission to hospital in the preceding 12 months, most often due to chest infections, seizures, and PEG-related issues. Five people experienced multiple (between 2 – 6) non-elective admissions within the preceding 12 months. Accidental injury did occur for some: 20% of the group experiencing such injuries in the preceding 12 months. Ambulance usage was apparent, with 32.5% of the group receiving assistance from Ambulance Services in the preceding 12 months. GP check ups were scheduled regularly for most participants (92.5%), however dental check ups were less frequently occurring (28% of the group had not visited a dentist in the preceding 12 months). Routine dental care is an important part of proactive health care management and poor dental hygiene can impact health, including increasing the risk of chest infection if people have a reduced ability to protect their airway due to dysphagia.

Mental health and behaviours of concern – When examining mental health status, the HoNOS-ABI indicated that 54.4% of the group were experiencing problems with depressive symptoms, 77.5% with active disturbance of social behaviour, 23% with problem drinking or drug use and 5% with self directed injury. The Overt Behaviour Scale demonstrated the high levels of behaviours of concern of this group, with 60% displaying verbal aggression; 25% displaying physical aggression against objects in the environment; 40% displaying physical aggression against others; 25% display sexually inappropriate behaviours; 47.5% displaying perseverative behaviours; 20% wandering or absconding; 40% displaying inappropriate social behaviour; and 55% displaying a lack of initiation.

Opportunities for choice and autonomy –

Choice making was explored using the Resident Choice Scale. Choices were available for most people in several areas:

- Clothes they wear (83%)
- Access to a private area (83%)
- Leisure activities they undertake (80%)
- Time they go to bed (73%) and
- Time spent in the bath or shower (73%).

However, substantially fewer participants felt there were procedures in place for them to choose:

- Where they go out (50%)
- Timing of their evening meal (41%)
- The content of their evening meal (37%)
- Keeping pets (28%)
- Removal of unsuitable staff (23%) and
- The furnishings of the house (23%).

Social networks and integration –

The size of participants' social networks were small to very small, e.g., Lubben Friendship subscale $M = 7.4$ (potential maximum of 30). So, unsurprisingly, participants displayed very low levels of social integration (CIQ social integration subscale $M = 5.3$ of potential maximum 12). Although 78% of the group actively spent time with a friend at least once per month, only 51% of the group reported having a best friend with whom they confide. Of note, particularly given the average length of time in their current SSA, very few participants knew or had contact with their neighbours ($M = 2.7$ of potential maximum of 30). Their most frequent contact was with members of their family ($M = 11.5$ of potential maximum of 30). However, varied but often limited contact with family was common for participants.

Community integration –

Home, social and productivity integration was measured using the Community Integration Questionnaire and social integration outcomes have been discussed previously. Involvement in home integration tasks (preparing meals, cleaning, shopping, budgeting) was generally low ($M = 1.9/10$, $R = 0-6$). Involvement in productivity tasks (working, volunteerism, study) was also low ($M = 2.5/7$, $R = 0-5$) and frequency of work, study and volunteerism roles are discussed below. Of note, 75% percent of the group travel outside the home almost every day, with a further 20% almost every week, and thus would positively skew the productivity subscale scores.

Life role participation –

Participation in life roles (worker, student, volunteer, caregiver, family member, friend, hobbyist, participant in organisations, religious participant) was explored using the Role Checklist and further demonstrated the varied outcomes of this group. Whilst two participants recorded no roles within which they currently participate, one participant was involved in all eight life roles examined. Three participants were studying part time, one was working part time, six were volunteering, eight were fulfilling caregiver roles, 17 were involved in home maintainer tasks, 29 recorded a role as a family member and 31 as a friend, 7 were religious participants, 25 were hobbyists and 8 were participants in specific community organisations.

Comparison with people with ABI living in Residential Aged Care –

Analysis of the data collected in this research has been compared with published data on a group of people with ABI living in Residential Aged Care (RAC) held by the researchers. Comparison of the findings highlighted that the groups were of similar age and gender distribution. On average, the SSA group has appeared to live longer in their accommodation setting than the RAC group (average of 90 months versus 58 months). Support needs of the groups were similar, and although both the SSA and RAC group participants most often required near 24-hour care (75% and 59% respectively), both groups included small cohorts who were able to be left alone for part of the day and overnight (10% and 14% respectively). There was one participant in both the SSA and the RAC group who were recorded as being able to be left alone for almost the whole week. SSA residents with lower support needs comprised the subgroup of participants living in cluster units or units at the rear of a

residential group home (total 12.5%). Refer to Tables 1 and 2 below for a comparison of Care and Needs and Overt Behaviour Scale data across groups.

