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Navigating the transition from hospital to community: experiences of people with acquired disability and complex needs

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ABSTRACT

Background. People with disability and complex needs frequently face long hospitalisations. They also risk being discharged without adequate housing and supports. Hospital discharge planning is crucial for a safe and effective transition to the community. The aim of this qualitative, phenomenological study was to understand the lived experience of hospital discharge and returning to the community for people with acquired disability and complex needs. **Methods.** Fifteen individuals (80% men) aged 31–66 years, recently discharged from hospital and eligible for access to the National Disability Insurance Scheme were interviewed 1 month post-hospital discharge. **Results.** Three primary themes were developed: being in hospital, preparing to return to the community and returning to the community. Participants shared their experiences navigating the hospital system, disability services and the National Disability Insurance Scheme. They identified factors that facilitated their community integration and highlighted barriers that hindered their ability to effectively navigate hospital and community settings. **Conclusion.** The current study findings underscore the complex interplay between hospital discharge and the transition back to the community for people with acquired disability and complex needs. These findings also highlight opportunities to co-design solutions that improve the experience of leaving hospital and preparing for life after discharge.

Keywords: acquired disability, allied health, coordination, discharge planning, hospitalisation, lived experience, National Disability Insurance Scheme, phenomenology, support needs.

Introduction

Young people (aged 18–65 years) with acquired disability and complex support needs (e.g. acquired brain injury (ABI), spinal cord injury: (SCI)) are at risk of extended hospital admissions, and face uncertainty about their home and living situation post-discharge (McIntyre *et al.* 2017; Holloway *et al.* 2019; Houston *et al.* 2020). Given the complexities around navigating the hospital, housing and disability sectors, people with complex needs risk being discharged to residential aged care or other inappropriate housing options after a hospital admission (Barry *et al.* 2019; Cvejic *et al.* 2022). Living in residential aged care negatively impacts younger people through limiting social and recreational opportunities, reduced access to rehabilitation, and poor functional outcomes (Dwyer *et al.* 2019; D'Or *et al.* 2021). Conversely, individualised housing options can support autonomy, social integration and psychological well-being (Oliver *et al.* 2020; Douglas *et al.* 2024). In addition to poor outcomes for individuals, hospital discharge delays are costly and impact the hospital ecosystem by reducing access to services, as hospital beds are occupied by people who are medically ready to be discharged (Buist *et al.* 2014; Rojas-García *et al.* 2018; Destino *et al.* 2019).

Complex support needs arise when a person experiences multiple significant health, disability or behavioural support needs. This may include people with ABI, SCI, stroke or other neurological conditions (Rankin and Regan 2004; Collings *et al.* 2016). Discharge outcomes for this cohort can vary based on disability type due to medical, social and

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environmental factors. For example, previous studies highlight that people with SCI are more likely to return to their pre-injury residence compared with those with ABI or progressive neurological disorders, where complex cognitive, psychiatric and behavioural impairments can necessitate alternative housing solutions (Fisher *et al.* 2012; Braaf *et al.* 2018; Schrage *et al.* 2023). People with complex needs who do not own a home or require major modifications to return home risk being discharged to unsuitable destinations (Wright *et al.* 2019).

An effective and safe hospital discharge is contingent on quality and well-coordinated discharge planning that commences at admission, and continues through the trajectory of the hospitalisation and discharge (Conti *et al.* 2016; Cubis *et al.* 2024). Hospital discharge for people with complex needs requires significant multidisciplinary care coordination (Larsson-Lund *et al.* 2022). Discharge planning, which involves arranging necessary resources after a patient leaves the hospital, is an iterative and collaborative effort that includes assessment, coordination and communication across disciplines (Gronda *et al*. 2011; Gonçalves-Bradley *et al.* 2022). Given that people with acquired disability often require specialised multidisciplinary input, disability-specific housing, disability supports and assistive technology, they are at risk of remaining in hospital beyond the time clinically necessary as these essential supports are put in place (Conti *et al.* 2016; Redfern *et al.* 2016; Abrahamson *et al.* 2017; Bohan *et al.* 2023).

A number of clinical practice guidelines exist for specific populations of people who may have complex needs including ABI (Jolliffe *et al.* 2019) and stroke (Stroke Foundation 2024). Although health condition-specific clinical practice guidelines are useful, an effective discharge is contingent on planning and coordination across hospital, housing and disability sectors regardless of disability type. Accordingly, a recent scoping review on hospital discharge for people with acquired disability and complex needs found that many experiences were characterised by poor coordination and communication, delays in assessment and funding applications, and limited proactive planning for possible issues in the community (Cubis *et al.* 2024). People often reported a lack of communication between hospital staff and themselves, and a general lack of essential information provision to prepare them for life after discharge (Conti *et al.* 2016; Abrahamson *et al.* 2017; Fitts *et al.* 2019). The review highlighted the importance of a cohesive and well-coordinated discharge plan where people with disability and close others are active participants in all stages of planning.

