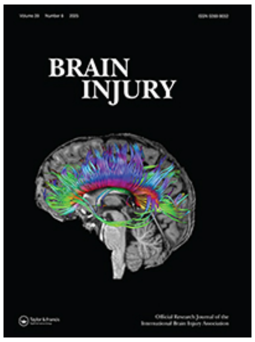

Brain Injury

Taylor & Francis
Taylor & Francis Group

ISSN: 0269-9052 (Print) 1362-301X (Online) Journal homepage: www.tandfonline.com/journals/ibij20

“Part of the world again”: qualitative enquiry into community participation during inpatient rehabilitation and transition years following severe brain injury

Suzanne Currie, Jacinta Douglas, Kate D’Cruz & Di Winkler

To cite this article: Suzanne Currie, Jacinta Douglas, Kate D’Cruz & Di Winkler (2025) “Part of the world again”: qualitative enquiry into community participation during inpatient rehabilitation and transition years following severe brain injury, Brain Injury, 39:6, 464-475, DOI: 10.1080/02699052.2024.2443772

To link to this article: https://doi.org/10.1080/02699052.2024.2443772

BRAIN INJURY
2025, VOL. 39, NO. 6, 464–475
https://doi.org/10.1080/02699052.2024.2443772

Taylor & Francis
Taylor & Francis Group

"Part of the world again": qualitative enquiry into community participation during inpatient rehabilitation and transition years following severe brain injury

Suzanne Currie[a,b,c], Jacinta Douglas[a,b], Kate D'Cruz[a,b], and Di Winkler[a,b]

[a]Living with Disability Research Centre, La Trobe University, Melbourne, Australia; [b]Research Unit, Summer Foundation, Melbourne, Australia; [c]Physiotherapy Department, Alfred Health, Melbourne, Australia

ABSTRACT
Purpose: To understand the experience of community and social participation for people with severe ABI during inpatient rehabilitation and the transition years.
Methods: Constructivist grounded theory methodology informed participant recruitment and data analysis. Adults with ABI were recruited using purposive sampling and data collected via in-depth interviews.
Results: Thirteen adults with severe ABI participated, with average age of 36.7 yrs at the time of injury, 9.1 months length of stay of in inpatient rehabilitation, and 4 years post discharge from hospital at time of interviews.
The core category developed from thematic analysis was 'lack of focus on community and social participation.' Additional categories included: restricted participation, a focus on impairment and function, acceptance and connection within the community, influence of family and delayed return to community participation.
Conclusion: Community and social participation are recognized as the goal of rehabilitation following ABI; however, experiences shared by participants revealed that community and social participation were not the focus of their rehabilitation.
Implications for rehabilitation: To support positive holistic outcomes, focus on community and social participation is required within the rehabilitation continuum, using participatory frameworks, contextual goal setting, transparent endorsement for community access and the provision of opportunities for meaningful experiences with family and friends.

ARTICLE HISTORY
Received 24 June 2024
Revised 12 December 2024
Accepted 13 December 2024

KEYWORDS
Qualitative; community participation; community integration; inpatient rehabilitation; transition; acquired brain injury

Introduction

Community integration and the maintenance of social connections are recognized as a complex and multifaceted challenge for people following severe acquired brain injury (ABI) (1–3). A sense of belonging and meaningful connection within the community, as well as spending time participating in valued activities and having agency over one's own life, are core concepts related to community integration (1). Positive community and social outcomes, where a person is actively participating in community-based activities with other people, are often considered the ultimate goal of rehabilitation after ABI (4–8). This is evidenced by the inclusion of community integration in international multi-disciplinary clinical practice guidelines (9–13). Accordingly, community integration is recognized as correlating with life satisfaction, emotional well-being and quality of life following ABI (7,14,15).

ABI is one of the most common causes of physical, communication, cognitive and psychosocial acquired disability in adults (16,17). People with severe ABI, as defined as a Glasgow Coma Scale (GCS) (18) of eight or less at the time of acute injury, frequently require assistance with many aspects of their daily life, including accessing the community to participate in activities of their choosing (19–21). Despite the availability of therapy and personal supports, community and social participation remains challenging for many individuals with severe ABI once they return home following inpatient rehabilitation and are required to adapt to an acquired disability (22–27). A recently completed scoping literature review highlights that there is no global consensus about how rehabilitation services support the transition into the community following brain injury (28).

The United Nations Convention on the Rights of Persons with Disability (29) recognizes the rights of people with ABI to participate as equal members of our community. Furthermore, Article 26 of the convention outlines the responsibility of multidisciplinary rehabilitation services to deliver programs to support participation and inclusion of people with disability in the community and that this should begin at the earliest possible stage. Specialist multidisciplinary, inpatient rehabilitation is recommended following an acute brain injury, to optimize functional outcomes and reduce support requirements on discharge to the community (8,30). In addition, the International Classification of Functioning, Disability and Health (31) guides the delivery of rehabilitation ensuring interventions to improve body functions are contextualized within participation in meaningful activities. With community

CONTACT Suzanne Currie suzanne.currie@summerfoundation.org.au Living with Disability Research Centre, La Trobe University, Melbourne, Australia
Supplemental data for this article can be accessed online at https://doi.org/10.1080/02699052.2024.2443772

and social participation recognized as a human right and a key outcome following severe ABI, it is important to understand how rehabilitation can optimize functional outcomes and prepare for life in the community. People with severe physical, communication and cognitive disability following ABI are underrepresented in the research, and therefore the evidence to support community integration for this cohort of the ABI population is sparse. Accordingly, there is limited literature (32) specifically exploring the role of inpatient rehabilitation in preparing people with severe ABI for life in the community, including community and social participation.

This qualitative enquiry starts to address this gap in evidence by focusing on the experiences of people following severe ABI. The aim of this study is to explore the lived experiences of community participation, from the perspective of adults with ABI, during inpatient rehabilitation and the transition to the community. We wanted to know what meaningful activities people engaged in with their family and friends whilst in hospital and identify what helped or hindered their return to community and social participation following hospital discharge. This is the first of four studies, as part of a doctoral program of research, to develop a holistic understanding of how the rehabilitation environment can prepare people for life in the community following ABI. The overall aim of this series is to co-design a framework, grounded in lived experience, guiding rehabilitation practices to support positive community integration outcomes. Our methodology enabled the gathering of co-constructed perspectives, first from the perspective of people with ABI and subsequently their close others. A companion piece to this study, sharing the family experience of supporting community and social participation, is the next addition in this series, followed by health professionals working in this area of clinical practice.

Methods

Qualitative approach

Given the aim of this study was to understand the lived experience of community participation for people with ABI, Constructivist Grounded Theory (33) research methodology was chosen. Constructivist Grounded Theory is a useful methodology when exploring a complex area of enquiry and supports the researchers to take a reflexive stance throughout the processes (34). Grounded Theory is well suited to social inquiry when there is a lack of established information available about a situation, to learn and better understand that situation from participant's experiences, whilst enabling the process of moving from data to theory rather than the testing of a preexisting theory (35). As there is little known about the return to community participation during inpatient rehabilitation, this methodology was chosen to understand this from the insider perspective. Given the nature of rehabilitation, in which the participants interact with many individuals including medical staff, allied health professionals, co-patients, relatives and members of the public, this study is situated within the symbolic interactionist methodological framework, consistent with a constructivist view of qualitative research (33,36). This methodology recognizes the data collection and analysis processes are influenced by the co-constructed experiences within the rehabilitation system and societal context, as well as the research team's interaction with the data (35).