The SSA group appeared less likely to be visited by family on a weekly or monthly basis compared to those in RAC accommodation - 35% and 54% respectively. In contrast, the SSA group were more likely to visit relatives in the relative's home on a weekly or monthly basis - 37.5% and 24% respectively. But again, large proportions of both groups seldom or never visited relatives – SSA = 37.5% and RAC = 43%. The SSA and RAC groups were similar with regard to visits by friends, which was very low (60% of the SSA group and 56% of the RAC group were visited by a friend less often than once a year or never). Refer to table 3 below for comparison of home, social and productivity integration of the RAC and SSA groups.

Three published measures of outcome were used with both the SSA and RAC groups: the Care and Needs Scale (table 1), the Overt Behaviour Scale (table 2) and the Community Integration Questionnaire (table 3). Comparisons of descriptive data for each of these two groups on these three measures are listed below:

Table 1: Care and Needs Scale: Level of Support

CANS Level	YPIRAC (% of group displaying specified level of care need)	SSA (% of group displaying specified level of care need)
Cannot be left alone. Needs nursing care, assistance and/or surveillance 24 hours per day.	37%	57.5%
Can be left alone for a few hours. Needs nursing care, assistance and/or surveillance 20 – 23 hours per day.	19%	17.5%
Can be left alone for part of the day but not overnight. Needs nursing care, assistance, supervision and/or direction 12 – 19 hours per day.	18%	12.5%
Can be left alone for part of the day and overnight. Needs a person each day (up to 11 hours) for assistance, supervision, direction and/or cueing for occupational activities, interpersonal relationships and/or living skills.	19%	10%
Can be left alone for a few days a week. Needs contact for occupational activities, interpersonal relationships, living skills or emotional support a few days per week.	5%	0%
Can be left alone for almost all week. Needs contact for occupational activities, interpersonal relationships, living skills or emotional support at least once per week.	2%	2.5%

Can live alone, but needs intermittent (i.e., less than weekly) contact for occupational activities, interpersonal relationships, living skills or emotional support.	0%	0%
Can live in the community, totally independently. Does not need contact.	0%	0%

Table 2: Overt Behaviour Scale

Overt Behaviour	RAC group (% of group displaying behaviour)	SSA group (% of group displaying behaviour)
Lack of initiation	56%	55%
Verbal aggression	44%	60%
Inappropriate social behaviour	42%	40%
Perseveration/repetitive behaviour	25%	47.5%
Inappropriate sexual behaviour	20%	25%
Physical aggression against other people	16%	40%
Physical aggression against objects	9%	25%
Wandering/absconding	9%	20%
Physical acts against self	4%	10%

Table 3: Community Integration Questionnaire

CIQ	RAC Group				SSA Group			
	Min	Max	Mean	SD	Min	Max	Mean	SD
Home Integration (out of 10)	0	7.25	0.94	+/- 1.03	0	6	1.88	+/- 1.88
Social Integration (out of 12)	0	7	2.38	+/- 1.77	0	11	5.33	+/- 2.336
Productivity (out of 7)	0	5	1.59	+/- 1.18	0	5	2.45	+/- 1.239
CIQ total score (out of 29)	0	13.25	4.92	+/- 3.00	0	17	9.65	+/- 3.833

Research Implications

Key implications for service planning and implementation stemming from this project are listed below:

Proactive healthcare management

The findings from this project point to the need for consistent implementation of proactive health care strategies with people with TBI living in SSA in order to maximise the physical health outcomes of the group. Such strategies would also be applicable to people with TBI living in other community settings, where the person is reliant on others for health care planning (as is the case for people with cognitive impairment). Further research should be undertaken to evaluate the impact of targeted and proactive healthcare on improved physical health outcomes for people with TBI and high and complex physical health care needs, as demonstrated in this cohort, and has been previously proposed to ISCRR by this research group.

Accommodation planning and transitions

Many people in this study had been living in the same SSA setting for many years. Although anecdotally some were satisfied with the accommodation option, it is apparent that this young group of people do not have the opportunities for the accommodation careers or typical housing transitions that are common in middle adulthood. With the inception of the RIPL housing trust, and new models of housing and support, it would be appropriate to consider offering the opportunity for people to receive a targeted accommodation review and exploration of the range of options and models that may be available to them, and which may not be highlighted through the traditional annual Functional Independence Review process in place. It is however also acknowledged that for some people, or their support networks, moving after such an extended period of time in the one supported accommodation setting may not be desired, may be anxiety provoking, or could seem unachievable.

