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'Thrown in the deep end': a qualitative study of community participation during inpatient rehabilitation and transition to community living from the perspective of family members of people with severe brain injury

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ABSTRACT

Background. To understand the experience of family members of people with severe acquired brain injury (ABI) as they support their loved one to commence community and social participation during inpatient rehabilitation and transition to the community. **Methods.** Constructivist grounded theory methodology guided the process of data collection and analysis. Data were collected via in-depth interviews using a semi-structured interview guide. **Results.** Eight family members were interviewed, inclusive of five parents and three spouses of people living with severe ABI. The participants' family member with ABI were on average 4 years post-discharge from hospital at the time of the interview. Data analysis produced a core category: 'An arduous journey' and four categories: adjusting to change, overwhelming responsibility, learning on the job and needing people to understand. **Conclusion.** Although family members clearly play an important role in the achievement of community and social participation, the participants of this study identified many factors that impact their experience of supporting positive outcomes. There are important implications for rehabilitation services, such as ensuring families feel welcomed and engaged within rehabilitation, positioning the person with ABI within their family context in rehabilitation, and providing opportunities for supported, meaningful and contextual experiences within rehabilitation.

Keywords: acquired brain injury, community integration, community participation, family members, inpatient rehabilitation, qualitative, social participation, transition.

Introduction

Family members are undeniably important to the lives of people with acquired brain injury (ABI). Inclusive of spouses, parents, siblings and other close social relations, the support they offer practically and emotionally often lay the foundations of rebuilding and reshaping life following the injury (Whiffin *et al.* 2021; Bystrup *et al.* 2023). Severe ABI is a common cause of acquired disability in adults. The physical, cognitive, communication, behavioural and psychosocial changes people experience following an ABI often have a significant impact on their engagement in usual routines, previous life roles and chosen leisure activities (Fleming *et al.* 2011; Abrahamson *et al.* 2017; Verberne *et al.* 2018; Tse *et al.* 2022). Additionally, people often experience disruption to their valued relationships, including within their family circle and wider social networks (Holloway and Tasker 2019; Douglas 2020).

Community and social participation are considered the ultimate goal of rehabilitation (Teasell *et al.* 2014; Shaikh *et al.* 2019; Douglas 2020; Flores-Sandoval *et al.* 2023); however, evidence suggests that inclusive participation in the community continues to be challenging for people following ABI (Anderson and Whitfield 2013; Walsh *et al.* 2015; Maratos *et al.* 2016; Fadyl *et al.* 2019). Integration into the community, including engagement in valued activities, a sense of belonging and maintenance of social connections, is recognised as correlating with life satisfaction, emotional wellbeing and quality of life following ABI (Douglas 2020; Nalder *et al.* 2023). Supporting the return to meaningful community participation for people with brain injury, alongside people they know and trust, is of utmost importance. Article 26 of the United Nations Convention on the Rights of Persons with Disability (UN General Assembly 2007) outlines multidisciplinary rehabilitation should commence at the earliest possible stage, and that social and community integration should be supported. Research demonstrates continued inconsistencies in how rehabilitation services support a successful transition to the community in clinical rehabilitation practice, corroborated by people living with ABI who report continued difficulties with this period (Turner *et al.* 2008; Piccenna *et al.* 2016; Abrahamson *et al.* 2017; Eliassen *et al.* 2023).

Sustaining an ABI not only affects the life course for the person themselves, but also has an enormous impact on those closest to them (Holloway *et al.* 2019; McIntyre *et al.* 2020; Whiffin *et al.* 2021; Stenberg *et al.* 2022). Often responsible for taking on a key support role throughout the recovery journey, many family members assume a commitment to ensuring the wellbeing and support of their loved one. They do this while simultaneously adjusting to the trauma of the injury, sitting in the uncertainty for what the future holds, and often grappling with grief, loneliness and psychological distress, all of which have a significant impact on their own quality of life (Ponsford and Schönberger 2010; Holloway and Tasker 2019; Holloway *et al.* 2019). In the immediate period following an injury, the focus within hospitals tends to be on the person with ABI (Holloway *et al.* 2019). This focus often continues across rehabilitation and into the community, and as a result, health professionals can miss opportunities to consider the impact of the injury on family members or leverage their capacity to support the person with ABI (Fisher *et al.* 2019; Holloway and Tasker 2019; Holloway and Norman 2022). Acknowledging the integral role family members play throughout rehabilitation, and the return to community and social participation, it is vital to determine the needs of the family to be able to successfully provide this support. With previous research demonstrating the overall wellbeing of both the person with ABI and their family members is influenced by maintaining a close social relationship, it is important to optimise efforts to achieve this connection (Douglas and Spellacy 2000). Little is known about family members' experiences of supporting their loved one to commence community participation during inpatient rehabilitation and the early years following brain injury.

