

**O** ASSBI

# 'Well, what are you going to do when you're out there?': a scoping review of successful hospital discharge for people with acquired disability and complex needs aged 18-65 years

Lee Cubis<sup>A,B,\*</sup>, Eve Roseingrave<sup>A,B</sup>, Emily Z. Gosden-Kaye<sup>A</sup>, Di Winkler<sup>A,B</sup> and Jacinta Douglas<sup>A,B</sup>

For full list of author affiliations and declarations see end of paper

\*Correspondence to: Lee Cubis Summer Foundation Ltd., PO Box 208, Blackburn, Melbourne, Vic. 3130, Australia

Email: lee.cubis@summerfoundation.org.au

Handling Editor: Petrea Cornwell

Received: 9 June 2023 Accepted: 17 July 2023 Published: 17 January 2024

**Cite this:** Cubis L et al. (2024) Brain Impairment **25**, IB23088. doi:10.1071/IB23088

© 2024 The Author(s) (or their employer(s)). Published by CSIRO Publishing on behalf of the Australasian Society for the Study of Brain Impairment.

This is an open access article distributed under the Creative Commons Attribution-NonCommercial-NoDerivatives 4.0 International License (CC BY-NC-ND)

**OPEN ACCESS** 

#### ABSTRACT

Background. Young adults with acquired disability and complex support needs often experience significant delays to hospital discharge, resulting in high costs for hospital systems and poor outcomes for people with acquired disability. A scoping review was completed to explore the components of successful hospital discharge for people with acquired disability and complex support needs aged 18–65 years. Methods. A systematic search of five databases was completed to identify studies that reported on hospital discharge outcomes for young people with acquired disability and complex support needs. Results. Many experiences of hospital discharge were characterised by delays, unmet needs and poor implementation of supports that align with an individual's needs and preferences. Components of a successful discharge included coordination and continuity of care from admission through to discharge and transition back to the community; the involvement of people with acquired disability and close others in discharge planning; and sufficient preparation for discharge, such as arranging timely and appropriate housing and community supports. Each of these individual components of discharge was influenced by the quality of communication between stakeholders throughout the discharge trajectory. Conclusion. Improving coordination of care, early initiation of applications for funding and supports and involvement of people with acquired disability and close others may enhance positive outcomes of hospital discharges for people with complex needs.

Keywords: acquired brain injury, complex needs, disability, disability support, hospital discharge, housing, spinal cord injury, stroke.

# Introduction

Acquiring a permanent disability is typically traumatic and unexpected, and usually results in a period of hospitalisation and rehabilitation (DeVivo *et al.* 1995; Duncan *et al.* 2005). Young people (i.e. aged 18–65 years) who acquire disability with complex support needs (e.g. acquired brain injury (ABI), spinal cord injury (SCI)) face lengthy hospitalisation and uncertainty around where and how they will live post-discharge (Holloway *et al.* 2019). Quality discharge planning can facilitate a successful transition back into the community; however, pressures on hospitals for fast discharges place people at risk of poor discharge outcomes, such as essential supports not being in place in the community or being discharged to residential aged care (RAC) (Foster *et al.* 2007; Barry *et al.* 2019).

Young adults with acquired disability who are hospitalised often require complex and multifaceted intervention, with their hospital stay typically extending from acute care to subacute care (e.g. rehabilitation) and post-discharge follow up in the community. Often, they cannot return to their previous living situation and require specialised support services, housing and/or equipment to return to the community (Holloway *et al.* 2019). Complex support needs arise when a person experiences multiple significant health, disability and/or behavioural needs within a complex environment. This cohort often includes people with ABI, SCI, stroke or neurological conditions that are newly

Brain Impairment 25 (2024) IB23088

acquired (e.g. Guillain-Barré syndrome) or progressive neurological diseases, such as multiple sclerosis, that have progressed to a point where health and disability supports are required (Rankin and Regan 2004; Collings *et al.* 2016). For these individuals, the transition from hospital to home represents a major milestone. The prospect of hospital discharge can represent a time of anticipation, hope and fear, and is frequently characterised by a period of significant adjustment (Turner *et al.* 2008, 2011; Levack *et al.* 2010; Nalder *et al.* 2012).

Many young people with acquired disability and complex needs face long delays to hospital discharge resulting in worsening health, functional impairment and increased psychological distress (Rojas-García *et al.* 2018). For hospitals, delays to discharge are costly and disrupt operational flow, affecting the admission of new patients who require hospital care (Destino *et al.* 2019). In a study in Australia, out of 200 sequential admissions, 33% of discharge delays related to non-medical reasons and amounted to a total cost of \$764 800 (Buist *et al.* 2014). Although any delays to discharge are a costly exercise for hospitals, expense increases considerably for people with complex support needs (Kritikou *et al.* 2016; Landeiro *et al.* 2016).