Quality discharge planning starts from admission (Gonçalves-Bradley *et al.* 2022). People with acquired disability often face additional challenges coordinating bureaucratic systems, ensuring adequate funding, receiving assessments when needed and navigating multiple service providers (Redfern *et al.* 2016; Braithwaite *et al*. 2017; Foster *et al.* 2022). With early identification of potential barriers to discharge, problems can be solved and proactively managed by the inpatient team. Timely formal assessments for tangible supports, including home modifications, equipment and supports on discharge, can mitigate the risk of people waiting in hospital beyond being clinically ready for discharge while they await implementation of these supports (New 2015; Redfern *et al.* 2016; Houston *et al.* 2020). Coordination is crucial at all levels of discharge planning including within the health system, between hospital and community and post-discharge (Conti *et al.* 2016; Skinner *et al.* 2023).

In Australia, most disability-related funding for adults aged <65 years is provided through the National Disability Insurance Scheme (NDIS), meaning that many adults with disability and complex needs aged <65 years will require NDIS-funded supports to be in place for hospital discharge. Individuals who receive funding through the NDIS are referred to as 'participants,' and their budget for a period of time is known as a 'plan.' The NDIS (2021*a*) identifies three primary support categories: core support, which includes daily necessities, such as disability support workers; capital costs, including mobility aids, home modifications and assistive technology; and capacity-building support, including allied health assessment and intervention. Many people with complex needs receive funding for support coordination: a capacity-building support intended to assist people to connect with and maintain their supports (NDIS 2021*b*).

Although previous studies have provided important insights into the unmet needs of people with acquired disability post-discharge (Abrahamson *et al.* 2017; Dwyer *et al.* 2019) and key components of a successful hospital discharge (Gonçalves-Bradley *et al.* 2022; Cubis *et al.* 2024), there are no recent studies that qualitatively evaluate the hospital discharge experience of people with acquired disability and complex needs in an Australian context. The policy landscape surrounding funding, housing and supports for people with acquired disability in Australia has changed considerably in recent years (i.e. the implementation of the NDIS in Australia). It is important to gain an understanding of the factors that influence hospital discharge outcomes for people with acquired disability and complex needs that arise from a variety of health conditions and progression of existing disability. Accordingly, the present study aimed to explore the lived experience of hospital discharge and returning to the community for people with acquired disability and complex needs.

Methods

Design

This qualitative research was guided by phenomenology (Liamputtong 2013), and explored the lived experience of individuals with acquired disability and complex support needs. Specifically, this research sought to understand how people with acquired disability and complex needs perceived their experience of hospital discharge and return

to the community, and constructed meaning from these experiences.

Participants

Fifteen participants were recruited from a metropolitan and a regional hospital based in Victoria, between December 2019 and January 2023. Participants were recruited using purposive sampling, focusing on people with acquired disability and complex support needs who had recently experienced hospital discharge. The recruitment period was prolonged due to the COVID-19 pandemic and associated logistical difficulties with recruitment (Willis *et al.* 2021; McGuinness *et al.* 2022). Hospital staff identified eligible participants for the study, and consent was completed by a member of the research team. Eligibility for the study included the person having had a recent hospital admission, being identified by the inpatient team as likely eligible for the NDIS (or being an existing NDIS participant who required increased supports post-discharge), being aged between 18 and 65 years, and being able to participate in a 60-min interview. Table 1 provides an overview of the sample, with pseudonyms used. Participants (80% men) were aged between 31 and 66 years (M = 52.3 years; s.d. = 9.3). Primary acquired disability included: stroke n = 5, spinal cord injury (SCI) n = 7, spina bifida n = 1, Parkinson's disease n = 1 and below knee single limb amputation n = 1. Three individuals with SCI also had ABI as a secondary disability. Mean length of hospital stay for participants was 109 days (s.d. = 54 days; range 15–194 days). Interviews were between 24.55 and 136.03 min (M = 67.8 min). A total of 47% of participants were single, with 53% being married or in a de facto relationship (n = 8). On discharge, four participants were awaiting approval of their NDIS plan.

Materials

Qualitative interview

Participants undertook a semi-structured interview informed by the research questions and developed by two senior researchers with extensive experience in qualitative research (JD and DW; see Table 2). The flexibility from a semi-structured interview guide supports the interviewer to explore topics in-depth with participants leading with their experiences, while following the interview guide (Saks and Allsop 2020).

