




ORIGINAL ARTICLE

# Mixed methods study to understand the experiences of adults with acquired brain injury and their family members who receive specialised rehabilitation

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## Abstract

**Background and Aim:** Rehabilitation therapy is a key part of the recovery pathway for people with severe acquired brain injury (ABI). The aim of this study was to explore inpatients' and their family members' experiences of a specialist ABI rehabilitation service.

**Methods:** A cross sectional, prospective mixed method study was undertaken at a metropolitan specialist ABI rehabilitation unit in Victoria, Australia. All inpatients and their family members of the service were invited to complete a satisfaction survey. Employing purposive sampling, semi-structured interviews were conducted with inpatients and/or their family members.

**Results:** In total, 111 people completed the satisfaction survey and 13 were interviewed. High levels of satisfaction with the specialist service were reported; the majority of inpatients (74%) and family members (81%) rated the overall quality of care received in the service as 'high' or 'very high'. Interviews revealed four main themes: (i) satisfaction with rehabilitation services, (ii) inconsistent communication, (iii) variable nursing care, and (iv) strengths and weakness of the rehabilitation environment. Overall, important components of a positive experience were being involved in decision making and discharge planning, effective communication and information processes, and being able to form therapeutic relationships with staff. Key sources of dissatisfaction for inpatients and family members related to inconsistency in care, accessing information about treatments in a format easily understood, and communication.

**Conclusion:** Specialised rehabilitation is valued by inpatients and their family members alike. The findings highlight the importance of exploring inpatient experiences to optimise service delivery in a tailored, specialised rehabilitation programme.

**Keywords:** Rehabilitation; satisfaction; consumer; quality; interview; survey

## Introduction

Following an acquired brain injury (ABI), cognitive, behavioural, physical, emotional and communication issues limit activity participation in many areas of life (Australian Institute of Health and Welfare, 2007). Inpatient rehabilitation is a key part of the recovery pathway for people with severe ABI as they work intensively with multidisciplinary health professionals typically over many months (Royal College of Physicians and British Society of Rehabilitation Medicine, 2003). Intensive neurological rehabilitation for people with severe ABI can optimise outcomes, including functional

independence and quality of life (Turner-Stokes, Pick, Nair, Disler & Wade, 2015). Optimal recovery and goal attainment are achieved when inpatients are actively engaged in their rehabilitation journey (Cullen, Chundamala, Bayley & Jutai, 2007; Fleming, Sampson, Cornwell, Turner & Griffin, 2012), and thus understanding the rehabilitation experience from the perspectives of both the inpatient and their family is key for ongoing improvement of the delivery of ABI rehabilitation services.

Most people with a moderate to severe ABI in Australia undertake rehabilitation in specialised facilities which offer intensive nursing care and specialist allied health services to manage complex brain injury issues (Vic Health, 2020). Highlighting the importance of high quality inpatient ABI rehabilitation ("Rehabilitation of persons with traumatic brain injury," 1998), it has been shown that early functional gains can be made by people with ABI who receive intensive programmes delivered by experienced, multidisciplinary teams early in their recovery (Turner-Stokes *et al.*, 2015). Further, receiving such programmes in a specialised brain injury rehabilitation unit can lead to greater functional gains than for people in non-specialised facilities (McKechnie, Pryor, Fisher & Alexander, 2020).

Rehabilitation interventions have been readily investigated, however, research into brain injury rehabilitation services and experiences of patients and family members is more limited (Oyesanya, 2017). Of the studies undertaken into inpatient and family member experiences of ABI rehabilitation services, many highlight areas of need. A 2017 systematic review of qualitative literature noted limited studies but reported negative patient perceptions of their rehabilitation, family members wanting to be more involved in patient care, and both patients and family members having unmet information needs (Oyesanya, 2017). More recently, a qualitative study highlighted that people with traumatic brain injury (TBI) in rehabilitation perceived a lack of autonomy as an inpatient (Panday, Velikonja, Moll & Harris, 2021). A survey study of family members of people with TBI reported their satisfaction with care provided to their relative declined as they progressed from the acute inpatient setting to community rehabilitation ( $p < 0.05$ ) (Manskow *et al.*, 2018). Another survey of people with TBI and their family members about their rehabilitation experiences revealed improvements were sought in health professional to patient communication, tailored rehabilitation, and the physical environment (e.g., access to gym equipment, loss of privacy) (Christie, Egan, Wyborn & Simpson, 2021). Given negative and diverse findings from limited settings about experiences with inpatient ABI rehabilitation, further research is indicated and important for enhancing rehabilitation care.