Implications for patients discharged too soon without adequate housing or supports are substantial. Qualitative analysis of submissions into a senate enquiry exploring the adequacy of RAC for young adults with disability and complex needs in Australia revealed that discharge was perceived by those who had been discharged to RAC to have been organised quickly with limited knowledge or lack of exploration of alternative options to RAC (Barry *et al.* 2019). A scoping review of 11 studies highlighted that discharges to RAC result in substantially poorer health, social isolation and quality of life for young people with acquired disability and complex support needs; hence, RAC is not an acceptable discharge destination (Oliver *et al.* 2020).

Discharge planning, or the organisation of required supports following hospital discharge, is an iterative multidisciplinary process of assessment, information gathering, communication and coordination (Gronda *et al.* 2011; Gonçalves-Bradley *et al.* 2022). Aims of discharge planning for a person with disability can include returning to the community, increasing or maintaining functional independence, and returning to a lifestyle aligned with their needs and preferences (Taha and Ibrahim 2020).

A recent systematic review on hospital discharge planning concluded that a structured discharge plan likely reduces length of stay and improves readmission outcomes and patient satisfaction (Gonçalves-Bradley *et al.* 2022). Although this review included one study with participants recovering from stroke, the average age range of participants across the included studies was 60–84 years. Further, most studies focused on people with health conditions (e.g. heart failure) and people recovering from surgery. Other research into discharge planning has focused on acute care settings (Lisby *et al.* 2019), people with mental health conditions (Haselden *et al.* 2019; Ådnanes *et al.* 2020; Smith *et al.* 2021), older adults (Popejoy *et al.* 2009; Altfeld *et al.* 2013; Durocher *et al.* 2019), people with lifelong disability (e.g. cerebral palsy; Manikandan *et al.* 2022), and people with stroke (Mayo *et al.* 2000; Langhorne and Widen-Holmqvist 2007; Langhorne *et al.* 2017). Such research, however, cannot be generalised to a population of young people with acquired disability and complex needs due to the variability and nuances associated with the discharge supports required by this population and the often-sudden onset of disability.

Clinical practice guidelines are useful for discharge planning due to the substantial variation in discharge planning processes and contexts internationally, locally and even within the same hospitals (Victor and Vetter 1988; Shepperd et al. 2013; Gonçalves-Bradley et al. 2022). Current clinical practice guidelines for people with disability typically relate to a specific health condition rather than being applicable across conditions and relating to people with acquired disability and complex needs (e.g. NICE 2013; SIGN 2013; Stroke Foundation 2017). Guidance across health conditions would be useful for health professionals as (1) disability and complex support needs can arise from a wide range of acquired health conditions; and (2) discharge planning requires assessment and co-ordination of supports across health, housing, and disability services irrespective of disability type. As the policy landscape surrounding housing, funding and supports for people with acquired disability has changed considerably in recent years (e.g. the implementation of the National Disability Insurance Scheme in Australia; NDIS 2021), this guidance should be based on contemporary sources of evidence relevant to hospital discharge for people with acquired disability and complex needs. Accordingly, a scoping review was undertaken to identify and integrate the findings of peer reviewed studies that report on the experience of hospital discharge for young people with acquired disability and complex needs from the perspectives of people with acquired disability and complex needs, close others (e.g. partners, family, friends) and health professionals.

# Method

A scoping review method was employed to gain a broad insight into recent literature highlighting the components of a successful discharge for young people with acquired disability and complex needs (Arksey and O'Malley 2005). Guided by Arksey and O'Malley (2005), the present scoping review entailed the following stages: (1) identifying the research question, (2) identifying relevant studies, (3) study selection, (4) charting the data, (5) collating, summarising and reporting the results, and (6) consultations. The Prisma Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation guided the reporting of the methods and results (Levac *et al.* 2010). This review was guided by the research question: what are the key components of a successful hospital discharge for young people with acquired disability and complex needs?

# Consultations

A person with lived experience of acquired disability (LW), employed as a research assistant with previous professional research experience, was actively involved in all stages of the review. The reviewers engaged with LW during the initial stages of the scoping review to outline the review and create a plan for consultation. The consultation role was to identify gaps in the literature, contribute to contextualising results, and provide feedback from a lived experience perspective on the language used and the findings and conclusions of the review. LW reviewed the literature review, preliminary framework, results, and conclusions. LW's feedback informed the interpretation and presentation of the review.

