Older adults' experiences of community integration following traumatic brain injury

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ABSTRACT

Literature suggests community integration should be the primary rehabilitation goal for older people following a traumatic brain injury (TBI). However, little is known about older people's lived experience of community integration following TBI. This mixed method study explores community integration from the perspective of four older adults following mild TBI, and compares findings with results from two community integration outcome measures: the Community Integration Questionnaire (CIQ) and the Community Integration Measure (CIM). Findings showed that TBI caused major disruption in life planning, with participants discussing a battle to maintain their pre-TBI independence and having to deal with the consequences of losing some independence following their injury. Setting up or maintaining good support networks were identified as vital to reintegration into the community following TBI, including with physiotherapists whose ability to engage and listen to their patients' experiences can play an important role in their recovery. Physiotherapists must take care when using the CIQ or CIM to measure the experiences of older adults' community integration following TBI as this study suggests that the measures do not wholly reflect people's lived experiences. Findings from this study may be referred to by the providers of community-based services for older adults with TBI to develop strategies for supporting older adults' community integration following TBI.

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Key words: Traumatic brain injury (TBI), Mixed methods, Community integration, Older adults, Lived experience

INTRODUCTION

Traumatic brain injury (TBI) is recognised as a major concern for older adults, with accidental falls being the main cause (Thompson et al 2006). In 2004, approximately eight in every 100,000 New Zealanders aged 65 or over were reported as experiencing a head injury, with the total population incidence rates being higher for men than women, and over twice as high (20 per 100,000) for Māori men (Barker-Collo 2009). Given these high numbers, understanding older people's post-TBI experience of reintegrating back into the community will be integral to achieving positive community integration outcomes for patients following TBI, a key role for physiotherapists working as part of the multidisciplinary team (Goranson et al 2003). Definitions of community integration typically include dimensions of social and community participation, participation in the home setting and participation in meaningful, productive activities (Salter et al 2008). Successful community integration has been shown to increase health related quality of life in TBI populations (Hawthorne et al 2009, Huebner et al 2003). In contrast, an inability to achieve adequate community integration can lead to social isolation for TBI populations (Hawthorne et al 2009, Struchen et al 2011). A retrospective cohort study exploring the long-term outcomes of rehabilitation in patients with moderate to severe TBI using 306 participants, found a greater percentage of the TBI population were living alone than in the general population (Colantonio et al 2004). Hawthorne et al (2009) conducted a study examining the health quality of life outcomes for Australian TBI survivors compared to matched controls and found that prolonged social isolation amongst TBI populations can lead to further issues such as depression, loss of friendships and an inability to formulate new relationships.

As long term rehabilitation programmes around the world are rare, care of TBI survivors often becomes the role of family care givers which can cause increased financial and psychosocial stress for the TBI patients and their families (Layman et al 2005, Lefebvre et al 2008, Rotondi et al 2007). When the head-injured person is unable to participate in employment at the pre-injury level, a large financial burden may be caused from additional health service needs and living costs which further compromises community integration (Layman et al 2005). Similarly, it has been shown that an inability to return to work, or for a partner to take time off work to become a carer, places additional stress during an already stressful period; leading to social isolation and a decrease in satisfaction with the person's attempts at social integration (Lefebvre et al 2008). Caregivers of persons with TBI have identified the need for better rehabilitation services within the community to equip them with the knowledge necessary to successfully reintegrate back into the community, such as long term planning, transitional training and access to support groups (Rotondi et al 2007). Consequently, community integration is considered by some as the primary goal of rehabilitation (Reistetter and Abreu 2005, Salter et al 2008). In addition, the literature suggests that rehabilitation practitioners, including physiotherapists, should use valid and reliable community integration measures as intervention guides and/or outcome measures.