Inpatient experience of rehabilitation is important to measure for a variety of reasons. Ratings of experience can help rehabilitation professionals to understand and deliver the sort of care that is needed and wanted, and assist to prepare inpatients and family members for successful discharge (Oyesanya, 2017). By identifying areas for quality improvement and practice change, the clinical effectiveness, safety and quality of care can be improved (Doyle, Lennox & Bell, 2013; Urden, 2002). Better inpatient care experiences are also associated with improved health outcomes including higher levels of adherence to recommended prevention and treatment processes, improved clinical outcomes and less health care utilisation (Anhang Price *et al.*, 2014). Moreover, those who report satisfaction with their rehabilitation experiences also report increased quality of life (Cramm, Strating & Nieboer, 2012) while those dissatisfied with their care have reported reduced quality of life and greater depressive symptoms (Arts *et al.*, 2008).

To further explore the reasons behind satisfaction or dissatisfaction with a specialist ABI rehabilitation service and draw on the strengths of both qualitative and quantitative methods, we selected a mixed methods approach. This approach enables both breadth in the results and detailed understandings of participants' perceptions and experiences (O'Cathain, Murphy & Nicholl, 2007). Using a mixed methods research design may also moderate the ceiling effect observed at times in satisfaction scales when exploring service satisfaction after significant health events (Andrew, Salamonsen, Everett, Halcomb & Davidson, 2011). Therefore, this study used a mixed methods approach to explore the experiences of both inpatients and their family members of a specialist ABI rehabilitation service which was in the initial years of operation.

## Method

This cross sectional, prospective mixed method study employed a concurrent triangulation strategy to broaden our understanding of the experiences of patients and family in a specialist ABI rehabilitation service. Survey administration and semi-structure interviews were conducted simultaneously to ensure both depth and breadth of data were obtained. The study was approved by the institutional human research ethics committee prior to study commencement; all participants provided informed consent [355/14].

## Setting

The study was conducted at one specialist, publicly funded ABI rehabilitation centre in a metropolitan area. The purpose-built 42-bed rehabilitation facility opened in late 2014, with the intent to provide both in-patient and out-patient rehabilitation to adults with non-progressive moderate to severe brain injuries resulting from trauma, stroke, and other medical causes of ABI. The severity level of the inpatient caseload necessitated a model of care whereby rehabilitation was considered to be individually tailored, and non-time-limited (Knox & Douglas, 2018). This model of care was consistent with the Australian Faculty of Rehabilitation Medicine standards for the provision of rehabilitation (The Royal Australasian College of Physicians & Australasian Faculty of Rehabilitation Medicine, 2019) and tailored based on the findings of a public engagement initiative (Lannin et al., 2021). With an overarching acknowledgement that the service strives to deliver patient-centred care and that families are considered partners in rehabilitation, rehabilitation was directed by joint goal setting among the patient, family, and interprofessional team. Therapy was delivered across all 7-days, and an evening and weekend programme sought family engagement (at the preference of the patient). The ward environment within the service contained lounges, dining and activity rooms to support socialisation and daily group programmes. There is a dedicated family lounge, internal courtyards which feature a horticultural garden, a sports facility including basketball court and table tennis table, and an interdisciplinary rehabilitation gym area. In addition to family meetings, families were provided with counselling (psychology), family support programme (social work and psychology group), education (interprofessional), and encouraged to support therapy programmes as able.

## Procedures

### *Study inclusion and exclusion criteria*

The inclusion criteria for the study included: 18 years of age or older and in patient or family member of a patient admitted to the rehabilitation service. Exclusion criteria for the qualitative component included non-English speaking, Medicare-ineligible patients and international patients, and those who had active legal cases pending.

### *Surveys*

Participants were inpatients admitted to the unit during its second year of operation, and their family members. The term 'family' for the purposes of this study also included a friend or carer nominated as next of kin (provided they were aged 18 years or over). In the week prior to a person's discharge, they and their family member were approached by a member of the research team and invited to complete the satisfaction survey. If ability to provide informed consent was unclear, the research team member consulted with the inpatient's treating neuropsychologist for clarification. The nine-question survey contained open and closed questions, and was provided electronically via computer or tablet, or as a paper copy if requested. Satisfaction was measured using a modified version of the hospital's Health Patient Experience Survey (available on author request); care aspects were rated on a 6-point categorical scale (never, rarely, some of the time, most of the

time, all of the time, cannot remember/recall/unsure, or a great deal, quite a bit, somewhat, a little, not at all, not sure). The survey (see Table 3 for the five areas explored) was modified to also include dimensions raised in a systematic review on consumer satisfaction in rehabilitation, specifically the dimensions of interpersonal communication, continuity of care and efficacy (Keith, 1998). Ratings for the overall quality of care question were recorded on a 7-point numerical scale while aspects of discharge were rated on a 5-point categorical scale (poor, fair, good, very good, excellent). A question about if participants would recommend the service to others was rated on a 3-point scale (yes, no, unsure). Open-ended questions also sought to capture the strengths of the service, as well as recommendations for improvements. The hospital's Health Patient Experience questions could be provided in languages other than English.