# Search strategy

A search of five databases including MEDLINE, CINAHL, SCOPUS, AMED, and EMBASE was conducted for literature published between December 2014 and January 2019. These databases were identified as having clear relevance to the aim and comprehensive coverage of associated literature. This time period was selected to include literature that

Table I. Literature search inclusion and exclusion criteria.

reflected recent practice and policy contexts. An individual search strategy was devised in consultation with a research librarian for each database using the following sets of keywords related to populations of interest and hospital discharge:

- 1. Acquired disability and complex needs, acquired brain injury, traumatic brain injury, spinal cord injury, brain injuries, multiple sclerosis, head injuries, hemiplegia, tetraplegia, paraplegia, progressive complex needs.
- 2. Discharge summary, discharge planning, discharge plan, discharge procedure, hospital discharge, discharge practice, discharge program, discharge intervention.

# Inclusion and exclusion criteria

The full inclusion and exclusion criteria are presented in Table 1. Only original research published in English, in peerreviewed outlets, and reporting quantitative, qualitative and/or mixed methods designs was considered for inclusion. Studies must have related to hospital discharge for young people aged from 18 to 65 years with acquired disability and were excluded if not published in a peer-reviewed journal, or if the study had a predominant focus on a population outside of people aged 18–65 with acquired disability and complex needs (e.g. children, people with developmental disability, people without high or complex needs). If the study sample included people with and without complex support needs/severe level of injury, it was still included if

Factor	Inclusion	Exclusion
Age	18–65 years	Elderly, older, geriatric, child, paediatric, neonate
	Mean age <70	Mean age >70
	Mean age >18	Mean age <18
Publication type	Peer reviewed journal	Book chapter, commentary, editorial, conference proceedings, opinion articles, study protocols, review
Time period	Published December 2014–April 2021	Before December 2014
Language	English	Not English language
Disability	Disability as a result of ABI, TBI, MS, Huntington's disease, SCI, stroke, high support needs/complex needs	Dementia, mental health condition (e.g. anxiety/depression), developmental disability (e.g. intellectual disability, cerebral palsy), psychosis, chronic health conditions
Hospital (setting)	Inpatient rehabilitation, hospital-linked specialist care centre, primary care	Discharge to ICU/other acute medical ward, discharge to other rehabilitation ward, psychiatric hospital
Including words	Transition, movement, journey, discharge, plan, discharge intervention, summary, program, practice, procedure, patient discharge, hospital discharge, discharge policy, care plan	Military discharge
Outcomes	Has extractable data on discharge planning	Not related to discharge planning (i.e. the focus of the paper does not include discharge plan)
Functional assessment <sup>A</sup>	Score of functional assessment (e.g. Functional Independence Measure, Barthel Index) that indicates high or complex support needs; qualitative data indicating high or complex support needs	No inclusion of the function, level of support or severity of injury of participants

<sup>A</sup>Added following full text screening.

data relating to those with complex support needs/severe level of injury could be isolated and extracted.

Following the database searches, all titles were imported into Covidence (Covidence Systematic Review Software 2022), and duplicates removed, for screening of title and abstract by two reviewers (EGK and ER) who applied the inclusion and exclusion criteria outlined in Table 1. An interrater agreement rate of 96% with a kappa score of 0.63 was obtained following title and abstract screening of studies gleaned from the initial literature search indicating substantial agreement (McHugh 2012). Conflicts were resolved through discussion by reviewers EGK and ER.

Due to a significant time lapse between the initial search and the preparation of the results of the scoping review, a second search was completed to include publications between January 2019 and April 2021. The literature searches were completed by the reviewers (EGK and ER) who had completed the initial search, and the same search methods and study screening protocol were followed.

A flow diagram outlining the selection of studies for the scoping review is provided in Fig. 1. As shown, the first search of electronic databases identified 9533 potentially relevant articles. Reference lists identified no new potential studies. After excluding duplicates and screening titles and abstracts, 182 studies were identified as potentially eligible. Two authors (ER and EKG) reviewed the full texts of the 182 articles. Overall, six studies met the inclusion criteria.

The second search for literature published between January 2019 and April 2021 (Fig. 1) yielded 5038 studies, including 2037 duplicates. A total of 3001 titles and



Fig. I. PRISMA flowchart of the selection of studies.

abstracts were screened, with 2913 studies excluded and 88 studies eligible for full text screening. Ten studies met the inclusion criteria for the second search with an overall total of 16 studies included for the scoping review.