The aim of this study is to explore the experiences of supporting community and social participation, from the perspectives of family members of adults with severe ABI, during inpatient rehabilitation and the transition to community living. Our methodology enabled the gathering of co-constructed perspectives, first from the perspective of participants with ABI (Currie *et al.* 2025) and subsequently their family members. Given the proximity of interpersonal relationships and the influence of family members on the return to community living, it is vital to learn from their experiences of supporting their loved ones as they begin to engage in the community, and spend time as a family, or with friends. We also wanted to know what they found helped or hindered their loved one's return to community and social participation.

Methods

Qualitative approach

Given the aim was to develop an understanding grounded in the lived experiences of family members who have supported a loved one to return to community living, constructivist grounded theory methodology was chosen for this study (Charmaz 2006). Constructivist grounded theory methodology is situated within the symbolic interactionist methodological framework (Liamputtong 2013; Charmaz 2014), in which the experiences of the research participants are considered within their social context. Therefore, this methodology allowed the researchers to actively engage with family members to develop an in-depth understanding of their experience of supporting their loved one's return to accessing and engaging in the community. This methodology recognises the data collection and analysis processes are influenced by the co-constructed experiences within the rehabilitation and societal context, as well as the research team's interaction with the data (Charmaz 2014).

Institutional (Hospital and University) ethical approval for this study was obtained on 4 November 2021 (Ethics Project No: 460/21) and the study design was guided by the COREQ checklist (Tong *et al.* 2007). Participants were reminded of the voluntary nature of their participation in the study. Consistent with the ethics approval, a distress protocol and details of support services were provided to each participant in the event of distress associated with the sharing of lived experiences.

Researcher characteristics

Together, the research team brings disciplinary perspectives from physiotherapy, clinical psychology, neuropsychology, speech therapy and occupational therapy. The first author (S. C.) is a female doctoral candidate and senior physiotherapist with >10 years' experience working clinically in specialist ABI rehabilitation. Collectively, the supervisory team (J. D., D. W., K. D.) have extensive experience as qualitative researchers, as well as clinical experience with this population.

Context

Participants for this research were recruited from a specialist, multidisciplinary ABI rehabilitation service, based in a metropolitan city in Australia. For the first study, people who had sustained a severe ABI (stroke, traumatic brain injury, hypoxia) were eligible for participation if they were aged >18 years, 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 tumour resection were not included, as the outcome trajectory often differs and the associated focus of intervention is variable. Severity was determined as indicated by Glasgow Coma Scale (Teasdale and Jennett 1974) score of 3–8 at the time of acute injury, and a score of ≤3 in a cognitive, communication or mobility domain on the Functional Independence Measure (Uniform Data System for Medical Rehabilitation 2009) at the time of admission to inpatient rehabilitation.

The participants living with ABI were asked to invite a family member to participate in the current study. The family members were eligible to participate in an interview if they were aged <18 years, and had visited the person with ABI weekly during their inpatient rehabilitation admission and continued to have regular contact, including active involvement in their rehabilitation journey and following the transition from hospital to community living.

Sampling strategy

Following identification of family members by the primary participants with severe ABI, a written invitation to participate in the study was sent from the research administrator(s). The research administrators were employees of the health network from which the participants were recruited, with a clinical role and significant experience working with people with ABI. The research administrators were provided with additional training related to the administration tasks of this research study and were not members of the research team.

We prioritised the experience of people following severe ABI as the primary participants; therefore, the number of participants of this study was determined by the number of family members of the primary participants who agreed to participate. This methodology was selected in preference to recruiting family members randomly and missing the opportunity to explore the dyad experience between the family system. Of the invited family members, two declined to participate in the study, with reasons relating to time constraints and distress related to recounting experiences.

Data collection methods and instruments

A semi-structured interview guide was developed for this study. The question design was based on the learnings from people with ABI in a preceding study who shared their experiences of community and social participation (Currie *et al.* 2025). This design allowed the research team to build on the unique experiences within each family relationship (person with ABI and their close other), and gain further insight directly from the family members included within this study. The interview opened with a broad question relating to the activities the participant with ABI previously identified that they engage in alongside their family. This question set the scene for community and social participation, including the primary participant's current levels of participation and the family members experiences of being involved. Additional questions explored areas, such as the experiences of accessing the community during inpatient rehabilitation and following the transition to community living, including reflections on factors that helped their ability to support experiences in the community, as well as factors that got in the way. The closing question asked family members to share any advice they have for a family member who currently has a loved one in inpatient rehabilitation, about how they can support the return to community participation.