Researcher characteristics

The research team brings disciplinary perspectives from physiotherapy, clinical psychology, neuropsychology, speech therapy and occupational therapy. The first author (SC) is a female doctoral candidate and senior physiotherapist working clinically in a specialist ABI rehabilitation service, with over 10 years' experience working with this population. Collectively, the supervisory team (JD, DW, KD) have extensive experience as qualitative researchers, as well as clinical experience with this population. The first author conducted the interviews with participants, guided by training and support from the second author (JD). Participants were provided written information regarding research team affiliations and the research aims prior to participation.

Context

Participants were recruited from a specialist, multidisciplinary ABI rehabilitation service in a metropolitan city in Australia. People were eligible for this study if they were over the age of 18, had sustained a severe ABI (Stroke, TBI or hypoxia), were living in the community and had participated in inpatient rehabilitation at the identified service between February 2017 and February 2020 (prior to the COVID-19 pandemic). Those with injuries related to encephalitis and brain tumor resection were not included as the outcome trajectory often differs and the associated focus of intervention is variable. Severity was determined by a Glasgow Coma Scale (GCS) (18) score of eight or less at the time of acute injury, and a score of less than or equal to three in the cognitive, communication or mobility domain on the Functional Independence Measure (FIM) (37) at the time of admission to inpatient rehabilitation. This information was reported within medical records for each participant.

Sampling strategy

Allied health professionals, working in the service, who were not connected to the study, identified potential participants who met the eligibility criteria, and the first author (SC) verified that participants met eligibility related to GCS and FIM as reported in the medical records. Potential participants received a written invitation to participate in the study from research administrators who were not members of the research team. Research administrators were clinicians employed at the health network, with significant experience working with people with ABI. To maximize the opportunity to inclusively recruit people with complex disability, additional supportive strategies were implemented. For example, research administrators were advised to call potential participants up to three times, in recognition of potential brain injury-related cognitive challenges that may be a barrier to their participation. The research administrators were also given additional training related to the study procedures and responding to distress.

Of the participants identified as eligible, six participants were lost during recruitment, with reasons related to declining to participate due to grief of recounting experiences, failure to respond, incorrect details on the health informatics system and incarceration. Purposive sampling (38) ensured representation across demographics and disability, to support exploration of results related to cognitive, communication and physical impairment resulting from ABI. The intention was to continue participant recruitment until data sufficiency was evident through the analysis process.

Ethical considerations

Institutional (Hospital and University) ethical approval for this study was obtained on the 4th November 2021 (Ethics Project No: 460/21). Several strategies were employed to support informed consent and the inclusion of people with severe ABI in the study. Strategies included the development of an aphasia friendly, easy language information video which was uploaded to YouTube and sent by text or e-mail to potential participants. Potential participants were encouraged to discuss their participation with a trusted person and were invited to have a trusted person and/or communication partner present during the interviews. For those with legal guardians ($n = 6$), consent was gained from the guardian to discuss participation with the person themselves, prior to completing consent with the participant directly. Participants were reminded of the voluntary nature of their participation and were asked additional questions about their understanding and expectations of the study to ensure they were making an informed decision to participate. Participants who were unable to participate in qualitative research due to the extreme severity of their disability could be supported or represented by a close other, however every effort was made to support their active participation.

Data collection methods and instruments

Prior to conducting the interviews, the first author (SC) made telephone contact with each participant to finalize consent and presented an opportunity to establish a relationship and build rapport in preparation for the interviews.

Demographic information such as age, gender, mechanism of injury, length of inpatient rehabilitation admission, discharge location and FIM scores were collected for each participant following consent and prior to the interview. This information was collected from the medical records, held by the health network, and allowed the interviewer to gain an early understanding of the participants' needs prior to meeting them.

A semi-structured interview guide was developed to address the aim of this study. The first question 'can you tell me about the activities you enjoy doing, out and about, in the community at the moment?' aimed to support rapport building and context setting, as a foundation to further exploratory questioning regarding experiences of community participation. Interview questions were broad and open-ended, with the interviewer (SC) taking an active, reflexive stance that enabled a flexible and responsive approach to the interviews, with further exploratory questions being asked, reflective of the overall objectives. Questions were asked to gather information about their experiences of community and social participation during inpatient rehabilitation and the transition to community living. Each participant was asked a concluding question 'what advice would you give to someone in hospital following a brain injury, to be able to get out and about and do the things they want to be able to do with their friends and family?.'

Interviews were conducted either face to face, in the participants home or online, via Zoom. Adjusted to the medium of interview, tailored strategies were incorporated to support inclusive participation such as giving additional time, reducing the speed of questions, writing key words, observing for verbal and non-verbal cues, including any signs of cognitive fatigue. In addition, building trust and the use of strength-based language was prioritized during each interaction (39).

Each interview was audio recorded, for transcription and analysis purposes. Immediately following the completion of each interview, written field notes were completed to capture reflections, such as the participants' level of engagement, displays of emotion and their environmental living context. None of the participants required or requested a second interview. Verbatim transcription of the audio recording of each interview was completed by the first author to support accuracy and familiarity with the data.

Data analysis

Consistent with Constructivist Grounded Theory methodology, analysis followed an iterative process, and was conducted concurrently with the interviews. Data collection stopped at the point that no new codes emerged through analysis of the interviews, therefore indicating data saturation (40).

Analysis followed a process of line-by-line coding, followed by focused and theoretical coding (33). Memos were documented throughout, and key quotes from interview participants were captured. Coding was completed by the first author (SC) for each of the transcripts, with the second author (JD) coding five transcripts to ensure consistency and to support analytical discussions. A data matrix and narrative summaries of each participant were developed by the first author (SC) to support a holistic understanding of each participant.

Trustworthiness

An interest in understanding lived experience informed all stages of this research. While the researchers brought their own clinical and research experience to the analysis, consistent with constructivist methodology (33,34), the use of field notes and a reflective journal supported reflexivity and an openness to learn from the experiences of the research participants. Assumptions or biases from previous clinical experience were interrogated through regular analytical discussions within the team. Field notes and a reflective journal also served as an audit trail. A subset of participants, reflective across impairment levels (cognition, communication, and mobility), were invited to 'member check' (33) the accuracy of the thematic summary, ensuring that it represented their experiences. Throughout the analytical and writing processes, the research team endeavored to stay close to the lived experience data, evidenced by the inclusion of quotations, with the use of pseudonyms, throughout the results presented in this paper. Additional quotes relating to the thematic results are presented within appendix 1.

Results

Participant characteristics

Thirteen people with severe ABI participated in this study between December 2021 and December 2022. Nine interviews were conducted in person and four via videoconferencing on Zoom. The interviews were completed either with the primary participant independently (*N* = 7) or with a close other present (*N* = 5, spouse, or parent) or by proxy (*N* = 1, parent/legal guardian).