# **Data extraction**

Two authors (ER and EGK) created a table in Microsoft Excel to extract and prepare data for analysis. Extracted data included: author, study aim, date of publication, country of publication, study design, participant inclusion criteria, participant type (person with disability/close other/health professional), number of participants, primary disability/ injury sustained, level or severity of injury, age of participants with disability, length of hospital stay, details of hospital/study setting, measures used, interventions completed, main study findings, and outcomes associated with hospital discharge and hospital discharge planning.

# Collating, summarising and reporting the results

Quantitative results (e.g. descriptive statistics, survey responses, hospital timeframes, outcome measures), study authors' interpretations and implications relevant to the research questions of this review were entered into the data extraction spreadsheet. Qualitative results and findings were entered into NVivo for content analysis. Results of each study were reviewed and summarised individually by authors LC, ER and EGK. A preliminary framework was developed by these authors outlining overarching concepts of discharge planning and specific themes within the overarching concepts. The preliminary framework was reviewed by LW and two independent reviewers (JD and DW), then all studies were analysed using this framework. Iterative discussions between the authors and LW focused on the integration of quantitative and qualitative findings.

# Results

Sixteen studies were included in the review. The characteristics of included studies are presented in Table 2. The studies were conducted in eight countries, including eight in Australia, two in China, and one each in Malaysia, Italy, New Zealand, Norway, England and the United States of America (USA). Study populations included people with acquired disability (nine studies), close others (two studies), close others and people with acquired disability (two studies), health professionals (one study), and health professionals and people with acquired disability (two studies). Regarding disability type, studies included people with ABI (including stroke and traumatic brain injury; 11 studies), SCI (three studies), ABI and SCI (one study) and various disability types (one study). Six studies used a quantitative methodology, eight used a qualitative methodology, one

used a mixed methods approach, and one used a case study design. The focus of individual studies varied but included understanding barriers to and efficiencies of discharge (New 2015; Redfern et al. 2016), evaluation and feasibility of discharge-related interventions and services (Borg et al. 2020; Chu et al. 2020), evaluating health and disability funding timeframes (Houston et al. 2020), understanding the hospital-to-home transition (Biester et al. 2016; Conti et al. 2016; Hodson et al. 2016; Abrahamson et al. 2017; Dwyer and Mulligan 2017; Fitts et al. 2019; Irgens et al. 2020; Hersh and Armstrong 2021), evaluating discharge documentation (Kable et al. 2018), evaluation of a transitional care model from hospital to the community (Qian et al. 2019), and development of an integrated care pathway for people recovering from stroke (Abdul Aziz et al. 2017).

# Components of a successful discharge

As illustrated in Fig. 2, four interrelated principles contributed to successful hospital discharge: (1) coordination and continuity, (2) preparation for hospital discharge, (3) tangible supports on hospital discharge, and (4) involvement of the person with disability and close others. Communication emerged as a crucial element in the successful implementation of each principle.

# **Coordination and continuity**

Coordination and continuity of care was described as important throughout the entire discharge continuum including within the health system, between hospital and community supports, between medical and allied health providers, and post-discharge.

Within the health system. Transitions were common during the hospital inpatient stay, including frequent changeover of health professionals, as well as physically moving between wards or hospitals (Conti et al. 2016; Redfern et al. 2016; Abrahamson et al. 2017). Problems arose when miscommunications occurred or there was a lack of cooperation between hospital wards. Further, people with acquired disability typically received input from multiple specialities and, hence, had numerous health professionals involved in their care (Conti et al. 2016; Redfern et al. 2016; Abrahamson et al. 2017). Challenges emerged when there was no centralised point of contact for information from the health team. When executed well, continuity and coordination allowed information to transfer between health professionals and wards, meaning that discharge planning could be a cohesive experience (Conti et al. 2016). Some people felt that a nominated person who coordinated the hospitalisation and discharge trajectory would improve continuity of care: 'if there was just one person that was dedicated to that family ... who could coordinate everything' (spouse of person with ABI; Abrahamson et al. 2017).