Participants were interviewed 1:1 by the first author (S. C.) who has considerable clinical experience working with people following ABI, and their family members within the inpatient and community rehabilitation settings. Each interview was audio recorded and written field notes were completed to capture reflections, such as the participants' level of engagement and emotional response to the interview. No repeat interviews were required. Verbatim transcription of the audio recording 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 generated from the interviews, field notes and memos were analysed following a process of open coding and focused coding (Charmaz 2014) that supported the development of categories and a core concept, grounded in the experiences of family members. At the point of development of the core category, it was deemed that analysis was not revealing further insights and theoretical sufficiency had been achieved (Vasileiou *et al.* 2018). Field notes and a reflective journal were utilised to support the first author's ability to remain open to learning from the specific experiences of the participant groups and served as an audit trail. Lived experience data was central to the analysis processes and the categories generated, which is evidenced through the use of quotatations within the Results section of this paper. Additional quotes related to each category are presented in Supplementary Appendix S1.

Results

Participant characteristics

Eight family members participated in an interview for this study. Interviews were conducted with five parents and

Table 1. Family member participant characteristics.

Variable	Mean, *n* (%)	Range
Gender of participant (*n* = 8)		
Male	5 (62.5%)	
Female	3 (37.5%)	
Relationship to injured person		
Spouse	3 (37.5%)	
Parent	5 (62.5%)	
Gender of injured person (*n* = 7)		
Male	3 (42.9%)	
Female	4 (57.1%)	
Age of injured person (years)	38.6	18–59
Mechanism of injury		
Traumatic brain injury	2 (28.6%)	
Stroke	4 (57.1%)	
Hypoxia	1 (14.3%)	
Length of stay in inpatient rehabilitation for injured person (months)	8.9	4–12
Discharge destination		
Home	5 (71.4%)	
Shared supported accommodation	1 (14.3%)	
Residential aged care facilities	1 (14.3%)	
Time since discharge at interview (months)	42.1	24–60

three spouses between December 2021 and December 2022. Two participants were interviewed in person, at their home, and six via videoconferencing. The interviews lasted between 28 and 136 min, with an average length of 61 min. Table 1 reports the characteristics for the participant group.

Across the participants' family members with severe ABI, each had a score of 1 on the mobility, cognition and communication domains of the Functional Independence Measure at the time of admission to inpatient rehabilitation. At the time of interview, each required support related to multiple functional areas due to cognitive, communicative and physical disability. Six people required a wheelchair for all community access, five had a severe communication disability, including dysarthria or aphasia, and five required the support of a legal guardian given their cognitive disability.

Analytical findings

The aim of this study was to gather family members' experiences of supporting their loved one, after sustaining an ABI, as they adapt to life in the community, including community and social participation. Following constructivist grounded theory methodology, analysis resulted in the development of a core category and four related categories (Fig. 1).

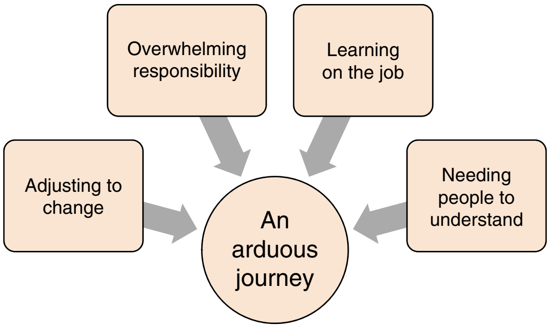

Fig. 1. Conceptualisation of the experiences of inpatient and community rehabilitation from the perspectives of family members of people with ABI. Description: the core category is represented as a circle and description of the interactional categories are in squares.

Core category: an arduous journey

The core category, 'an arduous journey', captures the complexity of the experience for families supporting their loved one during inpatient rehabilitation and the transition to community living. Family members recognised the importance and value of community and social participation experiences for their loved one; however, there were many factors along the course of the journey that got in the way of being able to facilitate and support positive experiences within the community context.

Analysis of the data generated four categories that further describe the course of the arduous journey for family members. These categories are: adjusting to change, overwhelming responsibility, learning on the job and needing people to understand.