Procedure

Interviews were conducted by an Occupational Therapist or a Speech Pathologist, both of whom were female with professional experience working with adults with acquired disability in rehabilitation settings. Interviewers were given training from senior researchers (LC and JD) for conducting qualitative research interviews. Interviewers maintained reflexive notes and participated in regular supervision with a senior researcher (LC) to discuss bias and review every meeting. In keeping with phenomenological methodology,

Table 1. Summary of participant characteristics.

Pseudonym	Age (years)	Gender	Disability	Length of hospital admission (days)	Existing NDIS participant
Doug	50	M	Spinal cord injury[C]	20	Yes
Peter	53	M	Spinal cord injury[C]	98	No
Jack[A]	31	M	Stroke	140	No
Beth	63	F	Below knee single limb amputation	15	No
Kevin	66[B]	M	Parkinson's disease	75	Yes
Catherine	60	F	Spinal cord injury	140	No
Renee	51	F	Spinal cord injury	112	No
Aaryn[A]	58	M	Stroke	216	No
James	53	M	Spinal cord injury	194	No
Blake	53	M	Spina bifida	146	Yes
Van	43	M	Spinal cord injury[C]	121	No
Carlos[A]	39	M	Stroke	99	No
Greg	62	M	Spinal cord injury	113	Yes
Ned[A]	58	M	Stroke	103	No
Winston	45	M	Stroke	48	No

[A]Supported by a communication partner due to speech and language impairment.
[B]Aged 65 years at time of recruitment.
[C]ABI as a secondary diagnosis.

Table 2. Interview topic and question guide.

Interview topic	Questions
Demographics	Date of birth.
	Sex.
	Marital status.
	Employment status.
Experience of hospital discharge	What was good about leaving hospital and moving home?
	What has been difficult since the move home?
	How did hospital staff involve you in the plan to move from hospital to home?
	What did the hospital do to prepare you for the move home?
	What could the hospital have done better to support you with the move home?
	What information and resources did the hospital provide?
	What would have been useful to know before the move?
Supports	What supports did you need when you left hospital?
	What supports were in place when you left hospital?
	Are you still waiting for any services to start? If so, please detail.
Equipment	What equipment did you need when you left the hospital?
	What equipment was in place when you left hospital?
	Are you still waiting for any equipment? If so, please detail.
Home modifications	What home modifications did you need?
	What home modifications are complete?
	What home modifications are you waiting for? If so, please detail.
NDIS	Please provide a copy of your NDIS plan.
	What else do you need to live an ordinary life; supports, equipment, modifications, skill development?
	If you were chatting to a friend who was in hospital today and planning the move home – what would you tell them?

semi-structured interviews allowed for in-depth exploration of participants' lived experience while remaining flexible to emergent themes (Liamputtong 2013). In-depth semi-structured interviews were conducted by videoconference ($n = 10$) or in-person ($n = 5$), with COVID-19 restrictions limiting face-to-face interviews. Time was spent building rapport with participants prior to the interview to support the creation of data through the interview process (Kvale and Brinkmann 2015). This included discussions about the aim of this research. People with speech and language impairment ($n = 4$) were supported by a communication partner; hence, some illustrative quotes in the results section were provided by the communication partner. All other interviews included only the participant and the researcher. If participants became fatigued during the interviews, they were conducted over two sessions, as guided by the participants. Interviews occurred in the month after being discharged from hospital, and were audio recorded and transcribed verbatim. Transcripts were generated by a professional audio transcription service, and the researcher applied pseudonyms prior to analysis. A methodical audit trail was kept, ensuring reliability and transparency of processes during the project.

Data analysis

In total, 15 transcripts from people with acquired disability were analysed for this study (see Table 1 for full description of participant demographics). Analysis was guided by Liamputtong (2013). Accordingly, theme development followed an iterative process, with ongoing refinement through cycles of open, axial and selective coding. Open coding involved two members of the research team (EM and ER) each reading through all transcripts ($n = 15$), and identifying broad patterns within the data. Axial coding involved grouping key phrases with common meaning to form a list of codes that were clustered to develop categories (Liamputtong 2013). The list of codes was uploaded to Nvivo selective coding, whereby transcripts were re-read by two authors (EM and LW). In-depth discussions with senior members of the research team (JD and LC) of the coding framework allowed

higher level analysis of the data and concepts identified from the data. Contrasting quotes were identified and explored between three members of the research team (LC, LW and EM) to ensure the voice of the participants was grounded within the data and themes presented. One author, LW, has lived experience of acquired disability and hospital discharge, as well as professional research experience.