The mean age of participants at the time of their injury was 36.7 years; seven participants were female and six male. Types of ABI included TBI (*N* = 7), stroke (*N* = 5) and hypoxia (*N* = 1), with an average GCS of 4.1 at the time of injury. Ten of the 13 participants had a score of 1 on each of the cognitive, communication and mobility domains on the FIM at admission to inpatient rehabilitation. Participants were on average five years post injury and under four years post discharge from hospital at the time of their interview. They had a mean length of stay of 9.1 months in specialist inpatient rehabilitation. Table 1 reports the characteristics for the participant group.

At the time of interview, six participants required a wheelchair for all community access and six required the support of legal guardians given their cognitive disability. Six participants have severe communication disability, including dysarthria or aphasia, three of whom required the support of a communication device and/or communication partner. Across the participants, eight require support related to multiple functional areas due to cognitive, communicative and physical disability. At the time of the interview, nine participants were living with family in their own home, three were in supported living and one in residential aged care. All participants reported attending allied health therapies, funded through government health funding, disability support funding or compensatory schemes. Two participants described a smooth transition to active community participation following discharge from inpatient rehabilitation, with no delay in engaging in the activities they enjoy with family and friends, while the remaining eleven participants experienced significant delays in returning to active participation in their community.

One of the participants, Kelly*, did not actively participate in the interview, rather she was represented by her parents who are her legal guardians. This decision was made by her parents, in acknowledgment of the grief and distress Kelly* experienced following her brain injury and subsequent transition into residential aged care in her 30's. Kelly* has a very severe physical and communication disability and was included in this study as the intent was to be inclusive to a range of participants with severe ABI.

Analytical findings

Following constructivist grounded theory methodology, analysis resulted in the development of a core category exploring the lack of focus on community and social participation and five related categories; restricted opportunities; impairment and function based rehabilitation; acceptance and connection within the community; influence of family; and delayed return to participation. Relationships exist between each of these categories, with the lack of focus on community and social participation tying the experiences together (see Figure 1).

Table 1. Participant characteristics (*n* = 13).

Variable	*Mean, N*(%)	Range[a]
Gender		
Male	7 (53.8%)	
Female	6 (46.2%)	
Age (years)	36.7	18–59
Mechanism of Injury		
TBI	7 (53.8%)	
Stroke	5 (38.5%)	
Hypoxia	1 (7.7%)	
Glasgow Coma Scale	4.1[b]	3–8
FIM at admission was ≤ 3		
Mobility	11 (84.6%)	1–5
Cognition	13 (100%)	1–3
Communication	13 (100%)	1–3
Length of stay in inpatient rehabilitation (months)	9.1	4–16
FIM at discharge was ≤ 3		
Mobility	6 (46.2%)	1–7
Cognition	8 (61.5%)	1–6
Communication	6 (46.2)	1–7
Discharge Destination		
Home (with family)	8 (61.5%)	
Shared Supported Accommodation (SSA)	3 (23.1%)	
Residential Aged Care Facility (RACF)	2 (15.4%)	
Time since discharge at interview (months)	45.6	24–64

[a] Range of individual participants scores.

[b] Note 54% of participants had a GCS of 3 at time of injury.

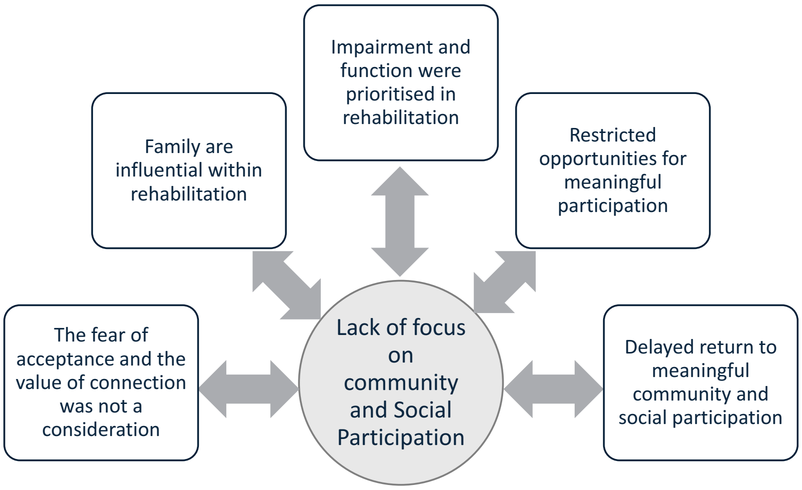

Figure 1. Conceptualisation of the experiences of inpatient and community rehabilitation from the perspectives of people with ABI. Description: The core category is represented as a circle and description of the interactional categories are in squares.

Core Category: Lack of Focus on Community and Social Participation

The core category developed from analysis of the lived experiences was that of the lack of focus on community and social participation during inpatient and community rehabilitation. Within inpatient rehabilitation, while some participants had opportunities for community participation, most experienced barriers. A few (3) participants experienced regular day leave during their inpatient admission, for example having coffee with family at the local shops, others (2) had a single opportunity, while the majority (8) participants had no opportunities to leave the hospital. Despite the range of experiences, the participants consistently described that community engagement, and spending time with their friends and family was not a focus of inpatient rehabilitation. This experience continued following the transition to the community, with participants describing that rather than community and social participation, other aspects of the transition took priority (e.g. instrumental arrangements and support provision).

Those who missed out on opportunities for community participation reflected on the value these opportunities would have presented. This is summarized by Perry* who had a 16-month stay in inpatient rehabilitation, 'Cause I would have liked to have done it, I would have liked to have gotten out. Felt like I was part of the world again. Felt like I was part of the community.'

Category 1: Restricted Opportunities

With the focus of rehabilitation not being community participation, the participants experienced restricted opportunities within inpatient rehabilitation to access the community. Most of the participants did not leave the hospital grounds for the entirety of their inpatient rehabilitation admission, and although they had regular visitors, they spent time with their loved ones within their rooms. An example of this was shared by Charles* with the support of his dad 'The only time he would go out from the ABI unit was for appointments, that was the only reason he would leave.' For some participants this resulted in a sense that their disability may limit their ability to access the community, and something they should not do. "I sort of had the idea that I don't do that and 'cause I got the brain injury and I really shouldn't do that [access the community] and I didn't because also my peripheral vision was damaged from my brain injury" (Michael*).

Consistent with restricted opportunities for accessing the community, each of the participants noted that they had to seek permission to leave the ward, and many felt that they were breaking the hospital rules if they participated in community activities with their loved ones. Erica* shared her experience of accessing the community during inpatient rehabilitation 'I think the hardest bit was explaining where I was, when I got back to hospital, telling people where I was,' and went on to describe herself within rehabilitation 'I was a naughty patient.'

Similarly, the opportunity for overnight leave varied across the participants, with some having the opportunity to spend time at home prior to their discharge, and others not. The model of care within the inpatient rehabilitation unit from which the participants were recruited allowed two overnight leave opportunities during an inpatient admission. Those who had the opportunity to experience overnight leave reflected upon the benefits of this experience, such as the opportunity to connect with family and friends. Participants described it as a welcome novelty being at home, sleeping in their own bed, cuddling pets and spending time with family, 'I had one overnight stay at my parent's house when it was my birthday because I wanted to spend one night away, because it was my birthday and wanted to wake up at home. I think I had pancakes' (Jasmine*). The positives are summarized by Divina*, with the support of her Husband, 'freedom … more comfortable at home … as they say, there is no place like home.'