Category 1: adjusting to change

Reflected within the families' stories of the journey through inpatient rehabilitation and the transition to the community was the emotional rawness experienced because of the abrupt change to life as they knew it. The nature of change encompassed the change to the person they love, a change within their relationship and a change to their vision for the future. This was summarised by Ethan, whose wife, and mother of their two children, sustained a severe stroke at age 46 years, 'It's going to be life changing, not only for her, but for those people close to her, so you just have to be prepared. The initial struggle, I went under a bit of depression, I couldn't accept that this had happened to us… to overcome the stress and the daily challenges. Then I think the most important thing is the acceptance, this is what it is now, this is the life you're going to lead, from here on, it's totally like 360 degrees from before, but at the end of the day, you just have to get on with life, so just go on and just treasure every single moment'. Kelly's mum also shared her personal journey when adjusting to the change, 'Kelly was as normal as can be for 38 years, and that's our normality, we've not experienced any of this, and all of a sudden in the last 5 years, we've just been thrown in the deep end'.

The family members expressed that the magnitude of change, and the subsequent need for an adjustment to these changes, influenced when they were able to start supporting their family member to engage socially and participate in the community with their loved one. They felt they needed to get used to the 'new normal' following the injury of their loved one, before being ready to focus on social and community participation. Related to this, many of the family members reflected on the adjustment required to shift their expectation of their own relationship with their loved one 'You know that your relationship will be changed forever' (Luke's mum). while also supporting other members of the family to adjust 'I am telling them [their two sons aged 18 and 20 years] that this is our new norm, so we just have to accept it' (Divina's husband). In the early stages, participants described being heavily dependent upon the guidance of the healthcare team regarding the next steps for their loved one as they navigated this period of adjustment. Following discharge from hospital, the need for adjustment continued to impact the family members' capacity to support community and social participation. Families consistently described this transition period as overwhelming, stressful and often chaotic. They were adjusting to a new routine with their loved one at home, and felt they should be celebrating that the hospital stay was over; however, they were instead faced with the enormity of their new situation. Malcolm's wife summarises the conflicted feelings she experienced, 'It was awful, I didn't want him to come home. I did, because I really missed him, but I didn't, because I wanted it set up properly and I felt like I was being bombarded…It's not till you actually do it then you realise what it is like'.

In coming to terms with and adjusting to their loved one's disability and subsequent support needs, each of the family members described their need to adjust to sharing their home and their private space with paid support workers (carers). They described often feeling conflicted, where they acknowledged this was best for their loved one; however, also reflected on the adjustment required from their family unit to having a stranger in their home. Malcolm's wife shared her reflection of the impact of a paid support team on her privacy 'before all this happened, I was extremely private…I didn't know how it was going to look, and I just felt it was like an invasion, and I still do'. This sentiment is shared by Divina's husband 'Like from my perspective there is less privacy now, because each and every day there is somebody in our house, but for Divina it's good, because she is well looked after by the carers'. Reflected within the experiences shared, there are layers of adjustment as family members begin to come to terms with the changes that have occurred to their life journey.

Category 2: overwhelming responsibility

When sharing their experiences of supporting their loved one to engage in the community, the family members shared the immense sense of responsibility they feel for their loved one. This responsibility was defined as a need to protect the emotional wellbeing and safety of their loved one when accessing the community, as well as a broader sense of responsibility. For example, family members said they needed to advocate for their needs, provide practical support, as well as being responsible for overseeing the management of support and therapy programs. The weight of this responsibility is encapsulated by Kellys dad 'it's just frustrating, because you feel as though it's all on you', and summarised by Luke's mum 'for me, I'm a mum, and a carer, I am also a coordinator and all that stuff'.

When exploring the responsibility of keeping their loved one safe within the community, many family members described a fear of something going wrong and second guessing their own skills to provide appropriate support. For example, Freya's husband shared his experience of resisting the opportunity to support Freya's desire to attend an appointment at her hairdresser's during her inpatient admission, 'I mean I guess I was worried that something happened and whether I would be able to handle it'. This concern fuelled a reluctance to explore the community together for many months following Freya's discharge from hospital.

Each of the family members recognised the value in supporting their loved one to access the community and engage in the activities they enjoy, while describing that this responsibility was often theirs to carry. Within their experiences, there were opportunities to connect as a family and support their loved one's overall wellbeing. Luke's mum shared her perspective of supporting her son to access the community during his 12-month inpatient rehabilitation admission, and the positive influence this had in supporting connection between Luke and his siblings. She voiced 'they [his sister, aged 16 years, and brother, aged 14 years] could see that he's still able to be their brother and you can do normal things… so I think having been able to take him out of that environment of the rehab centre, yeah just you know, so they could interact normally as they would with their brother and yeah we can go to the movies, we can go to the beach, we can go out for tea'. She went on to share the value these outings also had on her son's wellbeing, during his rehabilitation admission, 'I think it's important for their wellbeing as well to show them what they can still do, maybe they can't walk anymore, but he can still go to the movies, you can still go and get your parma. I think it's important that it is an option for people, to go out even if it is just for a walk around the block and stop for a cheeky slushie at 7-Eleven, you know, just because they're working really hard to get back to some kind of level of function and independence'.