Results

Open and axial coding stages identified three themes depicting distinct phases of the discharge process for patients (Fig. 1). The first theme, being in hospital, comprised two sub-themes related to the experiences of people with acquired disability during their hospitalisation. The second theme, preparing to return to the community, captured the transitional experiences of shifting from hospital to a community setting, with the sub-themes exploring the practicalities required to successfully leave hospital. The third and final theme, returning to the community, described the often overwhelming initial experiences of leaving the hospital setting, and navigating the new reality of living with disability.

Theme 1: Being in hospital

People with acquired disability spent prolonged periods as hospital inpatients, often away from home for many months while awaiting discharge. The sub-themes represent the emergence of issues with choice and control, and interactions with health professionals that ultimately impacted their discharge trajectory. Socially, people highlighted the importance and value of pre-existing and new social support networks.

Interactions with health professionals

People with acquired disability emphasised the need for clear communication between hospital staff and themselves. This was especially crucial for people with aphasia, who felt excluded from planning meetings, and relied heavily on informal supporters to navigate systems and discharge planning. During transitions between wards, some participants reported feeling uninformed, and that changing between teams led to confusion about roles and responsibilities. Having a key person to facilitate and encourage conversations was seen as highly beneficial to ensure consistent communication, handover between teams and to inform planning.

> We didn't know what was happening. We didn't know what the plan was … And then he got appointed a Primary Care Person … And from that moment it was fantastic. We had a go-to person who was really responsive and it was crucial. Ned's wife (communication partner for person with stroke, aged 58 years)

Many people with acquired disability reported having limited say over their therapeutic timetables, mealtimes, visitors and discharge time frames during hospitalisation. Some people reported that staff made assumptions about their choices, reducing the involvement of the person with acquired disability and inhibiting their ability to express their preferences. People wanted to be included in meetings, goal setting and planning for the transition after discharge.

> They had this meeting without me and without my daughter present, the doctors and the physios and the OTs and that, for my discharge. Beth (person with a below knee single limb amputation, aged 63 years)

People valued support from their allied health team when they were able to effectively navigate the NDIS and enable access to the support they required for hospital discharge. People particularly appreciated input from allied health professionals when they communicated with them respectfully, and their goals centred around the person with disability's needs and preferences.

> Whatever I do in the rehab setting of the hospital, it was always geared towards going home. It's a practical rehab. When they're making me do something, it's always about

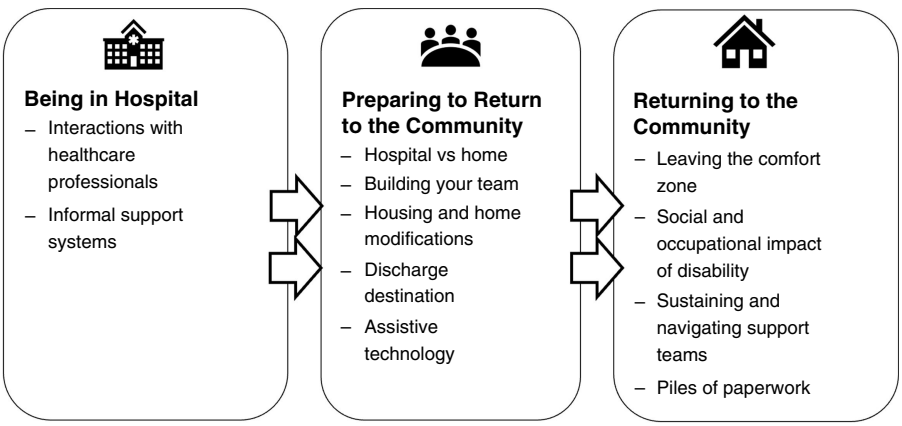

Fig. 1. The hospitalisation and discharge journey for people with acquired disability.

how would I apply this at home. Carlos (person with stroke, aged 39 years)

Some people reported needing more education about processes and medications, as they were expected to manage independently once discharged. Individuals with newly acquired SCI often reported a gap in education from health professionals around continence management. For some people, discharge was a rush or a surprise.

[discharge was] very rushed… it was, very overwhelming for me. Van (person with SCI, aged 43 years)

Informal support systems

The importance of informal support networks, such as partners, children and friends, was emphasised throughout a prolonged hospitalisation. Newly formed social connections in the hospital provided much valued support from others with a similar experience. People often relied on their pre-existing informal support systems for practical support during hospitalisation, and for assistance with day and overnight leave. Most people reported wanting to focus on their physical rehabilitation during their admission, and often felt overwhelmed with completing paperwork for things like NDIS and income support. Informal supports were often relied on for these administrative tasks.

I said to my – my partner, "Oh look, can you help me with that [paperwork] because I'm just not in the right headspace for all this sort of stuff?" Peter (person with SCI and ABI, aged 53 years)

Theme 2: Preparing to leave hospital

The theme, preparing to leave hospital, depicted the experiences of discharge planning from the perspective of people with acquired disability. Hospital clinicians assessed and made recommendations to meet functional and support needs at home, while people with disability began to anticipate life post-discharge.