People who completed the survey had the choice of returning/submitting it prior to discharge (in a locked box located in the ward or family lounge) or after discharge by post (for paper copies). Limited information about participants' age, gender, relationship to patient (family), injury details, and length of stay was also collected. Data were entered into a purpose-designed secure database and were extracted and combined from the respective database to prepare for analysis.

### *Qualitative Interviews*

Employing purposive sampling, participants were selected based on gender (male/female) and their role in the ABI rehabilitation service as a patient or family member.

Qualitative interviews were conducted with a selection of consumers who had completed the aforementioned satisfaction survey and indicated a request to further discuss their experience. Clinical staff were also encouraged to invite inpatients and / or families who may wish to provide feedback on their experiences. People who expressed an interest in participating in an interview were approached in person by a researcher who provided information about the interview and a participant information and consent form for their consideration. The researcher returned within the week to answer any questions and book a mutually agreeable interview time. To protect the anonymity of those who undertook the qualitative interviews, minimal demographic information was collected.

Interviews were conducted face to face prior to discharge from the rehabilitation unit, or over the telephone up to one-month post-discharge. The sample size was informed by evidence of data saturation and interviewing was ceased when no new themes or subthemes were identified during data analysis. The sample size was consistent with qualitative studies designed around a focused aim (Sandelowski, 1995). Two interviewers trained in qualitative research and semi-structured interviewing performed all data collection [EOS, LJ]. The interviewers were experienced neuro-rehabilitation occupational therapists (OTs) by background with over 5-years of clinical experience in neurorehabilitation. Both interviewers were employed independent of the service and were not involved in delivering patient care at the service. The semi-structured interview guide (Table 1) explored: experiences with the service and health professionals; goal setting and planning processes; and, met and unmet needs. Additionally, strengths and weaknesses of the service, and engagement in and communication about care, discharge and treatment decisions were also explored. Probes were used to elicit further information and to explore relevant topic areas. All participants consented to audio recording and transcription of the interview. The average duration of the interviews was 27 minutes.

### **Data analysis**

Descriptive statistics for all variables in the survey were calculated and reported as percentages. Quantitative data were analysed using Microsoft Excel. Qualitative data were thematically analysed using a framework approach (Ritchie & Spencer, 1994). Transcripts from the semi-structured interviews were managed in NVivo (QSR International, Doncaster). Each transcript

**Table 1.** Interview Questions

1. What stands out for you about your time at the ABI rehabilitation service? What do you think were some of the good and not so good things about the service?
2. Tell me about how involved you felt in the process of setting goals and planning your treatment while you were at the ABI rehabilitation service.
3. Tell me about how the ABI rehabilitation service did and/or did not meet your needs.
4. Tell me about the physical environment (e.g., buildings and equipment) at the ABI rehabilitation service?
5. Tell me about your experiences with planning discharge.
6. Would you recommend the ABI rehabilitation Service? Why / why not?
7. Are there any suggestions about how to improve the ABI rehabilitation service?

was read to ensure familiarity and initial notes made. Through iterative and inductive processes, data were indexed (coded) for seven transcripts based on content, meaning, repetition and in relation to the aims of the study. Charted data were then grouped into themes and subthemes as patterns were identified to create an analytical framework. Two researchers (EOS and SB) independently developed the framework and three researchers then mapped the transcripts to the framework (EOS, SB and SV), noting new connections, themes or subthemes. These were then discussed with the senior author (NL) and minor changes made to the analytical framework prior to interpretation. Ongoing discussions between the analysts and larger project team occurred to interpret and generate the results (Gale, Heath, Cameron, Rashid & Redwood, 2013).

### *Trustworthiness*

Trustworthiness in the qualitative study was achieved by ensuring credibility, dependability, confirmability and audit trails (Nowell, Norris, White & Moules, 2017). Credibility was addressed through using researcher triangulation (three analysts), peer debriefing (discussion and presentations to the larger research team) and data collection triangulation (survey and interview methods) (Morse, 2015). Dependability and audit trails were achieved by the researchers maintaining detailed, clear, and traceable records of coding and theme development and through recording methodological issues and decision making the throughout the study (Nowell et al., 2017). Confirmability was ensured through attaining credibility and dependability, and completing a statement of transferability and transparency of our analysis processes (Nowell et al., 2017).