Category 3: learning on the job

During inpatient rehabilitation, continuing through to community living, the family members shared that they had been required to learn many skills to adequately support their loved one. This impacted their capacity to focus on supporting community and social participation. They were initially focused on and prioritised the development of skills for practical day to day tasks, such as mobility transfers and toileting. In addition, they needed to learn how to complete all the required administrative tasks. Malcolm's wife and Kelly's parents provided examples of these: 'all of that financial stuff and legal stuff'; 'paperwork for NDIS [National Disability Insurance Scheme] and Centrelink [government disability payment]'.

Following the transition home, this learning continued in various ways. Family members expressed a need to learn how to navigate and set-up the supports needed upon discharge, including paid support workers and allied health therapists. This learning also involved the ability to build a sense of routine for their loved one and start to set expectations for those working with them.

To support this learning, the family members voiced that they needed the support of the health professionals. For example, Kelly's dad shared 'you need professionals to be able to give you information, because sometimes when you're in it, you feel you're the only ones in it'. There was variability within the participants' experiences of receiving the education they needed, with some of the family members feeling confident to engage in their new supportive role, where they had adequate education from health professionals and had been able to practice activities to build their skills. Whereas others described feeling unequipped as they embarked on their new role. Charles' dad shared advice for health professionals, 'Don't forget the family, the family is all part of the parcel, so just don't forget the family and don't treat them like idiots, they don't know what's going on, so they need to be educated'.

With regard to learning the skills related to community participation, there were examples of experiential learning for family members. Two of the family member participants of this study actively led and embraced opportunities to support their loved one to access the community during inpatient rehabilitation. They talked about the benefit of these 'hands on' experiences for problem solving and building confidence in their own skills to support their loved one to continue to be engaged and connected within the community. Sophie's dad spoke of his experience of working with his daughter to learn together within the community environment, 'Being able to practice the things I needed to be able to do meant I felt prepared. You learnt how to adapt, like gutters for example, I nearly chucked her out the wheelchair a couple of times. Initially, I was nervous when I first started taking her out, but we got the hang of it. Sophie and I were a team, we worked it out together'. Additionally, Luke's mum described how opportunities to engage in the community with her son helped her build confidence in her own ability, which aided her willingness to encourage Luke to continue community participation once he returned to his local community. She shared, 'eventually you know we got to the point where we could take him shopping and take him out for pizza and take him out into the community, which is good for me to be able to do that as well, so that we knew when we got home, we can do this'.

Category 4: needing people to understand

Reflecting on their loved one's journey to community and social participation, including socialising with friends, the family members shared the negative impact of a lack of understanding of brain injury by the general society. They shared their personal experiences of the new and often isolating encounters they had within the community, and how these impacted their loved one's ability to fully engage in the community and maintain meaningful connections with others.

Many family members expressed one of the initial challenges was the experience of people in the community staring at their loved one. From the stories shared, this was particularly confronting, and families expressed a need to protect their loved one from this unwanted attention. Subsequently, several family members described a desire to humanise their loved one within society. For example, Kelly's mum shared 'sometimes I want to put a sign on her and say you didn't know her before'. This was expanded on by Luke's mum, who expressed the confidence she gained with greater exposure to the general community, 'I felt like I needed to tell his story. This is my son, he's had an accident, he's in a wheelchair, big deal, just get out of my way'.

Maintaining friendships and socialising with friends was identified as challenging, and families spoke to a lack of understanding of disability being a barrier. The family members reflected on the influence of the lack of general societal understanding of brain injury, which is inclusive of the friends and, therefore, significantly impacts their ability to spend time together. This is summarised by Charles' dad, 'the friends aren't around, and I think maybe it's too much for them just to see Charles the way he is or to interact with him now…they didn't know how to treat someone with a brain injury. They were always under the impression that he was going to be the same and expected him to be able to do pretty much everything that he could, which he can't because of the brain injury'. In addition, family members described the emotional adjustment that friends experienced in the weeks and months following the ABI. Families shared experiences of an initial shock response from friends, where many of the friends either distanced themselves or required additional time to process and begin to accept. Luke's mum shared her perspective, 'they are getting over the shock that 'oh my God, this happened to my friend', you know they are also grieving'.