Hospital versus home

People with acquired disability reported the hospital environment was designed specifically for people with additional accessibility needs. This included wide hallways, accessible bathrooms and chairs that are easy to get out of, contrasting to most home environments that were not typically designed with disability access in mind. Although some found the hospital environment restrictive, others described feeling secure in the hospital setting and within the regular routine of the ward.

I started to understand the hospital itself and that, know how to run it, where everything was. I just didn't want to move. Winston (person with stroke, aged 45 years)

In preparation for discharge, allied health teams supported people to access their home and the community through weekend and overnight leave. This practice allowed people to identify difficulties and develop strategies to overcome these accordingly. Although this leave was designed to support a smooth transition home, many participants, on reflection, did not feel rehabilitation adequately prepared them for life after discharge.

I went home for weekend leave, from a Friday night to Sunday night, for the last four weekends. … I think they thought that the transition of me coming home was going to be pretty seamless. But, you know, the reality of the situation just sunk in when I got home. Van (person with SCI, aged 43 years)

For some, the cost of transport made it difficult to take leave. For others, especially those who were single, the prospect of returning home alone was daunting. Home visits for these participants was difficult to coordinate, and those without an approved NDIS plan often relied on informal networks for overnight support.

most of my rehab journey, I've been by myself, and just with my friends. Van (person with SCI, aged 43 years)

Some hospitals provided on-site transitional living units, where people could experience reduced physical assistance in a community-like setting. These units facilitated increased independence while providing access to allied health professionals to address any concerns.

That was kind of helpful to transition me [home]. Rather than just – hanging out on your bed and not doing a lot; you're in a self-contained unit. I eventually started to not need any help showering or dressing or anything like that…. So that kind of accelerated my progress and my recovery. Peter (person with SCI and ABI, aged 53 years)

An assessment of the home environment, typically by an occupational therapist, was often necessary to identify equipment and home modification needed for a safe and effective discharge. However, some people reported that hospitals had stopped conducting these visits at home due to COVID-19 restrictions and staff resourcing constraints, opting to do them remotely or through information collected from family or friends. Interviews conducted post COVID-19 restrictions indicated that remote home assessment has continued. People with acquired disability reported this method of assessing accessibility needs was inadequate, preferring the assessment to be physically undertaken in their home.

Well, just maybe, they could have come to my home environment and helped me manage setting it up, or more – a lot more user-friendly for me. Van (person with SCI and ABI, aged 43 years)

Building your team

During the inpatient phase, hospital discharge planners supported individuals to build their post-discharge support team. They would arrange disability support workers and support coordinators from different agencies to visit the hospital and meet them. Support workers sometimes received training from the inpatient team to learn how to support the individual. People with acquired disability wanted support workers who were friendly, skilled, proactive and reliable. One participant, who was from a non-English-speaking background, described challenges with sourcing support workers who spoke his primary language. This was critical, because his expressive language in English was significantly impaired following his stroke. Individuals highlighted the importance of recruiting support workers and booking in therapists in the community before leaving hospital.

> have a support outside, definitely, you know, line everything up early. Like all the physio, all the OT and … whatever they need … line that up early because, you know, when you're out there trying to look for it, it takes longer. James (person with SCI, aged 53 years)

Housing and home modifications

Sourcing suitable housing was identified as a common reason for discharge delays for people with acquired disability. For people who were unable to return to their pre-hospital home, identifying housing that is affordable, accessible, in a desired location, and can accommodate a family was difficult and time consuming. Often, existing housing required temporary or permanent modifications to ensure accessibility following an acquired disability. Accessing funding and home modifications was often a lengthy, complicated process through the NDIS.

Conversations between peers in the hospital revealed perceived discrepancies in funding decisions made about housing. The inequity led to an erosion of trust between people with acquired disability and the NDIS, as they could not understand the decisions that led to them receiving less financial support despite the perceived common diagnosis and support needs.

> Well probably the funding for the accommodation … I don't understand why they're paying his funding for virtually 12 months. We were only asking for maybe three months, if that. So I still don't understand it. It just doesn't seem right to me. Catherine (person with SCI, aged 60 years)

Some participants reported that hospitals considered the risks of delaying discharge against discharging them to a suboptimal home environment while awaiting home modifications. Often, the recommendations from the inpatient team involved assistive technology, compensatory strategies, increased reliance on formal or informal supports and temporary environmental modifications until community-based teams could implement permanent solutions after discharge.