## **Results**

### ***Profile of participants***

In total, 163 patients were admitted to the ABI rehabilitation centre between January and December 2015. Of those, 111 (69 inpatients and 42 family members) completed and returned the quantitative survey, providing a 68% response rate (42% response rate for inpatients and 26% of family members – a response was only accepted from one patient or a representative). Most inpatient participants were male (72%), and just under a third (31%) were aged between 18–24 years (Table 2). 41% of inpatient participants completed the survey 1–3 months post their admission. More than three quarters of family member participants were 45 years or older, with 45% of family members being a parent of the inpatient (Table 2). Five inpatients (two female and three male) and eight family members (five female and three male) participated in qualitative semi-structured interviews. Family members identified as parents (50%), partners (37%) and siblings (13%).

**Table 2.** Characteristics of Survey Participants (*n* = 111)

		Patients	Family member
<b>Total</b>		<b><i>n</i> = 69 (%)</b>	<b><i>n</i> = 42 (%)</b>
Gender <sup>a</sup>	Male	48 (72)	N/A
Age <sup>b</sup>	18–24	21 (31.3)	0 (0.0)
	25–34	13 (19.4)	2 (4.7)
	35–44	11 (16.4)	6 (14.3)
	45–54	10 (14.9)	12 (28.6)
	55–64	9 (13.4)	12 (28.6)
	65+	3 (4.4)	10 (23.8)
Relationship to patient	Parent	N/A	19 (45.2)
	Partner		16 (38.1)
	Other <sup>c</sup>		7 (16.6)
Time since admission <sup>c</sup>	<1 month	25 (36.7)	N/A
	1–3 months	28 (41.2)	
	4+ months	15 (22.1)	
Assistance to fill out survey <sup>d</sup>	None	32 (49.2)	37 (90.2)
	Assistance	33 (50.8)	4 (9.8)

Missing data:

<sup>a</sup>*n* = 2 patients;<sup>b</sup>*n* = 2 patients;<sup>c</sup>*n* = 1 patient;<sup>d</sup>*n* = 5 (1 family member, 4 patients).<sup>e</sup>Other includes sibling, child or grandparent.

### Results from the Survey

High levels of satisfaction with the specialist service were reported through the survey; the majority of inpatients (74%) and family members (81%) rated the overall quality of care received in the service as 'high' or 'very high'. All family members and 87% of inpatients reported they would recommend the service to other patients and families. Engagement with both inpatients and family members for decision-making and planning for discharge was also noted to be high, with more than half the inpatients (57%) and nearly three quarters (74%) of family members reporting they felt highly or extremely involved. However, some patients (20%) and a small number of family members (5%) noted their involvement in decision making and discharge planning never occurred or was rare. Over three-quarters of inpatients (76%) and family members (88%) felt staff listened to their important needs regarding discharge planning most or all of the time (Table 3). Nevertheless, over a quarter of patients (26%) and some family members (10%) were not at all or slightly clear about what would happen after discharge. We did note a difference between confidence to return to home between inpatients (71% of inpatients felt highly or extremely confident) and family members (52%) in the survey findings.

### Results from the semi-structured interviews

From the thematic analysis four main themes were identified: (i) satisfaction with rehabilitation services, (ii) inconsistent communication, (iii) variable nursing care, and (iv) strengths and weakness of the rehabilitation environment.



**Table 3.** Survey Responses from Inpatient and Family Respondents ( $n = 111$ )

	Patient/Family involvement in the processes of making decisions		Staff acknowledgement of the things that were important to patient/family		Confidence for discharge		Provision of information to assist decision making and planning for discharge		Clarity about what will happen after discharge	
	Patient, %	Family, %	Patient, %	Family, %	Patient, %	Family, %	Patient, %	Family, %	Patient, %	Family, %
Never/not at all	8.7	2.4	2.9	0.0	2.9	2.4	14.5	0.0	14.5	7.1
Rarely/slightly	11.6	2.4	5.8	2.4	14.5	16.7	10.1	4.8	11.6	2.4
Sometimes/somewhat	23.2	21.4	15.9	4.8	5.8	28.6	15.9	7.1	21.7	19.0
Most times/highly	36.2	35.7	39.1	45.2	27.5	42.9	30.4	52.4	37.7	45.2
All the time/extremely	20.3	38.1	36.2	42.9	43.5	9.5	27.5	33.3	13.0	23.8

#### *Satisfaction with rehabilitation services*

All participants reported being very satisfied with the commitment, expertise and skill of allied health clinicians that delivered therapies and services. Physiotherapists, OTs, psychologists, and social workers were described as ‘*exceptional*’ at the rehabilitation facility. One family member emphasised her approval of and confidence in allied health staff at the rehabilitation service:

*“The rehab staff were above and beyond. Physio was incredible, OT was amazing. The psychologist was fabulous.”* Family member #1

Inpatients and family members expressed positive experiences with allied health staff when they were noted to be working hard for improvement and provided regular intensive therapy. Some participants commented about how dedicated allied health staff were with assisting and motivating inpatients to reach their goals and optimal physical function:

*“People they got here, they really do physios. They work hard to get you on your feet, and there’s always something different you do each day. It’s busy on Saturdays as well.”* Inpatient #2

*“[Inpatient’s name] made an amazing recovery and he’s doing things that there was a time we never thought he would be able to do.”* Family member #6B

When allied health professionals developed positive interpersonal relationships with inpatients and delivered personalised physical and mental health care participants reported satisfying experiences. Allied health professionals were noted to be generous with their explanations and readiness to discuss issues and information. The following participants described how allied health professionals provided tailored care and communicated clearly:

*“My OT, my physio- these people are phenomenal; they seemed to care about me . . . to me, it was about sort of looking at the patient, caring about that patient, not just seeing it as another patient [ . . . ] they just blew my mind with their willingness to engage and sit and talk and answer questions.”* Inpatient #1

*"The physio is really good and will speak very well about we're working towards getting him up right at this."* Family member #6B

#### *Inconsistent communication*

Most inpatients and family members stated communication interactions about goal setting activities with allied health professionals were predominately positive and personalised. The following participant, however, expressed that such positive encounters with allied health staff were in contrast to discussion about his rehabilitation treatment:

*"Well in regards to treatment, I don't feel involved at all. But goals, very involved [ . . . ] I feel very involved with the Allied Health Assistants because they talk to you about things"*  
Inpatient #3

Similarly, other participants stated they experienced frustration with medical staff when they did not receive the level of attention, communication engagement and information they expected. In contrast, a small number of family members specifically commented on their satisfaction with some medical staff. Sometimes these contrasting perspectives existed within a family unit, as the following excerpts reveal the varying views of an inpatient and their family member:

*"I felt that the medical team also didn't engage with me at the level that I wanted to. I wanted to understand more [ . . . ] I had a lot of questions and I would ask questions to people and they just couldn't or wouldn't answer me. So, that was frustrating."* Inpatient #1

*"There were two doctors who were wonderful. [Name of doctor] was brilliant and then this other wonderful lady doctor [ . . . ] She would come and do the rounds every day. They would take the time to explain things both to [name patient's relative] and to me in detail and in a way that I could understand."* Family member #1

A number of participants and family members did outline some dissatisfaction with communication and information exchanges witnessed between nurses, or from nurses to inpatients. At times, participants perceived their questions to go unanswered, or that important information was not passed between nurses across shifts, or that sufficient attention may not be paid to information communicated across disciplines. As such, participants expressed some disappointment when care processes did not appear integrated, such as when information from posters allied health staff used to communicate personalised inpatient information were not followed by other disciplines:

*"They [nurses] don't look it [instructions] . . . all the posters in my room, they don't even look at them. I got posters all around the room to say how to do things and do different tasks."*  
Inpatient #2

*"There are signs on the wall she needs assistance by two to move via a sling and there's a picture of a sling and a crane. The nurse comes in when I say that she needs to go to the toilet and she says to [the patient], 'Can you walk?'. It's just devastating . . . it reminds her she can't walk, gets her panicky."* Family member #9b



Additionally, some family members raised that they wanted technical and medical information communicated in more detail but in more accessible formats to suit their own health-literacy levels. This suggestion was made to ensure that both family and the inpatient clearly understood the reasons for, and actions of, prescribed treatments:

*"[The patient] would say, 'What is this [medication]?' [The nurse] would give the technical name of the drug and that means nothing [ . . . ] They should say, 'You are taking a painkiller' or, 'You are taking a heart pill.' Something like that and then explain what that pill does for that person. Actually, my complaint with the nurse was, 'Can you please speak in layman's terms because I'm not a medical person?'"* Family member #1

#### *Variable nursing care*

Participants reported variable nursing care at the specialist facility, with both inpatient participants and family members describing contrasting experiences of satisfaction and dissatisfaction within the same interview. Dissatisfaction with nursing care arose mainly when staff were perceived as inexperienced in brain injury or rehabilitation processes, or in lacking in specialised knowledge about recovery from ABI.

*"The nurses generally, there have been a couple of people who I feel that either didn't know much about brain injury, or they seem to be part-time staff, or maybe even casual."* Family member #8

When nurses worked in a task-orientated way, or did not seem to personalise their interactions with inpatients, participants expressed negative experiences. Some suggested that such impersonal care was delivered predominately by casual staff who were temporarily employed by the facility and unable to maintain consistency in patient contact.