Author and year	Focus/aim	Participants and context	Sampling	Methodology	Outcomes
Abrahamson et al. (2017)	To explore the experiences of individuals with severe traumatic brain injury and their close others in the first month post discharge from an inpatient rehabilitation setting to living in the community	N = 20; patients with ABI ( $n = 10$ ) and close others (i.e. spouses/partners, adult children, friends; $n = 9$ ), recruited from 19-bed neurorehabilitation unit in an National Health Service (NHS) teaching hospital, England	Consecutive purposive sampling	Qualitative semi- structured interviews; critical realism	Participants reported inconsistent continuity and coordination of care during discharge; a dissatisfaction with discharge processes; poor communication between health professionals and participants; and persistence by close others required in the community to access services.
Abdul Aziz et al. (2017)	To design and obtain consensus an intersectional primary-care-led care pathway to manage stroke patients residing at home in the community was designed by a panel of expert stroke care providers	N = 23; expert panel group I $(n = 8)$ ; consultant neurologists $(n = 3)$ , family medicine specialists $(n = 5)$ ; expert panel group 2 $(n = 15)$ ; family medicine consultants $(n = 2)$ , rehabilitation physicians $(n = 2)$ , occupational therapists $(n = 2)$ , speech and language pathologists $(n = 4)$ , nurses $(n = 3)$ , Malaysia	Purposive sampling	Qualitative focus groups; modified Delphi technique	Gaps in transitional care were likely to occur post discharge from acute care. Two integrated pathways were developed to guide interdisciplinary approaches to intervention in the community following discharge. This included the development of guidelines around pathways to rehabilitation in the community and managing stroke-related swallowing problems, and a recommendation for caregiver screening.
Biester et al. (2016)	To assess how well individuals with TBI and their significant others felt, they were informed about the possible consequences of their injuries, and to assess satisfaction with regard to the type, quality, and quantity of information provided about TBI within the first 6 months after injury	N = 266; significant others (i.e. family, spouses/partners, friends; $n = 177$ ) and people with brain injury ( $n = 149$ ). The survey was distributed to state brain injury associations, rehabilitation facilities, support groups and health professionals in the United States of America	Online survey links distributed through brain injury associations, rehabilitation facilities, support groups and professionals	Quantitative online survey; descriptive statistics	People with TBI and their close others reported unmet information needs about brain injury on discharge. People with TBI who did not receive acute rehabilitation were less likely to report adequate information provision or satisfaction with services.
Borg et al. (2020)	To determine the influence of participation in a designated ABI transitional rehab service on outcome, in the context of a historical comparison group	N = 187; historical comparison group ( $n = 124$ ), transitional rehabilitation support group ( $n = 63$ ), tertiary ABI rehabilitation unit, Princess Alexandra Hospital, Queensland, Australia	Purposive sampling	Quantitative cohort study with a retrospective comparison	A multifaceted approach to discharge that begins prior to the transition and involves the patient can have positive impact for the person in terms of mental health, participation, and adjustment in the community.
Conti et al. (2016)	To explore the needs, emotional experiences, and positive and negative aspects of discharge of close others of individuals with SCI	N = 11; close others (i.e. spouses, parents, sibling and niece) of people with SCI, recruited from Spinal Cord Unit in an urban hospital, City Hospital Health and Science, Turin, Italy	Purposive sampling	Qualitative semi- structured interviews; phenomenology	Communication with patients and close others during discharge planning is essential. Close others have a significant role in providing support for the person with disability post discharge and should be involved in discharge planning.

#### Table 2. Characteristics of included studies.

(Continued on next page)

Author and year	Focus/aim	Participants and context	Sampling	Methodology	Outcomes
Chu et al. (2020)	Feasibility of a novel nurse-trained, family-member-delivered rehabilitation model for people with stroke in rural Southwest China	N = 61; people with stroke; intervention group ( $n = 31$ ), control group ( $n = 61$ ), patients recruited from a rural hospital in Chongqing, China	Purposive sampling	Parallel randomised control trial	Compared to usual care, a nursing intervention delivered by family members and supported through phone calls from nurses increased physical recovery for stroke survivors in rural Southwest China.
Dywer and Mulligan (2017)	To explore the interactions between health professionals and individuals with an SCI following discharge from inpatient rehabilitation	N = 6; people with SCI; recruited participants were living in the community in the Canterbury health district, New Zealand	Purposive sampling	Qualitative semi- structured interviews; thematic analysis	Understanding the roles and responsibilities of key community providers; provision of accessible information by health professionals; training of support workers in inpatient settings; and continuity of care can lead to better discharge outcomes.
Fitts et al. (2019)	To understand the lived experiences of Indigenous Australians during the 6 months post hospital discharge, identify supports accessed during the transition, and understand gaps in service provision	N = 11; people with TBI, recruited from three major trauma hospitals in Northern Australia: Royal Darwin Hospital; Townsville Hospital; Cairns base hospital, Australia	Purposive sampling	Qualitative semi- structured interviews; thematic analysis	Engagement in services on discharge was impacted by inaccessible or undisclosed information; physically or financially inaccessible services; and the person with disability having to coordinate multiple community-based services on discharge.
Hersh and Armstrong (2021)	To explore and document how the wife of a man with aphasia managed his discharge from hospital in the acute phase post stroke	N = I; spouse of person with stroke, person was admitted to public hospital and private hospital, locations unknown, Australia	Purposive sampling	Single case study in-depth interview and narrative thematic analysis	Involvement of close others/family can avoid inappropriate discharge planning decisions such as overestimating the capability of informal supports to provide daily care.
Hodson et al. (2016)	To understand the dimensions of home for people with stroke who had recently made the transition from in-hospital rehabilitation to home	N = 7; people with stroke, recruited from an inpatient rehabilitation centre in Princess Alexandra Hospital, Queensland, Australia	Purposive sampling	Secondary analysis of interviews from qualitative research study; template analysis	Informal supports were important in the discharge process. The availability of necessary home modificationd and the financial accessibility of community supports impacted engagement with discharge supports.
Houston et al. (2020)	To examine the NDIS participant pathway timeframes against discharge expectations for hospitalised adults with SCI or ABI and interrogate delays to discharge for the two groups	N = 54; people with ABI ( $n = 18$ ) and SCI ( $n = 36$ ), recruited from state-wide specialist rehabilitation services – brain injury rehab units (BIRU) and SCI rehabilitation unit, Queensland Division of Rehabilitation, Australia	Purposive sampling	Quantitative analysis of hospital administrative dataset	Patients with SCI and ABI experienced longer stays in hospital than was estimated. The most frequent reasons for delay included waiting for assistive technology, waiting for home modifications, obtaining appropriate housing, and waiting for loan equipment.