> I was told it would be months before I could have a shower. Kevin (person with Parkinson's disease, aged 66 years)

Discharge destination

Deciding where to go after hospital discharge was a significant discussion between people with acquired disability, their families and health professionals. Participants described a difficult balancing act between hospital recommendations, funding limitations, rehabilitation progress and the personal desire to return to familiar surroundings. As rehabilitation continued, some people realised that they would require temporary housing when they were clinically ready for discharge, but going home was not yet an option. Some people returned to live with family, whereas others moved into medium-term accommodation while they waited for housing, modification or to fully understand their longer-term support needs.

> you couldn't go back to where you lived before. Catherine (person with SCI, aged 60 years)

Assistive technology

Many people required assistive technology, including shower chairs to support personal hygiene and hoists to enable safe transfers. Discharge delays were often attributed to delays in sourcing equipment. As a temporary support, some hospitals provided equipment as a short-term measure to enable efficient discharge. Long-term equipment needs were not always known at the point of discharge, as people's physical recovery often continued past the transition into the community. Given that equipment can be bulky and take up significant storage, people valued the option of borrowing or hiring equipment, so that they were not left with items that they no longer needed taking up valuable space in their homes. As with arranging supports and appointments while hospitalised, most participants emphasised the importance of having equipment prior to discharge due to long delays once discharge.

> It's a little bit disappointing that again, six weeks later I'm still waiting for them [assistive equipment] to come. … because I've left the hospital, you're gone. Catherine (person with SCI, aged 60 years)

Theme 3: Returning home

Returning home from hospital presented participants with a sense of overwhelm, as they left the familiar environment of the hospital and attempted to adjust to life back in the community. Returning home was a significant transition

characterised by establishing or maintaining a local team, re-establishing social and informal support networks, and navigating the complexities of managing an acquired disability.

Leaving the comfort zone

Although all people with acquired disability were identified as medically ready for discharge by the clinical team, they often reported a sense of trepidation in leaving the hospital environment. Hospitals represented a structured, accessible and predictable environment with formal support for meal preparation, personal care, and readily accessible medical, nursing and allied health support. For many people, the return home where there was typically much less structure and support was a daunting prospect. People reported the hospital environment had masked the challenges of their newly acquired disability and were often surprised by how difficult things were at home. Some people felt a lack of follow-up support from the hospital, making unanticipated challenges difficult to manage:

> It was strange – all of a sudden you're on your own. Kevin (person with Parkinson's disease, aged 66 years)

Some people reported a lack of professional support to address the emotional and psychological adjustment of living with a life changing disability. The transition from hospital to home was often perceived as coming quickly for participants, with discharge dates changing due to hospital staffing, functional recovery, and availability of NDIS funding and support. People with acquired disability reported needing more professional support with strategies for adjustment, acceptance and preparation for transition to being more independent after a long-term hospitalisation.

> I really need some psychological support, so I'm on the waitlist for that. Renee (person with SCI, aged 51 years)

Social and occupational impact of disability

Individuals noted the difficulties adapting to home life, as early shifts in meaningful occupations and life roles became apparent. People with complex needs reported adjusting from the busyness of the hospital rehabilitation schedule to the daily home routine could be challenging. Some people reported missing the sense of community that had been cultivated within the hospital setting, and that their functional impairments impacted their social connections. People with aphasia relied on their friends and family to support communication in social environments, as well to educate carers and support workers.

> you're going from a hospital system where you had a very regimented routine… and they move you to home where you're sitting around doing nothing. Winston (person with stroke, aged 45 years)

Sustaining and navigating support teams

Participants found that maintaining their support teams post-discharge required significant effort. Managing appointments, hiring and firing support workers, advocating for their needs, and handling NDIS plans were all part of their new responsibilities. Despite inpatient training, continuous mentoring and adjustment were necessary, particularly for those who had to adapt to support workers in their homes.

> I'm used to being Mr Independence and it's like suddenly I've got this person coming into my house at night-time, telling me they've got to put me to bed. I'm like, 'I'll go to bed when I want to'. Blake (person with spina bifida, aged 53 years)

For pre-existing NDIS participants, trusting pre-existing providers facilitated smoother transitions from hospital to home. Participants valued hospitals engaging with their established support teams to leverage existing relationships.

> I have trust issues and I've got to get used to someone before I really open up to them. Blake (person with spina bifida, aged 53 years)

Navigating the system post-discharge was challenging, especially in coordinating care between disability, medical and rehabilitation services. Many felt isolated in bridging these gaps, often unaware of what they needed to know to access necessary services.

> But the fact that you don't know what you don't know, you still don't know what to ask. James (person with SCI, aged 53 years)

Support from specialised community services (e.g. SCI outpatient teams) and quality NDIS coordinators was crucial. These experts provided continuous support, and helped navigate the NDIS and community services, easing the transition from hospital to home.