Invitations to socialise were seldom extended by friends, with uncertainty regarding capability and a lack of confidence being identified as barriers. Luke's Mum shared her experience, 'You know he might throw a party, and they will come, it's not like that they don't come, but he has to make the invitation, they don't feel that they can just call him'. Kelly's mum reflected on a conversation she had with a group of Kelly's close friends, 'The girls said to me, 'The dynamics have changed, because Kelly was the talker, we'd listen and laugh and everything like that. We've now got to be the talkers', and that's put a lot of pressure on them'. These examples demonstrate how the adjustment and change in relationship dynamic can impact friends' availability to engage socially with the person with ABI. There were many examples of friends withdrawing, creating uncertainty regarding the stability of friendship groups, and fewer opportunities for community and social engagement.

Another factor identified by family as impacting their loved one's return to community and social participation was support workers' understanding of the wider implications of the ABI. To be able to successfully support engagement in the community, family members felt the support workers needed to understand how to communicate and engage with the person with brain injury in a meaningful way and, therefore, be able to support social communication within society, including with friends. The family members identified this understanding as a gap that has a negative impact on the success of community and social participation. For example, Charles' dad feels, 'there's not enough education about brain injury, or brain injured people and what they need and how to sort of treat them'. Additionally, Luke's mum felt the support workers had the knowledge regarding how to support activities of daily living and home-based tasks; however, they did not have a full appreciation of what support her son would need to be able to meet up with a friend for dinner or support him to make decisions about what valued activities he would engage in across the week. She shared, 'They knew all about how to help him shower and wheel his wheelchair and help him make a cheese sandwich that sort of stuff, but that more brain, that thinking functioning stuff, they didn't know'. The time taken to support the development of support workers and for them to get to know each other heavily impacted the timely return to community participation.

Discussion

The purpose of this study was to gain an understanding from family members of adults with severe ABI, regarding their experiences of supporting the commencement of community and social participation, during inpatient rehabilitation and the transition to community living. The stories generously shared by the participants of this study show that the experiences of family members have influenced the journey to community participation for people following ABI. Analysis of the data exposed the personal journey the family members are on as they are adjusting to change, wearing the overwhelming responsibility, learning on the job and needing people to understand the impact of the ABI. The findings highlight that family members recognised the value of community and social participation for their loved one's recovery and overall wellbeing; however, they identified barriers to achieving this. As these data were collected alongside the lived experiences of people with severe ABI, it is advantageous to contextualise the experiences captured, which adds to the depth of understanding of the rehabilitation landscape related to community and social participation. The family members' perspectives provide valuable insights into the role rehabilitation services can play in supporting the goal of achieving meaningful participation for people following ABI.

First, the strength and resilience demonstrated by the family members in this study is profound and must be acknowledged. Alongside this strength was frustration, challenge and uncertainty. Echoed in the existing literature, these data tell the story of how the brain injury not only impacts the person with ABI, but also has a significant rippling impact on how a family functions (Ponsford and Schönberger 2010; Checklin *et al.* 2020). In addition, these data demonstrate the demands placed on the key family members, demands that feel excessive and overwhelming. Given the challenges family members experienced as they started community and social participation, the need for family-focused rehabilitation is highlighted. Focusing on the person with brain injury within their family context is important to support collaboration, strengthen resilience and build the competence of those who will provide informal support to the person living with ABI into the future (Butera-Prinzi *et al.* 2016; Fisher *et al.* 2019; Holloway and Tasker 2019; McIntyre *et al.* 2020; Dawes *et al.* 2022; Jenkin *et al.* 2023). Supported within existing literature, family-focused rehabilitation, where family members are welcomed and engaged in rehabilitation, fosters trust, builds strong therapeutic relationships and supports capacity building. It is vital for rehabilitation services to have an understanding of the individual experiences of family members. Additional research identifies the benefit of health professionals validating the experiences of emotional turmoil, which often present, while encouraging family members to seek support for their own wellbeing (Holloway and Tasker 2019; McIntyre *et al.* 2020).

The results of this study also point to the importance of supporting both the person with ABI and their families to engage in shared activities within the community during rehabilitation. Mirroring the needs expressed by people with ABI in the preceding study (Currie *et al.* 2025), the provision of opportunities for meaningful community and social participation were viewed as important by family members. By providing opportunities for engagement in meaningful activities, alongside the people identified as important to the person with ABI (including spouses, children, siblings, extended family, friends), rehabilitation services may help foster confidence, support connection and encourage a focus on the person's strengths (Makela 2017; Fisher *et al.* 2019; Whiffin and Ellis-Hill 2022; Bystrup *et al.* 2023).