# Table 2. (Continued)

(Continued on next page)

## Table 2. (Continued)

Author and year	Focus/aim	Participants and context	Sampling	Methodology	Outcomes
Irgens et al. (2020)	To investigate how physiotherapists experience the way patient information is communicated across inpatient and community health care levels in ABI rehabilitation	N = 29; physiotherapists ( $n = 19$ ) and people with ABI ( $n = 10$ ), physiotherapists in primary and specialist health care levels and people with ABI who had been admitted to in- hospital rehabilitation in northern Norway were recruited	Purposive sampling	Qualitative semi- structured interviews, analysis of medical discharge summaries and reports; systematic text condensation	Written and phone-based communication between health professionals is essential for patient information dissemination and continuity of care. Siloed working from health professionals can disrupt continuity of care and communication channels during discharge.
Kable et al. (2018)	To evaluate transitional care for stroke patients during discharge, using expected discharge criteria	N = 54; people with stroke, recruited from regional territory acute rehabilitation hospital in Australia	Purposive sampling (hospital administrative dataset)	Quantitative cross sectional study	Discharge documentation was missing information around the mechanism of stroke; functional assessments; pending test results; types of support services required after discharge; and patient/ carer meetings with the multi-disciplinary stroke team. Readmission was associated with less discharge information provided to people with disability and close others.
New (2015)	To measure the prevalence of barriers to discharge, reasons for these barriers and measuring additional unnecessary days in hospital resulting from these barriers	N = 283; people with SCI, recruited from 12-bed adult inpatient unit spinal cord unit, located in a publicly funded hospital, Caulfield Hospital, Victoria, Australia	Purposive sampling	Quantitative cross sectional study	Deficits in discharge documentation were recorded in mechanism of stroke; functional assessments; pending test results; support services required after discharge and patient/carer meetings with stroke team.
Qian et <i>al.</i> (2019)	To establish a transitional nursing care model for stroke patients after hospital discharge and statistically compare the clinical efficacy between traditional and transitional nursing care services	N = 72; people with stroke; intervention group ( $n = 35$ ), control group ( $n = 37$ ), recruited from Grade II class-A hospitals, Chongqing, China	Convenience sampling	Quantitative randomised controlled trial	Statistical significance was found in patients receiving an enhanced transitional nursing intervention in attending outpatient visits, patient satisfaction with nursing service and increased engagement in rehab training, when compared with a control group.
Redfern et al. (2016)	To examine how transitions from acute hospital care to the next level of care could be more effective and efficient for adults with disability	N = 85; administrative data for patients on Adults with Disability Pathway (n = 80); qualitative interviews with social work staff members $(n = 5)$ ; recruited from tertiary hospital in Queensland Australia, which has Adults with Disability Pathway specific for adults with existing or newly acquired disabilities	Consecutive purposive sampling	Quantitative prospective open cohort case series of hospital administrative dataset; descriptive statistics. Qualitative thematic analysis.	Barriers to discharge were common and contributed to increased length of stay. The most common delays in discharge were related to: finding accommodation and care providers; equipment assessment and prescription; home modifications; family dynamics; and carer recruitment/training.