> We started with the support coordinator because, while you're in hospital you always have to start the NDIS process. So it was good to have a support coordinator while I was in the rehab, definitely, and helped my wife navigate through the – the process. James (person with SCI, aged 53 years)

For individuals who were single, employing, coordinating and navigating community support teams was an additional challenge. This was amplified for people with cognitive impairment who reported a strong sense of overwhelm managing personal timetables and directing their own therapeutic care team.

> there's so many appointments. I can't remember. Van (person with SCI and ABI, aged 43 years)

Piles of paperwork

The transition from hospital to home came with significant amounts of paperwork. People reported feeling overwhelmed with written information, leading to some feeling like they could not absorb the content provided. Finding the paperwork that needed to be completed and forms was also challenging when given so many pages of information. Many people felt the content provided was not personalised or specific, which led to them being less engaged with the materials.

> When you leave you are given everything all at once. And it's a little hard for me – to devour and turn pages and, you know, leaf through the information. So it's difficult. Kevin (person with Parkinson's disease, aged 66 years)

People who were discharged prior to their NDIS plan being approved reported significant challenges navigating the NDIS and the associated volume of paperwork. Two people with aphasia who were discharged prior to their NDIS approval found the system difficult to navigate with a language impairment.

> they're rubbish really, [people] who have problems expressing themselves require specialist check-in and translation to make sure they have it. They require a specialist interpreter. Ned (person with stroke, aged 58 years)

Discussion

The findings of this qualitative study highlighted important implications for policy and practice across the health, disability and housing interface. Mirroring previous research (New 2015; Abrahamson *et al.* 2017; Houston *et al.* 2020; Cubis *et al.* 2024), delays in access to suitable housing, home modifications, assistive technology, and supports emerged as barriers to effective and timely discharge. The present study highlighted the challenges faced in the hospital system when grappling with the risks of extending a hospitalisation versus discharging to a suboptimal destination. Once discharged, people often reported feeling overwhelmed by the amount of administration and coordination required to source and maintain supports, while also navigating the novel experience of living in the community with acquired disability.

In line with previous research (Gonçalves-Bradley *et al.* 2022; Cubis *et al.* 2024), having effective coordination was essential. When provided, people with SCI in this study reported the benefits of receiving specialised coordination of health and disability supports. Interestingly, previous research into an ABI transitional rehabilitation service incorporating inpatient multidisciplinary case management and community follow-up post-discharge found that although people reported being 'steered to the right services', many also felt that their rehabilitation needs were not matched to what was provided (Foster *et al.* 2022). A subsequent study found that 71% of people with ABI reported at least one unmet need post-discharge, and that accessing the transitional rehabilitation service did not mitigate this (Laurie *et al.* 2023). It is noteworthy that in the present study, external factors, such as the NDIS and housing, represented a source of dissatisfaction and unmet needs, indicating that successful hospital discharge is contingent on factors outside the control of the healthcare system. This finding aligns with a 2023 review of the NDIS that highlighted a lack of clear plans and communication between the NDIA and hospitals as a contributor to delayed discharges (Commonwealth of Australia 2023).

As identified in previous studies (New 2015; Abrahamson *et al.* 2017; Cubis *et al.* 2024), visiting the home overnight and for weekends was highly valued as an opportunity to gain real-world experience outside of the hospital. People required multiple home visits to gain a greater appreciation for the reality of leaving hospital; however, there were financial and logistical barriers that precluded some people from being able to achieve this. Given the importance of home visits in facilitating a successful discharge, overcoming these barriers to supporting people with acquired disability to access these should be a high priority for hospital discharge planners.

It is well established that the support needs of people with acquired disability may not be fully understood for many months post-hospital discharge as they make functional recovery and adapt to permanent impairments (Olver *et al.* 1996; Nas *et al.* 2015). In the present study, some people felt overwhelmed by the amount of equipment they received, but did not need long term. Foster *et al.* (2022) found that some people with ABI felt they received too much rehabilitation in the weeks post-discharge, but also were concerned that therapies were reduced too soon. Given that people's functional status and psychological readiness for equipment and supports are variable and difficult to predict soon after discharge, time-limited flexible funding for rehabilitation services and supports may allow people to receive the optimal level of supports they need to achieve their full rehabilitation potential. Early funding for equipment hire rather than purchase may allow some people to return home with equipment that can be returned or exchanged as their needs change.