Within these data, family members described the need for people to accept their loved one, and understand the changes that have occurred due to the brain injury. This finding builds on the perspectives of the participants with ABI who reported being accepted and valued by society was an important factor impacting their willingness to engage in the community (Currie *et al.* 2025). In the stories family members shared of their first outings into the community with their loved ones, there was a passionate desire to tell their story and humanise their loved one within society. Each of the family members showed immense resilience in the face of the perceived stigma. Those who continued to support their loved one within the community often demonstrated defiance, built confidence and at times bravely requested the general public to 'mind their own business'. The provision of supported opportunities to experience the community while in rehabilitation may enable family members to begin the process of adjustment to their loved one's acquired disability and empower them with strategies when faced with the general public (Douglas 2020; Leeson *et al.* 2024). In addition, community participation increases the exposure of people with disability to community spaces and supports connection within society.

Similarly, it was highlighted that there is a need for people to be accepted and humanised across the continuum of rehabilitation and community contexts, including by health professionals and support workers. Family members reported that support workers had a significant influence on community and social participation outcomes. They gave examples where they felt that the support workers did not have an adequate understanding of the unique needs of their loved one. Family members specifically wanted support workers to understand who their loved one is, what is important to them, the journey they have been on, including the impact of the ABI, and their goals for the future. Evidence from a recent study shows the need for support workers to recognise the person as an individual, with specific needs and preferences (Topping *et al.* 2024). The current study extends this concept to understanding the individual needs of the family, recognising every version of family is unique. To facilitate humanistic and strength-based relationships, evidence supports the use of narrative stories. Within clinical practice, a narrative resource could be developed by the person with ABI, alongside their family and rehabilitation team, in preparation for discharge (Bellon *et al.* 2022; D'Cruz *et al.* 2022; Ellis-Hill *et al.* 2022; Holloway and Ellis-Hill 2022; Kayes *et al.* 2022; Whiffin and Ellis-Hill 2022; Williams and Douglas 2022).

Participant-led videos is an intervention that supports people with disability to produce a short video that communicates who they are, their support needs and preferences, and their personal goals for the future (Douglas *et al.* 2022). This resource could also be used to clarify the role support workers might play in supporting a cohesive transition to community living. There may also be a need for co-designed resources that assist people with disability and families to set up and manage support workers in their home in a way that sets clear boundaries and maximises privacy for families. Rehabilitation teams can provide opportunities for support workers to spend time building positive relationships with the family system, prior to returning to the community, and therefore enable a smooth transition (Topping *et al.* 2024). Investing in this prior to discharge from hospital may support a pathway that facilitates meaningful and positive opportunities for community and social participation; however, for this to be implemented, this relies on support workers being funded prior to discharge.

A consistent thread across the data was the need for supported opportunities for learning. Family members describe the volume of learning required from them to be able to successfully support their loved one, where they felt that they had taken on a new role with no clear role description, and there was uncertainty regarding what was expected of them. There was a sense from the stories shared that several of the family members felt they had to learn on the job and work it all out alone. Interdisciplinary clinical practice guidelines (Mountain *et al.* 2020; NICE 2022; Stroke Foundation 2023; Togher *et al.* 2023) recommend the provision of education and carer training to family members in the inpatient setting, in preparation for discharge. To name a few, this includes activities of daily living, mobility recommendations, dietary modification and behavioural support. Within the community context, we know that there is a plethora of additional aspects to consider when supporting a person with ABI to return to community and social participation. This can include the use of communication devices, supporting community mobility, social cognition and addressing safety considerations, particularly when people require power wheelchairs or require tracheostomy care. It is important for rehabilitation teams working with the families to have an understanding that this volume of learning can feel overwhelming, and the weight of responsibility is heavy, which may result in a resistance to take opportunities to access the community. With so much to consider, alongside the responsibility for their loved one, there comes an immense cognitive overload, which ultimately reduced their bandwidth to even consider community and social participation.