In contrast, Freya's husband* shared his views on the restricted opportunities for overnight leave, 'they were reluctant to have her leave the hospital [for overnight leave], I am not sure why. I thought it would have been, especially after seeing that Freya* really enjoyed them, and it was very positive on her mental wellbeing, it would have been good to do a few more and earlier than they were.'

The lack of accessibility of the physical environment within the community was also found to restrict opportunities for participation in the community. Participants spoke of the unexpected need for problem solving to negotiate steps, public transport, busy environments, and how challenging this was, particularly when they required a wheelchair. As described by Malcolm* and his wife 'he has a huge circle of friends, but he's not actually been able to do that, go for coffee or brekkie, he used to do that a lot and we have found that a lot of places say they are wheelchair friendly, but they are not really.' Without community rehabilitation occurring in the local context, participants felt responsible for navigating the challenges faced within the community, expressing this as a barrier to reengaging in the community with friends.

Category 2: Impairment and Function based rehabilitation

Participants communicated that the focus of rehabilitation, across their experiences of inpatient and community rehabilitation, was to reduce the impairments caused by the ABI. Reflecting upon their time in inpatient rehabilitation, the participants described that they were striving to reduce their ABI related impairments and improve function, with little focus related to community participation and living well with a disability.

Striving to return to walking was a prominent focus of inpatient rehabilitation and the years following their transition to the community, as expressed in the following quotes 'so for me the walking was always the most important' (Erica*) and 'Well, I do a lot of Physiotherapy, I am still doing a lot of rehabilitation to try and get back on my feet' (Danny*). This focus on returning to walking supported the perception that people could not access the community whilst they were non-ambulant 'as soon as I started walking with the stick that was when I started being able to be active in the community, because earlier I couldn't, cause how could you participate in the community with the wheelchair' (Erica*) and 'She wasn't really able to leave the hospital, because early her mobility was very limited. She was taken outdoors in a wheelchair you know for some fresh air but just in the hospital there. And it wasn't really until her mobility improved that she was able to walk short distances and tolerate those activities better' (Freya's* husband). For many of the participants who remain non-ambulant years following their injury, this sentiment continues 'No I used to love going out before my accident. But like, because I am not mobile at the moment, that's why I stay home' (Danny*) and 'I can't cause of my wheelchair, I can't do things that I did do anymore, cause my arm is paralyzed as well' (Karen*).

Similarly, participants reflected on a perception of the need to delay community and social participation to focus on their rehabilitation, 'he had to do a lot of rehab first before he was able to get out into the community, a lot of rehab to try and get him as normal as he could' (Charles'* dad). At more than two years post discharge, participants described that often their scheduled therapy is prioritized over any of their leisure activities, 'Like I feel as if it's not time for friends, it's time for rehabilitation' (Danny*).

Category 3: Acceptance and connection within the community

A consistent theme across the experiences of the participants was a desire for acceptance from those they love, their friends and the wider community. Participants described a fear of being judged by others and lacked confidence being in the community. 'I was anxious about how I was going to be accepted, whether I was going to be accepted, those types of fears. How are people going to treat me' (Erica*). This was also linked to how the participants viewed themselves within society, shockingly illustrated by one participant who in describing himself asked, 'Would people be happy to talk to a spazzy guy?' (Malcolm*). There were feelings of shame related to their disability, for example, Perry* shared, 'I don't think I like being seen in a wheelchair' and Erica* said, 'I hated the wheelchair so much . . . . I was ashamed to be in the wheelchair.' Participants also expressed a desire to hide their brain injury 'I do not disclose to anyone that I had a brain injury, it's not something to be proud of, I just say I have had a car accident, and that's it. A car accident is nothing right' (Erica*) and a desire to be treated normally as expressed by Freya: 'I want my normal life. I don't want people to look at me and say "oh she's sick" I am not sick I had a stroke and boom, my head blow up . . . I am alive, that's all that matters' (Freya*).

Participants also described a loss of confidence in their relationships with family and friends, for example they described feeling like a burden. Many participants shared that their friends are now too busy and have moved on with their own lives. One participant, Karen*, shared 'I used to have so, so many friends, but I don't have it anymore. Friends embarrassed for me' and another, Perry* reflected on his intimate relationship ending 'they stayed with me for years after my accident but then I just realized I was holding them back from moving forward with their life.'

In contrast, participants who had positive experiences shared examples of the benefits of community participation during their inpatient admission. Some felt that spending time in the community supported connection with family members, for example children and siblings, which also supported a sense of normality, and adjustment following the ABI, 'It [going for ice-cream with her dad and children] made me feel more normal (Jasmine*),' and Luke* talked about going for a meal with his family 'Just the parmas, cause I love parmas.' Often, the activities people commenced with their loved ones in the community during the inpatient admission also continued when they transitioned out of hospital, such as Luke* who continues to go for a meal every week with his friends. Others shared how the opportunity to connect with the community created a sense of normality, 'well I think it is probably getting out and about, getting reconnected with the outside world. The differences, the noise everywhere and different lights, it's different, that's for sure' (Luke*) and 'Everything, trees, walkways, everything, all types of people' (Sophie*).

Category 4: The influence of family

The overwhelming perspective of the participants was that their family were a key support throughout their inpatient admission and the transition to community living. Given the lack of focus on community and social participation within rehabilitation, some family members compensated for this by facilitating opportunities for community access. The participants who had the opportunity to leave the hospital to participate in activities such as shopping, hanging out with friends, or going for an ice-cream, were supported to do so by their family members. Many participants shared the positive influence their family had upon their rehabilitation journey, including Sophie*, who accessed the community most days toward the end of her inpatient rehabilitation admission, with the support of her dad. She reflected upon the negative impact upon her wellbeing without these opportunities alongside her dad 'I think lying in bed and watching television loses all your drive to improve. Not doing it [accessing the community] would have made me feel lonely and sad.'

One participant who required very high levels of support and specialized equipment reflected on the integral role his mother played in supporting even the most basic connection to the community 'I was bed bound when I was [in rehabilitation]. I was left on a mattress on the floor and I didn't really get up, out of bed much. I got out of bed when my mum would come in and take me out, she would push me outside to get some fresh air.' (Perry*).

Following discharge from hospital, many of the participants shared that their engagement in activities they enjoy continued to be organized and supported by a key family member. This was highlighted by a conversation with Freya* 'Yeah, yup, yes, I do [activities that I enjoy]. My husband makes sure I do. He is a very good carer.'

Contrary to these experiences, there were also examples of families resisting opportunities to support their loved one to access the community, both within inpatient and community settings. This included examples of family members demonstrating risk averse behaviors, feeling a need to protect their loved one and therefore gatekeeping community participation. Jasmine* reflected on her experience 'I was out of hospital, they [parents] were nervous constantly about what I could and couldn't do so they didn't want to let me venture out and make mistakes, they just wanted me to do right and be right 100% of the time.' Jasmine* expanded upon this reflection by stating, 'It made me feel like a small child.' Erica* described her mother's involvement in supporting day and overnight leave from hospital 'She did her best, I know there is a conflict of interest, I know those things are better to be done by support workers, than family members. Sometimes she was a bit too engaged emotionally.' Michael* also shared his perspective of the influence of his parents' advice 'even my father said when I came here, he said well, don't be in a hurry to do, to do a lot of things.'