Choice making and autonomy

The home integration subscale of the CIQ, as well as the RCS, provided data regarding the opportunities for residents to be involved in the running of their home, as well as opportunities to make daily choices. This group were offered a range of choices in some areas (e.g., clothing they wear, leisure activities), but were often not involved in routine daily tasks (e.g., meal preparation, timing and content of meals) that are usually available to a person. This may be for a range of reasons, including the cognitive ability of the person, a personal preference of individuals to not be involved in such tasks, or the attitudinal environment of the SSA as a place of “care” rather than having a focus on participation and independence.

Daily support of this complex group is most often delivered by disability support workers, whose training and expertise can vary considerably. Recent research commissioned by ISCRR has provided further evidence of the workforce capacity and skill issue in this area. Creating environments of choice, and providing a model of person-centred active support, has been demonstrated as critical to improved outcomes of people with congenital disability, but to date has had undergone limited examination in the brain injury field. The findings from this current study further point to the need for research and evaluation of models of support that can improve participation, choice and community integration outcomes for people with TBI.

Management of behaviours of concern

The high presence of behaviours of concern in this group points to the need for targeted interventions to attempt to improve behavioural responses, provide positive behavioural

support, and thus influence outcomes in this area. This work is being focused upon through ISCRR's Behaviours of Concern program of research. Consideration of the impact of supported housing design on behaviours of concern (e.g., five to seven people living in a traditional residential-scale house where there are restricted private spaces) should also be further explored.

Community integration outcomes

Participants in this study were most often socially isolated, with restricted social networks. Further research is required to fully understand the size, density and multiplicity of social networks available to people with TBI, and work to maintain existing social networks post injury or develop new networks over time. Participants' very limited contact with neighbours was an interesting finding of this research, particularly for those people living in the same setting for many years, and one that has not been examined previously. Strategies to increase community based productivity roles for people with TBI is needed (e.g., supported employment, serious leisure or volunteerism roles, or study) however requires tenacity, ongoing monitoring, and evaluation of outcomes as often the cognitive behavioural sequelae of TBI may impact a person's ability to secure or maintain participation in such roles. This will be further examined through the extension of the current study into a longitudinal observational design.

Finally, the varied, but often poor, health and participation outcomes identified in this study may also be caused by the interaction of the outcome areas explored – e.g., behaviours of concern may be exacerbated by boredom or loneliness, impaired cognitive communication ability or pain; mental health issues can be impacted by but may also lead to reduced social contact and integration. Further research is required to understand the influence of personal, environmental and attitudinal factors on outcomes for this group.

Use of the research

This pilot study, the first of its kind with a population of TAC and WorkSafe clients with TBI living in SSA, offers some valuable insights into this group's situation, as well as areas of outcome which may be influenced through targeted interventions and which may impact TAC and WSV key performance indicators including client experience, client outcomes and scheme viability.

Findings, however, must be interpreted with caution, given this is an observational study with limitations that include small sample size, reliance on the person with brain injury and a paid support workers as the primary informants, and the heterogeneity of the participant characteristics.

In consultation with ISCRR and the TAC, this project has been extended into a longitudinal study of outcomes of people with TBI living in SSA (over 2 years), thus will offer a detailed picture of whether outcomes may change over time for this group. This longitudinal data will be compared with data on TAC and WSV clients entering new RIPL developments, as well as a longitudinal study on a group of people with TBI living in their own homes with high levels of paid attendant care.

Potential impact of the research

A key focus of this project has been to translate research project findings to begin to inform future community practice with this client group, and the design of housing and support models for people with severe TBI. The research project group has presented the project findings to a range of stakeholders, including key TAC, WSV and RIPL representatives; SSA

service providers involved in the research; clinicians working with this client group (occupational therapists, neuropsychologists, physiotherapists); and new service providers commencing work with TAC and WSV clients with neurotrauma through RIPL developments. It is anticipated that dissemination of the results of this project can be used to influence change in allied health, accommodation provider and direct support worker practice with this target group, thereby influencing the health status, and independence and participation outcomes. However, further research is also required and has been pointed to in other sections of this report.

For the TAC, this project identifies a number of areas that should be targeted through the Independence planning process as well as claims management. It has pointed to the need for further research to understand the use of ambulance and medical services, as well as management of complex physical healthcare needs in community settings, in order to improve outcomes and reduce cost of care. This study also provides detailed data on TAC and WSV clients' opportunities for choice, independence and participation in the traditional SSA setting, and points to areas of support model design that can be influenced (e.g., opportunity for choice regarding staff working in the SSA; capacity to participate in menu planning and meal preparation) to improve both client experience, and client outcome. These areas of influence are being explored through the new housing and support model frameworks designed for RIPL developments, and will be evaluated as part of a longitudinal study of outcomes of TAC and WSV clients moving into RIPL settings which is being led by this research project group.

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