*"The nurses are a bit more permanent[now], which is good. Previously, there were lots of casual nurses, they will come here one or two days and then that's it. So they don't have the sense that it's "their" patient that they have to look after. Now, it's getting better, because a couple of months back so they got some full-time nurses which at least there is some consistency going."* Carer #7

Inpatients and family members conveyed satisfaction with nursing care when it was delivered by permanent staff who were familiar with and 'trained' in recovery from brain injury. Further, interpersonal communication that was perceived as clear, engaging and caring was valued by participants. Some mentioned instances of 'exceptional' nursing care, such as when nurses took time to listen and connect with inpatients to provide tailored care:

*"There was one nurse . . . they [nurse and patient] talked for about 15 minutes about where [name of patient] used to live. Honestly, the 15 minutes that she took to talk to him and have a little bit of a laugh was so healing for him. He just felt like a person and she enjoyed being with you. She was laughing and it was just such a pleasant human encounter as opposed to 'All right. What do you need? All right, it's time for your medication.'"* Family member #6b

#### *Strengths and weakness of the rehabilitation environment*

Most inpatients and family members were very positive about the physical environment of the new hospital, and emphasised its role in facilitating recovery. Private rooms, bathrooms, open spaces with natural light and overhead hoists and tracking systems were all positively commented on. Additionally, ample space to accommodate family and visitors was welcomed by inpatients and family members.

*"It's excellent that he has a private room. It's excellent that the bathroom is there. It's excellent that he has natural light . . . the sun coming in is wonderful. It's big enough to accommodate visitors and chairs and things like this."* Family member #6b

*"There are lots of well-maintained open areas, which is good because I don't take her for a long walk because she continuously needs fresh medication, this and that, which is good because she likes open areas. That's a good thing."* Family member #7

Some participants raised that noise levels were problematic, in particular for people who still required a low stimulus environment post-brain injury. For others, noise interrupted their sleep or negatively impacted on their sense of reality:

*"Noise levels can really do my head in, especially whilst you're trying to sleep. You know, hearing beeps and everything, and screams."* Inpatient #3

*"Her room is right outside the nurse's station but it's also part of this paranoia and her picking up words and putting them into her own reality. Because there's a lot of chatter outside the door that comes straight into the room and she'll pick up some of the words they use."* Family member #9a

In addition to the noise, participants were also dissatisfied with the meals provided within the service. Many inpatients had particular dietary requirements and preferences that were reportedly not accommodated. Meals were also perceived to be non-appetising or inconsiderate of dietary preferences (such as vegetarianism). The following family member, however, described how she worked around the issue with the assistance of the staff:

*"When we are talking about patients who have brain injuries and have very specific needs in terms of the provision of really good quality nutritious meals [ . . . ] There's nothing on the tray that I would allow my husband to have because it was so bad. Anyway, I did speak to the dietitian and talked about my concerns, and she was adaptable enough to allow me to provide the meals based on her recommendations. I think that was great."* Family member #8

Some participants reported that they felt emotional and vulnerable in the rehabilitation environment; the reasons for these feelings were noted to be multifactorial and it was not clear if this was the service or an outcome of the brain injury itself. Inpatients stated that they did not *'feel like themselves'*, or had no prior experience with inpatient healthcare settings thus contributing to the sense of dependency on the service. Some also described feeling like they had limited control in an unfamiliar rehabilitation environment or were unclear about their treatment programme. The following participant and their family member explained their viewpoint on feeling vulnerable:

*"I probably felt that vulnerability more because I've never really [experienced] something like [this] in my life."* Inpatient #1

*"He was in a very different situation to what he has ever been in before. He's a high performing individual. He was always the one arranging people what to do . . . From that point of view, I can understand why he would have felt vulnerable."* Family member #1

Some family members described feeling protective and wanting to advocate for their relative during their inpatient stay. This perspective appeared to stem from the serious nature of a brain injury and its residual effects, at times a discontent with aspects of care, and the inpatient expressions of vulnerability. Efforts by family members to ‘advocate’ for the inpatient, however, were described as an added emotional burden;

*“Obviously as his wife, it’s very emotional for me. We lost him, you know . . . he basically died from the injuries and there’s that side first.”* Family member #6a

*“I’m feeling like the patient needs an advocate just to get the best outcomes, and luckily [name of inpatient] has me, watching what’s happening. I need to be able to come home and know that he’s being taken care of in the same way that I would take care of him if I were here.”* Family member #8

## Discussion

Overall, the specialist rehabilitation facility was considered a highly valued service. The goal of this study was not, however, only to summarise how well the service performed, but to also understand aspects of care delivery that will ensure ongoing service improvement based on patient and family member perspectives (Urden, 2002). While the survey results provided an overview of participant satisfaction with respect to decision making, discharge planning and returning home, the qualitative results provide detailed insights into inpatient and family member experiences with the service. Collectively, the findings revealed positive experiences relating to allied health services, planning for discharge, the physical environment and having the important needs addressed. The qualitative findings highlighted, however, some areas of dissatisfaction, including variability in nursing care with managing a large number of beds and use of casual staff, as well as aspects of the physical environment such as noise control.