Category 5: Delayed Return to Participation

Following discharge home many participants described delays of several months in recommencing activities in the community with their family and friends. While some described participating in weekly activities in the community, such as attending social groups with peers, going to hydrotherapy at their local pool or shopping with their support workers, others shared that home-based leisure became the norm. For example, Malcolm* shared the occasional coffee at home with his friends rather than their previous weekly catch up at the local coffee shop, or Danny* who previously went out for dinner every week with his mother and sister, instead spent time together at home. Almost all the participants shared their experience of community rehabilitation occurring either in their own home, or traveling to specially designed therapy clinics. There were few examples of community rehabilitation occurring within community settings, such as cafes, community gyms, libraries or local parks.

Participants expressed significant delays in returning to community participation, however eventually for many, the focus did shift toward increased community participation and a sense of hope for the future. Some of the participants shared their experiences of how they adapted and increased their community participation over time. Many participants spoke of their goal of being able to contribute to society, something they consider as a normal aspiration, something everyone aspires to, 'I just want normalcy, I want a normal life and working is part of that' (Perry*). Additionally, those who have returned to work, volunteering or study expressed the positive value this has made 'I'm working also, which is good for my brain to get back to you know working again but also a social environment too and I met friends there and just get back to normal bit of life again' (Michael*).

The participants who expressed this shift in focus also shared other aspirations for the future, for example living independently, returning to dating and taking care of their health. The messages they shared were of continuous self-improvement, a shift from wanting to focus on reducing the impairments they have experienced following their ABI. For example, Perry* who shared his current goal 'I am moving out of here [supported living] in a few months. I am looking for a place to live, a single, two-bedroom apartment just so I can have guests stay over too.' Erica's* response when asked about what else she would like to achieve was 'you know, just normal things I was doing before, doing prior. Basically, everything I was doing before I am doing now, and I am doing my Master of Business studies which was always my dream.' Another participant (Danny*), when asked about his goals for the future stated 'I want to be a youth support worker,' and following a positive response from the researcher, he went on to ask, 'And you think I could do that even though I am in a wheelchair?.'

Discussion

The purpose of this study was to gain a better understanding of the lived experiences of community and social participation, during inpatient rehabilitation and the transition to community living. This study is the first in a series to develop a holistic understanding of how the rehabilitation environment can prepare people for life in the community following ABI.

The stories generously shared by the participants of this study show that the experiences people have within inpatient and community rehabilitation influence the journey to community participation. As evidenced across the participants' experiences, opportunities to focus on the goal of community and social participation are missed. Within both inpatient and community rehabilitation, the participants shared barriers that they encountered in returning to the activities they hold as the most meaningful in their lives. Our findings highlight that people held a sense that they could not do the activities they enjoy because of their disability and were awaiting the achievement of functional gains before attempting these activities. Many of the participants placed immense value on getting back to walking and limited their engagement in other activities to focus on achieving this often elusive goal. With participants sharing their experience of impairment-focussed rehabilitation, there is sadness in reflecting on how this has negatively impacted their return to community and social participation and the achievement of personally meaningful, contextually relevant goals. This is summarized within Danny's* question during his interview when discussing his future career hopes 'And you think I could do that even though I am in a wheelchair?,' where he clearly remains unsure of what is possible for his future.

Achieving positive community participation outcomes and building a fulfilling life after ABI is the goal of rehabilitation (1,4–8). A goal which serves as a shared aspiration between people with ABI, their families, health professionals and researchers alike. Given the significance of community participation, rehabilitation programs are well placed to provide an opportunity for people, with newly acquired disability, to build the skills they require to engage in the activities they enjoy, with the people they love (3). As Shaikh and colleagues (1) highlight within their conceptualization of community integration from the literature, the process is multidimensional and complex, given the changes in function and the necessary adaption to the change in life circumstances. Within the literature (28), there is a lack of descriptive information available on how to conduct rehabilitation that targets community and social participation. This is confirmed and built upon within the experiences shared by the participants within this study, where community participation is not an explicit focus within inpatient and community rehabilitation. From the participants, we gain a better understanding of the factors influencing positive and negative experiences within the community. The findings suggest the need to target opportunities for meaningful engagement to support community inclusion following severe brain injury, which is delayed without this focus within rehabilitation.

The results of this study are consistent with previous research recognizing the importance of collaborative goal setting in ABI rehabilitation, which is contextualized to the person's life, within their own homes and community, as well as within their family and social networks (30,41). Participatory frameworks of rehabilitation, such as the ICF, have been developed to guide goal setting and rehabilitation delivery, ensuring the transferability of skills into the community context (31,42). Within the experiences shared by the participants, the goals communicated clearly reflected that the experience of rehabilitation continues to be driven largely by the reduction of impairments and achievement of functional progress rather than participatory outcomes, as reported in previous studies (43,44). It is important to reflect on the influence contemporary methods may have in driving this focus, whereby the success of services is determined using outcomes on the FIM. Improving the connection between inpatient and community rehabilitation may well support a shift from this impairment focus to a more holistic focus on community living. In addition, incorporating lived experience within evaluation of health service delivery is crucial to the ongoing development of rehabilitation practice and to incentivize services to focus effectively on individually meaningful goals during rehabilitation.

Participants' reflections on their experiences revealed how institutional policies within rehabilitation programs could influence community and social participation. They talked about the rules and restrictions communicated to them within the hospital setting (for example permission requirements for day leave) which resulted in subsequent limitations on experiences of accessing the community. Previous research (7,8,15,23,30,45–48) affirms the wide ranging benefits of rehabilitation programs facilitating opportunities to learn through experiencing real-life community participation in meaningful and valued activities. In contrast, experiences of rehabilitation that are not contextualized within the engagement in personally meaningful activities are unlikely to achieve sustained learning or transferability of skills (49). By providing contextually focused rehabilitation people can be encouraged not to put their life on hold to improve their impairments and function, rather supporting them to participate in life activities, whilst concurrently supporting the optimization of functional outcomes. Practical examples, shared from the participants, include practicing and problem solving going for breakfast with a group of friends at a wheelchair accessible café (Malcolm*), planning a trip in a maxi taxi to go out for a meal or to the cinema with siblings (Luke*) and connecting with children, as a parent, by going for an ice-cream (Jasmine*). In addition to these being personally meaningful rehabilitation achievements, in supporting the participation in fun and future focused activities there is space created for the development of positive memories, as well as building people's confidence to try new things, which they may have considered impossible (50).

To be able to set goals like those mentioned, the interdisciplinary teams are required to explore who the person was before their injury, develop an appreciation of the journey so far, whilst also supporting the ability to be future focused, asking themselves 'what will life in the community look like for this person?.' To set personally meaningful goals, there are fundamental concepts to be followed, such as recognizing the person beyond their brain injury, observing their strengths, having an awareness of the whole trajectory and the skills to consider the person within their community context (51). Within the literature, and attested by the experiences shared within this study, a culture of humanizing approaches to rehabilitation is required, where services have the structures and environment in place to enable health professionals to develop a genuine interest and connection to the person they are working with (52–55). A humanistic approach, combined with a participation and strengths focus, enables rehabilitation services to facilitate positive opportunities to target individualized routines and relationships, empowering people with ABI, as well as their families, to connect what they are practising in rehabilitation to what they do in the community. Ultimately building hope, optimism and a belief in a positive future.