Following a review of the literature, two outcome measures were identified as being valid, reliable and responsive measures of community integration with injured populations; the Community Integration Questionnaire (CIQ) and the Community Integration Measure (CIM). The CIQ is a 15-item questionnaire created specifically for TBI populations to measure community integration using the three subscales of home integration, social integration and productive activities (Willer et al 1994). The total score is ranked from 1-29 with a higher score indicating superior community integration (Willer et al 1994). The subscales are scored; out of 10 for home integration, out of 12 for social integration and out of seven for productivity (Willer et al 1994). The scoring of the CIQ places value on the frequency with which people engage in certain activities. For example, performing an activity by oneself is scored higher than performing it with someone else. The CIM is a 10-item questionnaire, developed to be used with people with brain injury (McColl et al 2001). The CIM does not prioritise activities or relationships and focuses on a personal perception of the person's integration into the community (Griffen et al 2010). The scoring is ranked from 10-50, with a higher score representing a high level of community integration (McColl et al 2001). Evidence of validity for the psychometric properties of both scales is good (Griffen et al 2010, McColl et al 2001, Salter et al 2008, Sander et al 1999, Willer et al 1994, Willer et al 1993). However, within the New Zealand setting it is unknown which tool would be most suitable to measure community integration in future service evaluations or research. This study aimed to explore community integration from the perspective of older adults following mild to moderate TBI who live within the Waitemata District Health Board (Waitemata DHB) region in Auckland, New Zealand. The study also compared people's narrated experiences with the results of the CIQ and CIM to test the appropriateness of the outcome measures in addressing important aspects of community integration.

METHODS

This exploratory summer studentship project was a mixed methods study, using qualitative descriptive and quantitative questionnaire based methods. Ethics approval was granted by the Auckland University of Technology Ethics Committee. Written informed consent was gained from all participants.

Older New Zealand men and women, Māori aged 55 or older or non-Māori aged 65 or older (due to different life expectancies), who had sustained a mild or moderate traumatic brain injury in the last two years were eligible for participation in the study. Further eligibility criteria included having lived in their own home for at least 3 months following discharge from treatment by the Waitemata DHB or as an outpatient by a general practitioner, at an emergency department, or other community rehabilitation service, and were resident within the Waitemata DHB region. People who were unable to speak or understand English, or unable to provide informed consent, were excluded.

Recruitment

Three people responded to an article in the North Shore Times, a free community newspaper, and one person was referred from ABI Rehabilitation, a brain injury rehabilitation facility in Auckland.

Data gathering

Qualitative descriptive data were gathered using a semi-structured interview guide to explore participants' community integration experiences and needs. Participants had the option of being interviewed at home (two participants) or at the multi-disciplinary clinic at the North Shore campus, Auckland University of Technology (two participants). None of the participants opted to have a family/whānau support person present. Interviews were conducted in English. Interviews were approximately 60-90 minutes duration. Participants were asked to complete the CIQ[1] and the CIM[2] standardised questionnaires at the end of the interview. The order for completion of each questionnaire was randomly assigned to each participant.

Data Analysis

With participant consent, the qualitative descriptive data were audio taped and transcribed verbatim. Line numbers were added to all transcripts to assist with location of narrative data. The interviews were analysed using thematic analysis as outlined by Braun and Clarke (2006). The thematic analysis began with transcribing and re-reading the data to become familiar with each interview. Each interview was then re-read with codes added to the side of text where appropriate such as 'lack of understanding' or 'not wanting help'. Themes were generated and put into a mind map connecting relevant themes and sub-themes like 'loss of independence' and 'isolation'. Mind maps from each interview were collated and reviewed to generate a collective set of themes in a thematic map, which were 'independence' and 'support networks'. These themes were then further refined as the data were applied to each theme and sub themes to come up with a final set of themes; 'returning to my normal life' and 'having support networks'.

The analysis was conducted using an inductive method and at a semantic level. Quotes presented in the results section are identified only by the person's self-chosen pseudonym.

The CIQ and CIM data were analysed using descriptive statistics and reported using frequency tables. Data analysis examined whether themes identified as important by the participants in the qualitative interviews were captured by the standardised outcome measures. The CIQ and the CIM were then critiqued for how well they measured community integration outcomes for the participants.

RESULTS

Four participants were recruited for this study with their details outlined in Table 1 below. All four participants reported they had suffered a mild TBI following injury.

Two main themes were identified from the thematic analysis: *Returning to my normal life* and *having support networks*. These themes are discussed below. Highly illustrative quotes drawn from the participant interviews are presented. Pseudonyms are used to protect participant confidentiality.