Our results highlight that high levels of satisfaction with a newly establish specialist ABI rehabilitation service can be achieved in a relatively short timeframe (1 year). But they also confirm that the non-physical aspects of rehabilitation care are equally as important to service satisfaction. While hospital surveys tend to focus on amount or type rehabilitation delivered, our findings also suggest that consistency of staffing and staff ability to personalise care and build relationships with patients and families should also be monitored. The findings also emphasise the need for tailored strategies to enhance the autonomy of all people with ABI and ensure that planning for discharge and discussion about what happens after returning home is able to occur at the right time, with the right people and in the right format. These results are important for informing the development of quality in healthcare as inpatient experience is associated with clinical effectiveness, patient safety and patient compliance (Anhang Price et al., 2014; Doyle et al., 2013). Additionally, with satisfaction linked to self-management and quality of life (Cramm et al., 2012; Keith, 1998) ensuring the rehabilitation programme is able to deliver not only an effective programme but also one that meets the expectations of inpatients and their families is critical.

Therapy sessions with allied health clinicians are considered a core component of specialist brain injury rehabilitation (Cullen et al., 2007; Lannin et al., 2021; “Rehabilitation of persons with traumatic brain injury”, 1998) and it is unsurprising, therefore, that both survey and qualitative interview findings focussed on these. Inpatients who report positive interpersonal relationships with their clinicians mainly describe positive and satisfying therapy experiences (Peiris, Taylor & Shields, 2012) as they did in this present study. Consistent with our findings and others, inpatients and family members positively appraise the quality of rehabilitation services and commitment by staff to support rehabilitation goals and make recovery gains (Christie et al., 2021). Indeed, such positive personal engagement with physiotherapists has even been suggested to

be more important than the amount of therapy inpatients receive (Peiris *et al.*, 2012). Confirming the importance of non-physical aspects of rehabilitation care, inpatients and family members in our study reported allied health staff personalised their interactions to convey care, motivate and build relationships. Other researchers have similarly found that developing a therapeutic relationship with people with ABI and their families is core to rehabilitation success (Bishop, Degeneffe & Mast, 2006).

While technical contact with inpatients (e.g. giving a medication, taking a blood pressure) is a common nursing activity, inpatients value the development of interpersonal relationships and patient-centred interactions with the nursing team (McCabe, 2004). The qualitative interviews however, suggested that some nursing care lacked this patient-centred focus; it is possible that staff may have lacked confidence or skills in developing relationships with people with ABI, which is known to be “difficult and time-consuming” for staff (Nielsen, Power & Jensen, 2020). As the service in our study was in its first two years of operation, the nursing workforce may have been in development, and this evolving workforce may account for the reported agency and casual staff or staff suggested by families to not hold specialised rehabilitation knowledge. Our findings, therefore, support other research which reported where negative experiences with agency and casual nursing staff in specialised rehabilitation settings (Christie *et al.*, 2021). Education and training about care provision and forming therapeutic relationships with people with ABI could be provided during staff orientation in specialist ABI rehabilitation services; in particular training in communication strategy use (Nielsen *et al.*, 2020). Such educational opportunities may also support inexperienced or casual nurses to provide patient-centred care to people with ABI within specialised rehabilitation settings (Cook *et al.*, 2013; Kneafsey & Gawthorpe, 2004).

Preparation for and the transition to community living from inpatient ABI rehabilitation can be a challenging time (Piccenna, Lannin, Gruen, Pattuwage & Bragge, 2016; Turner, Fleming, Ownsworth & Cornwell, 2008). Successful preparation for discharge from rehabilitation is considered to be a collaborative effort between the rehabilitation service, the inpatient and their family (Abrahamson, Jensen, Springett & Sakel, 2017; Piccenna *et al.*, 2016). Involving inpatients and family members in decision making, formulating plans about discharge, and ensuring inpatients and family members feel informed, supported and confident, are important for a satisfactory experience (Abrahamson *et al.*, 2017; Piccenna *et al.*, 2016). While our survey results suggest the majority of inpatients and family members felt engaged and informed by staff in both decision-making and discharge planning, these findings are somewhat contrasting to recently published qualitative studies on the experiences of adults with TBI and their family members. This qualitative research noted a lack a cohesive planning, as well as service fragmentation, was perceived to lead to dissatisfaction among inpatients and family members with respect to returning home (Abrahamson *et al.*, 2017; Piccenna *et al.*, 2016). Different findings in the literature to our results are likely related to varying aims of the studies, as well as different methods of data collection and potentially the timing of data collection with respect to the time of discharge. Further, it is plausible that the longer length of stay within the service (i.e. non-time-limited programme) led more time to collaboratively agree to and plan towards discharge, and subsequently, a higher level of satisfaction was found in our survey results in comparison to other research.