Those with the most severe brain injuries can also be the most disconnected from their social world (7,22,56). Perceptions of being accepted and valued by society were identified by the participants of this study as an important factor impacting their willingness to engage in the community, which is mirrored within other qualitative literature (3,15,57). The complexity of inequality and ableism in our wider society is outside of the scope of this study. It is however pertinent to acknowledge the potential influence of health professionals working in rehabilitation upon people's experiences of feeling accepted and valued as an individual (3,58,59). Adding to the existing literature (7,60,61), the participants of this study shared that participation in meaningful activities contributed to an increased sense of self within society and a sense of normality, which is particularly pertinent following a traumatic life event, such as sustaining an ABI. Participating in valued activities with others is an opportunity to develop a reconstruction of self, feel socially connected and supports the maintenance of interpersonal relationships including valued friendships (7,46,62,63). Within both the inpatient and community contexts of this study, there are many examples of missed opportunities to support people to experience a sense of belonging in the community. Lengthy hospital admissions, with restrictions placed on community access, followed by the cycle of home-based leisure perpetuates the disconnect of society people with ABI experience.

Ultimately, the message from the lived experience, is that rehabilitation services can provide a pathway which facilitates meaningful and positive opportunities for community and social participation. These opportunities can serve as a bridge to community living, which supports people to build a positive life course following ABI. While some people require a wheelchair to get across the bridge, others a communication device, and others may require someone to walk alongside them, participation is the goal.

Limitations and future research

Although the results of this study clearly indicate the lack of focus on community and social participation across the rehabilitation continuum, it is appropriate to recognize the potential limitations of this study. A limitation is that it reflects thirteen participants who engaged in rehabilitation at one specialist site in Australia, therefore care must be taken before generalizing the experiences analyzed within this data. It is important to acknowledge that this study was conducted within the Australian context, where people have access to funded ongoing rehabilitation and supports through health, accident and disability systems. Furthermore, this study included participants with severe injury, therefore does not reflect all levels of severity. However, despite these limitations, given the data is rich and supports the existing evidence base surrounding the complexities and experiences of community participation, it is likely that many of these experiences are shared more broadly, albeit with nuances across health care contexts and service delivery models globally.

This study shares the thematic findings from the lived experience of thirteen participants, and it is important to recognize that each journey following ABI is unique. Further, while it is vital to understand the lived experience, it is only one part of the larger story. Given the unexpected journey thrust upon family members when a loved one sustains an ABI, it is important to gather their perspectives of supporting the return to community and social participation. The companion piece, outlining the reflections of family members, will follow and complement these findings.

Additionally, rehabilitation is an interactional and complex space, therefore it is important to understand the landscape across the relational aspects that exist. An exploration of the perspective of the health professional regarding their experiences of rehabilitation delivery, including goal setting, rehabilitation program priorities and policies related to community access, for example risk assessment and safety procedures, will be explored as part of the ongoing research plan in this series.

The participant characteristics, related to severity of injury and level of disability, is both unique, and a strength of this study. As the research team have extensive experience working clinically, and in the research field, with people with ABI, the inclusive practices implemented within this study supported the development of rich qualitative data from an underrepresented population group. Future research aimed at further refining inclusive and ethical practices to increase representation of people with very severe cognitive and communication disability following ABI would be of immense value.

Clinical implications

Despite the limitations, analysis of personal accounts of the rehabilitation journey offers invaluable insights about the pathway through inpatient and community rehabilitation from the lived experience. This group of people sustained extremely severe injuries and have severe residual disability; however, they generously shared their time and their stories with a desire to help improve clinical services for others. The results suggest several practice relevant implications to support preparedness for community and social participation, these include:

- The use of participatory frameworks to guide rehabilitation across inpatient rehabilitation and the transition years to support continuity toward the goal of community and social participation;
- Setting individualized and strength-based goals, which are future focused and contextualized to the person's life;
- Transparent endorsement and encouragement by inpatient rehabilitation services of community access and spending time as a family in the person's own home, at the earliest possible stage;
- Seeking supportive opportunities within inpatient and community rehabilitation for the person with ABI to have meaningful and contextualized experiences, within community environments, to promote community inclusion and connection;
- Empowering the person with ABI, and collaborating with their family and friends, to explore and practice community participation together and build practical skills within the community context.

Conclusion

In summary, community and social participation is a human right and is recognized as the ultimate goal of rehabilitation following ABI. However, the participants of this study have told us that from their experiences of participating in rehabilitation, community and social participation was not prioritized. Resulting from this lack of focus, there are missed opportunities to prepare people for life in the community, impacting their return to community and social participation.

Therefore, rehabilitation services, across the continuum, must create meaningful opportunities for contextual experiences of community participation, led by individualized goal setting, with a future focused lens and humanizing connections. These experiences are important to support people to feel part of the world again, developing a sense of living well with a disability and broadening the lens of recovery beyond impairment and function level outcomes.

Acknowledgments

We would like to sincerely thank the participants who generously shared their experiences, perspectives and reflections of a time that is often challenging following a traumatic life event. This thanks extends to all the people we have had the privilege to work with during their journey following sustaining an ABI. Without your guidance and insights over the years, this research would not have come to fruition.

We would also like to extend our thanks to Michelle Farquhar for her expertise, valuable insights and support throughout the completion of this project and to the research administrators for their role in recruitment.

Disclosure statement

The authors report that there are no competing interests to declare(s).

Funding

This work was supported by the Alfred Health Physiotherapy Department and was undertaken by the first author while completing a PhD at La Trobe University, supported by Summer Foundation, Melbourne, Australia.