**Fig. 2.** Schematic representation depicting the interrelated principles that emerged from the scoping review.

A focus group of specialised stroke care providers and academics recommended a specific pathway for younger people with stroke to identify the type of supports required by the person, liaise with necessary services and deliver essential information to such services during transfers of care (Abdul Aziz *et al.* 2017).

#### Between hospital and community

Coordination and continuity of care was particularly important during the transition from hospital to community. A randomised controlled trial (Qian *et al.* 2019) in two hospitals in Chongqing, China compared usual nursing care with transitional nursing care (i.e. predischarge health and stroke education, telephone calls from nurses and encouragement to keep diaries about rehabilitation and health exercises). The intervention group reported better subjective quality of life (SQOL) and greater satisfaction with nursing care than those in the usual nursing care group; however, the measures of SQOL were not well defined and the intervention did not improve readmission rates.

Qualitatively, the transition from hospital to home was identified as a stressful time where people sought consistency and a smooth transition; however, their experience was often the opposite (Conti *et al.* 2016; Abrahamson *et al.* 2017; Dwyer and Mulligan 2017). People reported chaotic transfers home with little information, limited supports in place and no time for close others to prepare. They

experienced distress as a result of poorly planned transitions and in one case it led to a hospital readmission (Abrahamson *et al.* 2017). In contrast, having the same support workers from the time of discharge onwards reassured people and provided consistency in a continuously changing environment; 'They found someone that would be able to assist me as a caregiver; she came and did some training in TR [transitional rehabilitation unit] and then when I came out she was available so that worked really well' (person with SCI; Dwyer and Mulligan 2017).

Redfern *et al.* (2016) highlighted health professionals' experiences of organising and coordinating support from multiple service providers in the community. Challenges with coordination of support were linked to the collaboration required between service providers to set up multiple supports on discharge: 'so when you're dealing with [health department], but within that Housing and Disability Services, there's a communication between the three ... one can't happen without the other, because you can't have suitable housing unless Disability feel that they're going to be able to support this person, otherwise they're not going to get this housing and vice versa' (social worker; Redfern *et al.* 2016).

#### Medical and allied health

Discharge summaries were crucial for providing insight into the medical status of the person with disability and information for continuing rehabilitation in the community

(Kable et al. 2018; Irgens et al. 2020). One study (Kable et al. 2018) evaluated the quality of discharge documentation for people with stroke returning home. It found limited evidence (20%) of documented patient/caregiver meetings with the multidisciplinary team to discuss plans or goals and that only 55% of patients were discharged with a 7-day supply of medication. Instructions for accessing therapies (e.g. frequency) were only provided for 74% of patients. Although most discharge summaries included information such as medications on discharge (100%), pathology results (94%) and a summary of medical treatment (96%), other important information was not routinely included such as allied health recommendations (42%), functional capacity assessment (58%) and support services required on discharge (59%). Surveyed close others (n = 12) reported that they all received a copy of the medical discharge summary, whereas less than 50% received information about any outpatient appointments or the ability of the person with disability to drive. It is noteworthy that only 12 (22%) of close others approached completed this survey.

Hospital health professionals reported that providing a handover to their community counterparts was paramount during discharge, with one highlighting the benefits of telephone calls in addition to the standard written discharge summaries: '[a phone conversation] is worth gold. It gives me the opportunity to transfer even more information [than a discharge summary]' (hospital physiotherapist; Irgens *et al.* 2020).

Early connections between hospital health professionals and general practitioners (GPs) could set up a safe and satisfactory discharge where the GP is able to understand the person's medical and allied health needs when they return to the community. One study (Abrahamson *et al.* 2017) outlined how close others assumed that the GP would be informed and well positioned to provide coordination and support for the person post-discharge; however, some reported that GPs were not adequately informed about the person's health and support needs and were unable to identify or coordinate the services they needed: 'somebody that could just say: this is who you need to speak to. I don't necessarily want someone to actually do it for me' (spouse of person with ABI; Abrahamson *et al.* 2017).

# Post hospital discharge

The contrast between life in a hospital rehabilitation unit and life in the community became evident upon discharge: 'Once you were out you were out. That was it you were gone ... there was a big gap about how you were looked after in [inpatient rehabilitation] and now you're out in the community and that's what it looks like. If it's not too good, well that's become my problem' (person with SCI; Dwyer and Mulligan 2017).