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[1] The CIQ is available from http://tbims.org/combi/ciq/ciqrat.html

[2] The CIM available from http://www.disabilitypolicyalliance.ca/latest-news/the-community-integration-measure.html

Table 1: Demographic data with CIQ and CIM scores

Name	Age	Gender	Ethnicity	CIQ				CIM
				Home	Social	Productivity	Total	
Susan	75	F	NZ/Euro	10	11	4	25	49
Kate	78	F	NZ/Euro	10	7	4	21	49
Dane	84	M	NZ/Euro	0	7	4	11	36
Richard	73	M	NZ/Euro	10	10	2	22	50

* The CIQ consists of three subscales that give a total out of 29. Home integration is out of 10, social integration is out 12 and productivity is out of 7; † The CIM has a total score out of 50.

Returning to my normal life

Participants spoke about TBI as causing major disruption in life planning, and discussed their 'battle' to return to their normal life. This was often a balance between maintaining the independence that they had before their TBI and dealing with the consequences of losing their independence following their injury. Interestingly, the term 'independence' meant different things for different people. Three participants reflected on their independence as being their ability to do all the activities they enjoyed undertaking before their injury without needing the help of others; whilst for another participant it meant being able to go for a walk once per day just to get out of the house.

A loss of confidence and fear of activities outside the person's comfort zone were identified as an important precursor to a loss of independence. Susan is a 75-year-old woman who suffered a mild TBI from a fall on a bus in 2011. Having been an active person up until the accident, she found that her loss of confidence in doing what used to be everyday tasks such as walking down steps debilitating:

> *"Steps are my big problem. I almost get vertigo at the top of them…. I was in Rotorua on Monday and I went walking and I was talking and we climbed up the hill to look at a cemetery and then I realised I had to come back down again and that was horrible, I almost vomited with the fear" (crying slightly as talking) (Susan).*

This loss of confidence can also translate into a perceived reliance on others, which amplifies the person's feelings of lost independence. For Susan this meant resenting having to ask for help when doing a task that she once found simple:

> *"One of the chappies had to take me down [to the bottom of the hill] and I hate that. I'm a very independent person but it's taken all that away from me" (Susan).*

The participants did not always view a reliance on others as negative. Richard, a 73-year-old man who suffered a mild TBI following a fall, was comfortable enough with the friends he had around him to ask for help:

> *"I accept it. They don't think any less of me. If I felt they thought I was a nuisance I wouldn't bother" (Richard).*

Dane, an 84-year-old male stroke survivor with a history of TBI from numerous falls, was reliant on his wife for day to day assistance and to do chores around the house. Without this support he felt he would not have been able to cope alone in his own home. His appraisal of their relationship sums up his reliance on his wife's support:

> *"I couldn't exist without her" (Dane).*

A catalyst for a further loss of independence amongst these older adults with mild TBI was a reluctance or inability to return to driving immediately following their accident. Although all participants did return to driving some time later, the initial period of non-driving led to either an increased reliance on others or feelings of isolation:

> *"I wasn't allowed to drive straight away, I had a month off. This added to the isolation, as people didn't understand. I would never ring up and ask people to take me, so I didn't go. And I wasn't allowed to get in the bus either so I got stuck at home" (Susan).*

Another participant, Kate, is a 78-year-old woman who walked into a glass wall at an airport and suffered a mild TBI. An important excursion for her was to visit her son and daughter's farm 45 minutes away, but her TBI symptoms left her unable drive long distances so she could not visit without the help of others:

> *"We organised rides out to the farm as I couldn't drive for a few days. I don't like that either though as I lose my independence you see. I felt very independent before the injury" (Kate).*

Losing the ability to easily access family, friends and other support networks can leave the person isolated within their community, unable to easily interact with family and friends:

> *"Isolated, that was a big thing. I was up a drive and everybody worked so I didn't see anyone from dawn to dusk. Isolation was a huge factor as I'm totally independent" (Susan).*

For Susan and Kate, this enforced isolation was in contrast with the way they saw themselves, which was as independent, sociable people. Their ability to engage in activities that keep them busy makes them feel part of the wider community. This was important to them before their injury and it was important for them to regain this connection with their community as part of their recovery.