References

1. Shaikh NM, Kersten P, Siegert RJ, Theadom A. Developing a comprehensive framework of community integration for people with acquired brain injury: a conceptual analysis. Disability Rehabil. 2019;41:1615–31. doi:10.1080/09638288.2018.1443163.
2. Mahar C, Fraser K. Barriers to successful community reintegration following acquired brain injury (ABI). Int J Disability Manag. 2012;6:49–67. doi:10.1375/jdmr.6.1.49.
3. Walsh ME, Galvin R, Loughnan C, Macey C, Horgan NF. Factors associated with community reintegration in the first year after stroke: a qualitative meta-synthesis. Disability Rehabil. 2015;37 (18):1599–608. doi:10.3109/09638288.2014.974834.
4. Brookfield K, Mead G. Physical environments and community reintegration post stroke: qualitative insights from stroke clubs. Disability & Soc. 2016;31(8):1013–29. doi:10.1080/09687599.2016.1223606.
5. Ylvisaker M, Mcpherson K, Kayes N, Pellett E. Metaphoric identity mapping: facilitating goal setting and engagement in rehabilitation after traumatic brain injury. Neuropsychological Rehabil. 2008;18 (5–6):713–41. doi:10.1080/09602010802201832.
6. Douglas J. 'The things that help, the things that get in the way': working together to improve outcome following acquired brain injury, presidential address. Brain Impairment. 2018;19(3):258–69. doi:10.1017/BrImp.2018.17.
7. Douglas J. Loss of friendship following traumatic brain injury: a model grounded in the experience of adults with severe injury. Neuropsychological Rehabil. 2020;30(7):1277–302. doi:10.1080/09602011.2019.1574589.
8. Teasell R, Rice D, Richardson M, Campbell N, Madady M, Hussein N, Maurie-Fernandez M, Page S. The next revolution in stroke care. Expert Rev: Neurother. 2014;14(11):1307–14. doi:10.1586/14737175.2014.968130.
9. Togher L, Douglas JM, Turkstra L, Welch P, Janzen S, Harnett A, Kennedy M, Kua A, Patsakos E, Ponsford J, et al. INCOG 2.0 guidelines for cognitive rehabilitation following traumatic brain injury, part IV: cognitive-communication and social cognition disorders. J Head Trauma Rehabil. 2023;38(1):65–82. doi:10.1097/HTR.0000000000000835.
10. Mountain A, Lindsay MP, Teasell R, Salbach NM, de Jong A, Foley N, Bhogal S, Bains N, Bowes R, Cheung D, et al. Canadian stroke best practice recommendations: rehabilitation, recovery, and community participation following stroke. Part two: transitions and community participation following stroke. Int J Stroke. 2020;15(7):789–806. doi:10.1177/1747493019897847.
11. National Institute for Health and Care Excellence. Rehabilitation after traumatic brain injury (NG211). London: NICE; 2022 [accessed 2024 Apr 24]. https://www.nice.org.uk/guidance/ng211/chapter/Recommendations#supporting-access-and-participation-in-education-work-and-community-adjustment-and-goal-setting.
12. Flores- Sandoval C, Cao P, MacKenzie H, Harnett A, Marshall S, Teasell R. Community reintegration post acquired brain injury. In: Teasell R, Cullen N, Marshall S, Harnett A Bayley M, editors. Evidence-based review of moderate to severe acquired brain injury. London, Ontario, Canada: ERABI Group; 2023. p. 1–125.
13. Stroke Foundation. Clinical guidelines for stroke management. Australia: Informme; 2023 [accessed 2024 Apr 24th]. https://informme.org.au/guidelines/clinical-guidelines-for-stroke-management.
14. Mayo NE, Anderson S, Barclay R, Cameron JI, Desrosiers J, Eng JJ, Huijbregts M, Kagan A, MacKay-Lyons M, Moriello C, et al. Getting on with the rest of your life following stroke: a randomized trial of a complex intervention aimed at enhancing life participation post stroke. Clin Rehabil. 2015;29(12):1198–211. doi:10.1177/0269215514565396.
15. Nalder E, King G, Hunt AW, Hartman L, Szigeti Z, Drake E, Shah R, Shahzad M, Resnick M, Pereira G, et al. Indicators of life success from the perspective of individuals with traumatic brain injury: a scoping review. Disability Rehabil. 2023;45(2):330–43. doi:10.1080/09638288.2021.2025274.
16. Ezekiel L, Collett J, Mayo NE, Pang L, Field L, Dawes H. Factors associated with participation in life situations for adults with stroke: a systematic review. Archiv Phys Med Rehabil. 2019;100:945–55. doi:10.1016/j.apmr.2018.06.017.
17. Mahar C, Fraser K. Strategies to facilitate successful community reintegration following acquired brain injury (ABI). Int J Disability Manag. 2012;6:68–78. doi:10.1375/jdmr.6.1.68.
18. Teasdale G, Jennett B. Assessment of coma and impaired consciousness: a practical scale. The Lancet. 1974;304(7872):81–84. doi:10.1016/s0140-6736(74)91639-0.
19. Anderson S, Whitfield K. Social identity and stroke: 'they don't make me feel like, there's something wrong with me'. Scand J Caring Sci. 2012;27:820–30. doi:10.1111/j.1471-6712.2012.01086.x.
20. Tate RL, Lane-Brown AT, Myles BM, Cameron ID. A longitudinal study of support needs after severe traumatic brain injury. Brain Inj. 2020;34(8):991–1000. doi:10.1080/02699052.2020.1764101.
21. Gerber GJ, Gargaro J, McMackin S. Community integration and health-related quality of life following acquired brain injury for persons living at home. Brain Inj. 2016;30(13–14):1552–60. doi:10.1080/02699052.2016.1199896.
22. Abrahamson V, Jensen J, Springett K, Sakel M. Experiences of patients with traumatic brain injury and their carers during transition from inpatient rehabilitation to the community: a qualitative study. Disability And Rehabil. 2017;39(17):1683–94. doi:10.1080/09638288.2016.1211755.
23. Fleming J, Braithwaite H, Gustafsson L, Griffin J, Collier AM, Fletcher S. Participation in leisure activities during brain injury rehabilitation. Brain Inj. 2011;25(9):806–18. doi:10.3109/02699052.2011.585508.