Of note, our survey results did reveal that some patients were dissatisfied with regards to knowing what happens after discharge, and with being involved in decision making and discharge planning. Panday *et al.* (2021) similarly noted that people with ABI perceive a lack of personal autonomy in decision-making in a rehabilitation setting. To meaningfully engage people with ABI in discharge processes, and enhance their autonomy, multimodal strategies are likely needed. While tailored education, involving personalised printed information with repeated verbal reinforcement maybe helpful to both the patient and family (Eames, Hoffmann, Worrall, Read & Wong, 2013), others have shown that in a general medical cohort a pilot tailored interdisciplinary audio-visual summary record was helpful and acceptable (Newnham *et al.*, 2015). Audio-visual records allow patients to watch the content repeatedly as well as view it with others (e.g., family,

doctors, other health professionals, etc.), and helped patients to understand and engage in discharge processes (Newnham et al., 2015). Further research is needed, however, to specifically address methods of engagement for people with ABI in rehabilitation discharge transitions.

Effective communication enables consistent and accurate information to support appropriate and tailored decision making, as well as safe and successful care transitions such as discharge from rehabilitation to the community (Australian Commission for Safety and Quality on Health Care, ACSQHC, 2016). Communication during inpatient ABI rehabilitation and discharge from rehabilitation to home, however, has been noted as inconsistent and at times ineffective (Christie et al., 2021; Nielsen et al., 2020; Piccenna et al., 2016). These findings reflect those in our study. Ineffective communication can lead to feelings of uncertainty and anxiety for inpatients and their family members, and a lack of information and shared understandings can impair decision making (Lannin et al., 2021; Lefebvre, Pelchat, Swaine, G elinas & Levert, 2005). Furthermore, the feelings of vulnerability expressed by some inpatients in our study when they experienced difficulty accessing information likely related to ineffective communication. To support active engagement and therapeutic relationships between people with brain injury, family members and their rehabilitation team working, communication skills training for health professionals can improve inpatient satisfaction with services (Fleming et al., 2012; Foster et al., 2012). Additionally, inviting inpatients and family members to engage in regular and open discussions about progress and future plans, as well as acknowledging and responding to issues in a timely manner, can lead to service satisfaction and drive participation in rehabilitation (Christie et al., 2021). With inpatient experience associated with clinical effectiveness and patient safety (Doyle et al., 2013), future research should continue explore inpatient and family member experiences in rehabilitation to support shared learnings for service improvement.

The main strengths of this study include the use of a mixed method approach, and involvement of both inpatients and family members as respondents. Our results outline a detailed description of and information about the study, to enable judgement regarding transferability (Nowell et al., 2017). It is not, however, without limitations. This study was conducted at a single specialist facility, and all inpatient participants had receptive communication and the ability to provide some response to surveys and interview questions, even if supported by augmented communication devices. Therefore, the findings may not be applicable to other rehabilitation services or populations who experience severe expressive aphasia. Additionally, the findings might not relate to other countries with different types of service delivery models, since our model of care is non-time-limited with respect to length of stay. We also acknowledge that people less satisfied with care or who hold strong opinions on an issue are more likely to participate studies about service experiences and that there may not be representativeness among the participants. Thus, the qualitative issues highlighted in this study should not be taken to reflect all inpatients admitted to the service. Finally, all qualitative interviews were conducted in English, and we were only able to interpret free-text survey responses completed in English, and so we acknowledge that the experiences of people who speak a language other than English may vary.

## Conclusion

Specialised rehabilitation is valued by inpatients and their family members alike. Important components of a positive experience were being involved in decision making and discharge planning, effective communication and information processes, and being able to form therapeutic relationships with staff. Key sources of dissatisfaction for inpatients and family members related to inconsistency in care, accessing information about treatments in a format easily understood, and staff communication style (irrespective of language or behavioural challenges). These findings highlight the importance of exploring inpatient experiences to address the needs of people living with ABI and their family members, so as to optimise service delivery in a tailored, specialised rehabilitation programme.



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**Ethical standards.** The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national and institutional committees on human experimentation and with the Helsinki Declaration of 1975, as revised in 2008.

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