Expanding on previous research in hospital discharge for people with disability and complex needs, this study presents a contemporary, policy-relevant perspective. Although previous research has identified logistical delays and service gaps within the hospital systems (Abrahamson *et al.* 2017; Houston *et al.* 2020; Cubis *et al.* 2024), this study highlights the complex interplay of external factors, such as NDIS responsiveness, support coordination and housing availability. Furthermore, the results reveal inconsistencies in home visit practices and transitional living programs, reflecting a need for structured, best-practice guidelines for proactive planning to ensure a timely transition when somebody is

ready for discharge. Finally, this study provides novel insights into the experience of building and maintaining support teams, and the significant administrative burden placed on individuals during and after hospitalisation. This skillset is assumed under the NDIS model, but is especially challenging for those with limited informal support or cognitive impairment (Fitts *et al.* 2019).

Ultimately, the experience of participants in this study was characterised by a difficult transition from hospital to home. As described in previous studies (Abrahamson *et al.* 2017; Borg *et al.* 2020; Cubis *et al.* 2024), there is a need for discharge planning to occur early in a hospital admission, and for coordination and continuity between disciplines within the hospital, post-discharge and in the community. People require multiple opportunities to spend time in their home environment to increase preparedness for returning home. Despite this, adjustment to life with acquired disability will likely continue to be a complex, nuanced and individual process. Therefore, people should be funded to receive expert psychosocial support to navigate the complexities of living with life with acquired disability and complex support needs. Given the strong evidence that maintaining and rebuilding social connections is associated with better psychological well-being in the context of neurological disability (Haslam *et al.* 2008; Tabuteau-Harrison *et al.* 2016; Cubis *et al.* 2024), and the emphasis on the importance of social connections in the present study, social contact should be included as an area of priority throughout the hospitalisation and discharge trajectory.

Implications for practice

The current findings highlight the crucial role of an early and sustained focus on discharge planning during hospitals admission for people with acquired disability. To support effective discharge, hospital clinicians should ensure that administrative paperwork, including applications for NDIS, welfare and transport access, is started and submitted early in the hospital admission, even if the final prognosis is not clear. People with acquired disability and their close others require multiple opportunities to spend time in the home environment prior to discharge. Hospital clinicians should check in after each home visit to gauge the barriers encountered, and the person's evolving readiness to discharge from hospital. Remote home visits to assess the safety of the home, and the need for modifications and equipment did not work well for all participants. Further research is needed to compare the efficacy of remote versus face to face home visits in supporting a smooth return to community living. Where possible, support workers and support coordinators should engage with the person with acquired disability during their inpatient stay to receive training and handover. Successful discharge is contingent on effective hospital and disability support systems, including a funding scheme that provides required supports in a timely manner, and expert co-ordination that extends post-discharge.

Limitations

The participant selection process involved convenience recruitment, and there is a notable lack of participants with traumatic brain injury. Despite the diversity in participants' demographic profiles and disability types, the research was carried out within a particular socio-cultural framework. Although the goal of qualitative research is not to extrapolate results to a wider clinical demographic, detailing the demographic and clinical specifics of participants might help readers determine the applicability or potential relevance of the study's outcomes to their specific context and patient cohort. Due to recruitment occurring within a metropolitan and regional hospital, results cannot be extrapolated for rural and remote communities due to unique challenges faced within these communities.

Discharge destination can significantly impact post-acute recovery, influencing long-term rehabilitation and social integration outcomes (Schrage *et al.* 2023). Although participants highlighted the role of social networks in easing transitions, our study did not systematically capture pre-injury living situations, limiting our ability to assess the role of pre versus post living arrangements. Recruitment was protracted due to policies implemented as a result of the COVID-19 pandemic (Spagnolo *et al.* 2020; Willis *et al.* 2021; McGuinness *et al.* 2022). Furthermore, some participants' experiences were likely influenced by the changing processes resulting from hospital COVID-19 responses. This study relied on self-reported experiences of hospitalisation and the weeks following discharge. Retrospective recall can lead to bias, particularly from people experiencing cognitive impairment (Nakling *et al.* 2017). Although the rich lived experience of people with disability is a strength of this study, it captures only one perspective of the hospitalisation and transition process. Further research exploring the experiences of healthcare professionals and informal supporters would provide a more comprehensive understanding and deepen the current findings.

Conclusion

This study highlights the unique experiences of people with acquired disability navigating the hospital and disability sector following their return to the community. The complex interface and transition between the hospital and the disability sector highlighted opportunities for increased collaboration and simplified processes to support people during a challenging time psychologically adjusting to an acquired disability. Further research is needed to explore if interventions across the hospital and disability sectors can improve the experience of discharge and improve long-term outcomes.

Given the complex, trans-system nature of hospital discharge, meaningful engagement and integration of people with lived experience is essential to inform the development and evaluation of processes, procedures and programmes (World Health Organisation 2023). Thus, future studies should adopt a co-design approach with people with acquired disability, close others and stakeholders from hospital, disability and housing sectors to address gaps, barriers and facilitators to successful hospital discharge.

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