There was evidence of the benefits of experiential learning, as a few of the family members did take steps to initiate community access during inpatient rehabilitation. These experiences empowered them to practise together, gain hands-on experience, build confidence in their own abilities and enable this to continue when they left hospital. This highlights the need for rehabilitation services, across inpatient and community, to support opportunities for family and friends to master their new role alongside their loved one. Working alongside the person with ABI, their family and social networks, building an understanding of where they are on their journey of learning, taking opportunities to share interdisciplinary education – which is bespoke and well considered – while creating space for an open dialogue regarding specific concerns and risks potentially supports the confidence to 'give it a go'. This increases the likelihood of this learning being translated across contexts, including when transitioning to community participation (Carlson *et al.* 2006; Gagnon *et al.* 2016; Ghazzawi *et al.* 2016; Holloway and Ellis-Hill 2022). These positive shared experiences may reduce the risk of the distancing of friends, instead supporting the maintenance of those valued family and friend connections, and provide the opportunity to create a more positive narrative, where there is hope for the future (Butera-Prinzi *et al.* 2016; Douglas 2020; Ylvisaker and Feeney 2000; Douglas 2018; Kayes *et al.* 2022; Leeson *et al.* 2024).

Ultimately, the message from the lived experience is that family members are on their own journey as they navigate life following a loved one sustaining a brain injury. This is a journey that belongs to both people living with ABI and their family members, with clear connections reflected within the experiences captured within this paper and the preceding paper (Currie *et al.* 2025). Family members are integral to achieving positive participation outcomes; therefore, it is important to appreciate factors that influence their capacity to support their loved one. By supporting opportunities for community and social participation, rehabilitation services can create space for people with ABI, alongside their family to build the skills required to construct a positive and inclusive life following ABI.

Limitations and future research

Although the results of this study clearly indicate the arduous journey family members experience as they support community and social participation across the rehabilitation continuum, it is appropriate to recognise the potential limitations of this study. A key limitation to this study is the sample size, as this was determined by the number of consenting family members identified by the 13 primary participants with ABI. Despite the small sample, there were sufficient data to gain clear convergence within the experiences of family members.

The sample range was an additional limitation, with no siblings or extended family included. It is also important to note that not all people with ABI have committed family members who can provide support during rehabilitation. To meet eligibility criteria, this group of participants visited their family member at least weekly during inpatient rehabilitation; therefore, they were inherently committed and involved, and this reduces the range of perspectives we were able to study.

A further limitation is that it is only representative of the primary participants, and their identified family members, who experienced rehabilitation at one specialist site in metropolitan Australia, impacting generalisation of the experiences analysed within these data. Additionally, within the Australian context, there is access to lifelong support for people following ABI, through the National Disability Insurance Scheme and Transport Accident Commission, which impacts generalisation of findings across contexts.

As we did not purposively sample culturally diverse groups, only one participant was not born in Australia, and we did not have Aboriginal or Torres Strait Islander representation. This points to the need for planned and systematic evaluation of the impact of culture on the experiences of community and social participation following ABI.

Due to the relational nature of rehabilitation, it is important to understand the landscape across the relational aspects that exist and the policies that drive rehabilitation delivery. The next step is to gather the experiences of health professionals regarding their experiences of supporting community and social participation across the continuum and the influencing factors. The research team will subsequently utilise each of the perspectives to build a comprehensive understanding, through the comparing and contrasting of experiences across key interactions. The overall aim is to utilise the experiences of people with severe ABI and their family members to inform the development of processes and procedures within rehabilitation to support positive community and social participation outcomes.

Clinical implications

Analysis of personal accounts of the rehabilitation journey from family members' perspectives offers invaluable insights about the pathway through inpatient and community rehabilitation. The results suggest several practice relevant implications to support preparedness for community and social participation, these include:

- Rehabilitation across the continuum should be focused on the person with ABI within their family context, welcoming family and friends to participate in rehabilitation;
- Acknowledging the magnitude of responsibility being carried by the family and the resultant impact on their capacity to provide support across the rehabilitation journey;
- Setting participatory goals within rehabilitation, and exploring opportunities for meaningful, contextual community experiences to empower people, alongside their friends and family;
- Facilitate humanistic and strength-based relationships within therapeutic teams, social networks, family and community supports, which develop a shared understanding of the individual needs of the person with ABI, with the goal of facilitating a positive transition to community living.

Conclusion

In summary, community and social participation is a human right, and is recognised as the ultimate goal rehabilitation teams are working towards following ABI. Although family members clearly play an important role in the achievement of community and social participation outcomes, the participants of this study identified many factors that impact their experience of supporting community and social outcomes for their loved ones.

Effective rehabilitation services work alongside people with ABI and their family members to create meaningful, positive opportunities for contextual experiences of community and social participation. Prioritising the facilitation of these experiences, across the continuum, is important to support people with severe ABI to be included and connected to the community, alongside those who are important to them.

Supplementary material

Supplementary material is available online.

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