Maintaining a level of independence had both psychological and physiological benefits. All participants identified walking as a current pastime. For Dane walking was important for fitness, but also as a way to get out of the house and remain active:

> *"I do it for exercise so I can keep reasonably fit. You have got to get out otherwise you are stuck in a chair" (Dane).*

The participants were returning to their normal lives with an understanding that they may never be the same as they were before. For some, this left bitterness about how they came to be the way they are. However, Richard had a different outlook; to dwell on the past would make returning to his normal life much harder:

> *"You can't dwell on the past. You use the past as a guideline but you've got to work towards what you're going to do. Like I've got my bucket list, things I need to do. I don't think about the injury. Except when I have a headache or I bounce into the wall" (Richard).*

Following even a mild TBI, these findings show how many factors impact on the sufferer and long-term changes can contribute significantly on people's ability to return to their normal life. Understanding and accepting such changes is important and having the right support available makes this transition possible.

Having Support Networks

The importance of setting up or maintaining good support networks was identified by all participants as being vital to their ongoing recovery and reintegration. Within this study there seemed to exist a fine balance between being able to accept help and being hurt by people's responses to their situation.

All participants had at least one person close to them whom they could rely on for help and support. Kate was able to confide in her sister and not feel the need to hide her true feelings:

> *"My sister was very important as I could tell her anything. A friend would call and ask how I was I would say I'm fine, but if Mary (pseudonym) called I would tell her the truth. If I had a rotten day yesterday or I got tired, I could tell her and I still do. That was a great release for me and it would have made it harder without her" (Kate).*

As well as having a close confidant to talk to, three participants were able to confide in healthcare professionals. Susan had a home visit by an occupational therapist and a physiotherapist whom she chose to confide in:

> *"The physiotherapist and occupational therapist that came round were lovely and that was lovely, someone coming into your home and chatting. I loved the therapy. I didn't choose to talk to a lot of people but they knew what I was going through" (Susan).*

Not all support was considered beneficial though as three participants resented having to ask for help or being given sympathy.

> *"I hate giving in to where I need help. I hate fuss. I'd sooner keep it all to myself and get by without anyone knowing" (Kate).*

Richard felt that encouragement from those around him was more beneficial than sympathy:

> *"I don't want sympathy. I want encouragement more than anything; Someone just to say that you're handling it well, that's all; rather than someone who says 'what the hell are you doing" (Richard).*

Susan and Kate both held back from discussing their problem too much to avoid making a fuss, which may have left some people close to them unaware of the severity of their symptoms. This led Susan and Kate to resent the reactions from some of the people close to them as they felt they were showing a lack of understanding. Susan described her experience as being unique and misunderstood:

> *"I have all the sympathy in the world for someone who goes through this or has anything to do with concussion. I mean unless you go through it you never understand it" (Susan).*

The psychological impact and symptoms of TBI often cannot be seen. This means that other people are not always receptive to the ongoing suffering that can occur. This makes having people around to confide in about these issues following TBI such an important part of the healing process

CIQ and CIM comparison

Table1 shows the results for scores on the CIQ and the CIM. CIQ home integration was 10/10 for three participants and 0/10 for one; Dane relied on his wife to do the house chores and planning social arrangements resulting in zero points. Kate and Dane only scored 7 out of a possible 12 on the social integration subscale, suggesting a lower level of activity than that reported by Susan and Richard. No participant gained full points for the productivity subscale, reflecting their lack of engagement in paid and voluntary work. Three of the four participants scored high on the CIQ and very high on CIM. Yet, all three reported ongoing problems in returning to their normal lives. Although this was a small sample it suggests that the questionnaires do not detect community integration issues in some people with a mild TBI. Two issues could be at play: firstly, it is possible the measures suffer from a ceiling effect for people with a mild TBI. Secondly, the CIQ puts value on how often someone takes part in an activity and neither questionnaire asks the person whether he or she is satisfied with their level of community participation. Whether the number of times activities are undertaken is adequate to indicate high social integration is a subjective opinion. For example, Dane may be content visiting friends two times a week, whereas Kate may consider this an extremely low number that leaves her feeling isolated. This may explain why Dane and Kate had identical scores in the social integration section of the CIQ despite Dane seeming less socially integrated.

DISCUSSION

Two reoccurring themes from previous research which closely matched the data were the feelings of social isolation (Colantonio et al 2004, Hawthorne et al 2009, Lefebvre et al 2008, Struchen et al 2011) and the need for ongoing support in the community (Huebner et al 2003, Rotondi et al 2007). Within this study, the experience of being social isolated seemed related to an inability to return to a normal life as known before the accident. The participants' return to normal life was also affected by an unwillingness to ask for help from friends and family leading to feeling of resentment due to a perceived lack of others' understanding. This was mentioned by all participants as sequelae of their mild TBI and reflected in the CIQ with low scores in the social integration subscale from two participants.