24. Govender P, Naidoo D, Bicknell K, Ayob Z, Message H, Njoko S. 'Non one prepared me to go home': Cerebrovascular accident survivors' experiences of community reintegration in a peri-urban context. Afr J Primary Health Care & Fam Med. 2019;11:1–8. doi:10.4102/phcfm.v11i1.1806.
25. Tse T, Lentin P, Douglas J, Carey LM. Understanding activity participation 3-months after stroke: a mixed methodology study. Disability And Rehabil. 2022;44(12):2868–78. doi:10.1080/09638288.2020.1849429.
26. Turner B, Ownsworth T, Cornwell P, Fleming J. Reengagement in meaningful occupations during the transition from hospital to home for people with acquired brain injury and their family caregivers. The Am J Occup Ther. 2009;63:609–20.
27. Verberne DPT, Post MWM, Kohler S, Carey LM, Visser-Meily JMA, van Heugten CM. Course of social participation in the first 2 years after stroke and its associations with demographic and stroke-related factors. Neurorehabil and Neural Repair. 2018;32(9):821–33. doi:10.1177/1545968318796341.
28. Eliassen M, Arntzen C, Nikolaisen M, Gramstad A. Rehabilitation models that support transitions from hospital to home for people with acquired brain injury (ABI): a scoping review. BMC Health Serv Res. 2023:23. doi:10.1186/s12913-023-09793-x.
29. UN General Assembly. Convention on the rights of persons with disabilities: resolution adopted by the general assembly. United nations. 2007 [accessed 2024 Apr 24]. https://www.un.org/en/development/desa/population/migration/generalassembly/docs/globalcompact/A_RES_61_106.pdf.
30. Turner-Stokes L, Pick A, Nair A, Disler PB, Wade DT. Multi-disciplinary rehabilitation for acquired brain injury in adults of working age. Cochrane Database Systematic Rev. 2015:12. doi:10.1002/14651858.CD004170.pub3.
31. World Health Organization (WHO). International classification of functioning disability and health. Geneva: WHO; 2001.
32. Currie S, Douglas J, Winkler D. 'Whats next?' the journey from hospital to community engagement from the perspectives of adults following severe acquired brain injury: a scoping review protocol. BMJ Open. 2022;12(9). doi:10.1136/bmjopen-2022-064226.
33. Charmaz K. Constructing grounded theory: a practical guide through qualitative analysis. London: Sage; 2006.
34. Charmaz K. Constructing grounded theory. 2nd ed. Los Angeles: Sage; 2014.
35. Charmaz K, Belgrave LL. Modern symbolic interaction theory and health. In: Cockerham WC, editor. Medical sociology on the move: new directions in theory. New York (NY): Springer; 2013. p. 11–40.
36. Liamputtong P. Qualitative research methods. 4th ed. Australia & New Zealand: Oxford University Press; 2012.
37. Uniform Data System for Medical Rehabilitation. The FIM System® clinical Guide, version 5.2. Buffalo: UDSMR; 2009.
38. Liamputtong P. The science of words and the science of numbers: research methods as foundations for evidence-based practice in health. In: Liamputtong P, editor. Research methods in health: foundations for evidence-based practice. 2nd ed. London: Oxford University Press; 2013. p. 3–24.
39. Leeson R, Collins M, Douglas J. Finding goal focus with people with severe traumatic brain injury in a person-centered multi-component community connection program (M-ComConnect). Front Rehabil Serv. 2021;2:1–14. doi:10.3389/fresc.2021.786445.
40. Vasileiou K, Barnett J, Thorpe S, Young T. Characterising and justifying sample size sufficiency in interview-based studies: systematic analysis of qualitative health research over a 15-year period. BMC Med Res Methodol. 2018;18(148). doi:10.1186/s12874-018-0594-7.
41. Doig E, Prescott S, Pick V, Turner B, Suleman S, Douglas D, Foster M. Normalising interdisciplinary role-based goal setting in inpatient brain injury rehabilitation: reflections and recommendations of clinicians. Disability And Rehabil. 2023;45(4):673–83. doi:10.1080/09638288.2022.2040612.
42. Honan CA, McDonald S, Tate R, Ownsworth T, Togher L, Fleming J, Anderson V, Morgan A, Catroppa C, Douglas J, et al. Outcome instruments in moderate-to-severe adult traumatic brain injury: recommendations for use in psychosocial research. Neuropsychological Rehabil. 2019;29(6):896–916. doi:10.1080/09602011.2017.1339616.
43. Prescott S, Fleming J, Doig E. Goal setting approaches and principles used in rehabilitation for people with acquired brain injury: a systematic scoping review. Brain Inj. 2015;29(13–14):1515–29. doi:10.3109/02699052.2015.1075152.
44. Wade D. Rehabilitation – a new approach. Overview and part one: the problems. Clin Rehabil. 2015;29(11):1041–50. doi:10.1177/0269215515601174.
45. Bellon M, Kelley J, Fisher A. "The bucket of gold at the end of the rainbow": personal experiences of hope after acquired brain injury. Disability And Rehabil. 2022;44(25):7974–84. doi:10.1080/09638288.2021.2005162.
46. Carlson PM, Boudreau ML, Davis J, Johnston J, Lemsky C, Ma M, Minnes P, Smith C. 'Participate to learn': a promising practice for community ABI rehabilitation. Brain Inj. 2006;20(11):1111–17. doi:10.1080/02699050600955337.
47. Fadyl JK, Theadom A, Channon A, McPherson KM. Recovery and adaptation after traumatic brain injury in New Zealand: longitudinal qualitative findings over the first two years. Neuropsychological Rehabil. 2019;29(7):1095–112. doi:10.1080/09602011.2017.1364653.
48. Sansonetti D, Fleming J, Patterson F, Lannin NA, Toglia J. Online awareness: a concept analysis and review of assessment approaches for adults with neurological conditions. Disability Rehabil. 2024;1–16. doi:10.1080/09638288.2024.2338876.
49. Ylvisaker M, Feeney T. Reconstruction of identity after brain injury. Brain Impairment. 2000;1:12–28. doi:10.1375/brim.1.1.12.
50. Williams LM, Douglas JM. It takes two to tango: the therapeutic alliance in community brain injury rehabilitation. Brain Impairment. 2022;23:24–41. doi:10.1017/BrImp.2021.26.
51. D'Cruz K, Unsworth C, Roberts K, Morarty J, Turner-Stokes L, Wellington-Boyd A, Matchado J, Lannin NA. Engaging patients with moderate to severe acquired brain injury in goal setting. Int J Ther And Rehabil. 2016:23. doi:10.12968/ijtr.2016.23.1.20.
52. Leeson R, Collins M, Douglas J. Interventions that aim to increase social participation through recreation or leisure activity for adults with moderate to severe traumatic brain injury: a scoping review. Disability Rehabil. 2023:1–17. doi:10.1080/09638288.2023.2246377.
53. D'Cruz K, Douglas J, Serry T. Humanising brain injury rehabilitation: a qualitative study examining humanising approaches to engagement in the context of a storytelling advocacy programme. Brain Impairment. 2022;23:91–103. doi:10.1017/BrImp.2021.16.
54. Ellis-Hill C, Kayes N, Douglas J. We are human – an invisible and fundamental aspect of rehabilitation in acquired brain injury. Brain Impairment. 2022;23:1–3. doi:10.1017/BrImp.2022.1.
55. Kayes NM, Cummins C, Km M, Worrall L, Bright FAS. Developing connections for engagement in stroke rehabilitation. Brain Impairment. 2022;23:42–59. doi:10.1017/BrImp.2021.27.
56. Wood JP, Connelly DM, Maly MR. 'Getting back to real living': a qualitative study of the process of community reintegration after stroke. Clin Rehabil. 2010;24:1045–56. doi:10.1177/0269215510375901.
57. Maratos M, Huynh L, Tan J, Lui J, Jarus T. Picture this: exploring the lived experience of high functioning stroke survivors using photovoice. Qualitative Health Res. 2016;26(8):1055–66. doi:10.1177/1049732316648114.
58. Panday J, Velikonja D, Moll SE, Harris JE. Experiences of inpatient rehabilitation from the perspective of persons with acquired brain injury. Disability Rehabil. 2021;44:5539–48. doi:10.1080/09638288.2021.1938706.

59. Sarre S, Redlich C, Tinker A, Sadley E, Bhalla A, McKevitt C. A systematic review of qualitative studies on adjusting after stroke: lessons for the study of resilience. Disability Rehabil. 2014;36 (9):716–26. doi:10.3109/09638288.2013.814724.
60. Martin R, Levack WMM, Sinnott KA. Life goals and social identity in people with severe acquired brain injury: an interpretative phenomenological analysis. Disability And Rehabil. 2015;37 (14):1234–41. doi:10.3109/09638288.2014.961653.
61. Ownsworth T. Self identity after brain injury. Hove (UK): Psychology Press; 2014.
62. Allen N, Hevey D, Carton S, O'Keeffe F. Life is about "constant evolution": the experience of living with an acquired brain injury in individuals who report higher or lower posttraumatic growth. Disability Rehabil. 2022;44(14):3479–92. doi:10.1080/09638288.2020.1867654.
63. Ford A, Douglas JM, O'Halloran R. From the Inner circle to rebuilding social networks: a grounded theory longitudinal study exploring the experience of close personal relationships from the perspective of people with post stroke aphasia. Aphasiology. 2023;38:1–20. doi:10.1080/02687038.2023.2185480.