Participants acknowledged the important role of family, friends, church and healthcare professionals in their recovery. Relating these findings to a clinical setting, the understanding from healthcare professionals of their role to engage and listen to their patient becomes vital to good practice and plays an important role in their patients' recovery and reintegration into the community.

Sub-themes identified through this paper's qualitative research such as a loss of confidence with everyday activities and a loss of, or interrupted, driving ability are not identified within either questionnaire. Although these themes are not specific to community integration, they were identified through the interviews as important constructs that affect people's ability to reintegrate successfully back into the community. This highlights an area for additional research as to whether these or other constructs identified within this research may be included in the questionnaires to improve content validity.

The development of the questionnaires utilised must also be considered when using them in the New Zealand context. Both questionnaires were formulated using an American population who had sustained moderate to severe TBI with the age range for participants in these studies 18-64 years for the CIQ and 19-58 years (35.8 average) for the CIM (McColl et al 2001, Willer et al 1993). This may affect the validity of the tools' use in the New Zealand environment due to potentially different needs, expectations and services of older adults with mild or moderate TBI. This also brings into question the use of either questionnaire with older adults, particularly those with mild TBI. The mild nature of the TBIs suffered by older adults within this study may be a reason for the apparent ceiling effect that occurred during testing, particularly for the CIM, as past tests for validity and reliability were not tested on this population. This indicates that further research should be undertaken to test the validity and reliability of the CIQ and CIM specifically on older adults in New Zealand, particularly those with mild TBI.

Description of study limitations and implications

The sample size for this exploratory study was small with four participants and lacked ethnic diversity. Because of this, these results cannot be regarded as transferable to all individuals with mild TBI in New Zealand. However, the findings may 'ring true' for others. Also the research did not set out to achieve data saturation due to the narrow scope of the project.

Recommendations for future research and clinical care

All previous research reviewed in this paper was based on work undertaken overseas, with no studies specific to the older adult population in New Zealand who may have unique or particular community integration needs. The majority of research into people's experience of community integration following TBI looks at younger adults and people with moderate or severe TBI. Further research must be done within New Zealand to fully understand the New Zealand context of older adults' experiences of community integration following TBI. Any future studies must use a larger recruitment base to increase the sample size and attempt to represent the multicultural make up of New Zealand by including a more ethnically diverse sample. Further research must also be completed with the specific population that this study addressed: older New Zealanders. This research suggests a gap exists in knowledge specifically studying older adults with mild to moderate TBI and their experience of community integration that may inform physiotherapy practice. This study also identified a possible ceiling effect of the CIM and component of the CIQ. Other measures could be explored; in particular those that examine how satisfied people are with their social integration, such as the Impact on Participation and Autonomy questionnaire (Cardol et al 2001, Kersten et al 2007) or the Activity Measure for Post-Acute Care (Jette et al 2007) participation measures developed by the Patient Reported Outcome Measurement Information System (PROMIS) group.

CONCLUSION

The incidence of older adults suffering TBI in New Zealand is increasing (Thompson et al 2006). As the population ages and health resources become scarcer, physiotherapists' understandings of how best to achieve community reintegration of older TBI patients must be addressed. This requires further research as, despite the fact that community integration has been identified as a primary goal of rehabilitation; this study has identified a paucity of research specifically into older adults' experience of community integration following TBI. Physiotherapists should be aware that the CIQ and CIM may have a possible ceiling effect when used to measure the experiences of older adults' community integration following mild TBI.

KEY POINTS

- Successful community integration following TBI should be the primary goal of rehabilitation.
- Physiotherapists should be aware that the CIQ and CIM may have a possible ceiling effect when used to measure the experiences of older adults' community integration following mild TBI in New Zealand.
- Further research is needed into the validity of outcomes measure for older adults' experiences of community integration following mild TBI in New Zealand.
- Physiotherapists have an important role as a support network and their ability to engage and listen to their patient is vital to good practice and plays an important role in their patients' recovery and reintegration into the community.

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PERMISSIONS

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