Starting with new post-discharge supports was difficult, especially when service providers had not received any handover from the hospital regarding an individual's disability and support needs. Self-referrals to services were completed by some people with acquired disability in the community, without sufficient supports from the hospital or the service they were referring to: 'I called up [service name] or whatever the hell it's called, she's like 'oh you can just fill out the form by yourself and do it, it's easy' and I'm like 'well, I've had a traumatic brain injury and I need assistance" (person with TBI; Fitts et al. 2019). Similarly, one participant's wife was told by a nurse in the inpatient setting, 'When you get him home, if you're not happy, just refer him to the mental health unit' (spouse of person with ABI; Abrahamson et al. 2017). In contrast, those whose services were set up on discharge reported satisfaction regarding the continuity of health professionals in the community: 'I've been lucky I've had complete continuity of service [of physiotherapists and occupational therapists], I haven't been spread around the different people' (person with SCI; Dwyer and Mulligan 2017).

Borg et al. (2020) described a transitional rehabilitation service in Australia that acted as a conduit between the inpatient stay and return to community living for people with ABI. Participants received 2 weeks in-reach support from a multidisciplinary allied health team prior to discharge and for 10 weeks post discharge in the home. Therapies and case management services were provided throughout this time before a thorough handover was provided to people's ongoing community supports. When compared to a historical cohort who received treatment as usual, a significant improvement was recorded in levels of anxiety, depression, and community participation. Although this study presents positive results in favour of the transitional service, the comparison cohort data was recorded approximately 10 years prior, thus variability in service delivery, resources available and environmental factors should be considered on interpretation of the results.

Chu *et al.* (2020) explored the effectiveness of a postdischarge rehabilitative program, focusing on activities of daily living, delivered by family members in rural China. Family members received training from inpatient nursing staff to deliver a stroke specific home-based rehabilitation program post hospital discharge. They also received follow up phone calls from the nursing team during the second, fourth and eighth week post-discharge. A greater improvement in physical recovery of those who participated in the discharge program was recorded 6 months post-discharge when compared to those in the control group (Chu *et al.* 2020).

In Malaysia, a panel of stroke experts developed a primarycare-led discharge pathway and post-discharge screening tools to improve coordination of care post-discharge (Abdul Aziz *et al.* 2017). Two distinct cohorts were identified: those who could be managed at primary healthcare facilities in a shared care approach, and those who required specialist outpatient clinics in a tertiary health centre. Those requiring specialist outpatient input included people under 40 years of age and those with uncontrolled stroke risk factors. Screening tools and recommendations were developed to improve continuity of care in a developing country; however, these were not evaluated.

## Preparation for hospital discharge

Having support to be prepared for the realities of life postdischarge was considered crucial to a successful return to the community. This support included having adequately trained formal and informal supports, practical support to access medical and therapy appointments and psychological preparation for navigating the realities of life postdischarge. It is noteworthy that there is substantial interrelatedness between preparation for discharge and continuity and coordination.

## Training of formal and informal supports

The training of close others and support workers in the inpatient setting prior to discharge was highly valued by people with acquired disability and close others. Caregiver training fostered a sense of predictability and mastery during the discharge process and highlighted necessary areas for development of skills: 'I agree with the care training because we are supposed to guarantee safety to our relative once discharged home' (spouse of person with SCI; Conti *et al.* 2016). When this training was not provided, people described this as a gap in their preparedness for discharge: 'I would like the homecare staff provided by the National Health Service to come to the SCU in order to be trained. In this way there would be fewer complications and problems' (spouse of person with SCI; Conti *et al.* 2016).

Familiarity with support workers and having confidence that support workers knew how to provide appropriate support reduced uncertainty and helped people adjust to their acquired disability: 'The difference that it makes for me to have the same people who know me, know my house, what I need, and can do things, is the difference between me waking up in the morning and not feeling like this disability is a big thing' (person with SCI; Dwyer and Mulligan 2017). The breadth and quality of caregiver training was important. For example, family members in the Conti *et al.* (2016) study identified managing challenging behaviours and maintaining boundaries as gaps in their training: 'Sometimes we do not have enough answers to what they [SCI survivors] have asked us or we do not know how to treat or cope with some behaviours' (niece of person with SCI; Conti *et al.* 2016).

#### **Home visits**

Home visits were a valuable opportunity to learn about life post-discharge and address potential issues prior to discharge (New 2015; Abrahamson *et al.* 2017). Although valued, some close others felt that home visits did not provide enough experience or education to prepare them for life after discharge: 'He had a couple of weekend visits, but that still wasn't somehow really enough to prepare us' (spouse of person with ABI; Abrahamson *et al.* 2017). One study reported that waiting for a health professional to be available for a home visit led to discharge delays (New 2015).

#### **Feeling prepared**

People with acquired disability and close others frequently felt ill-prepared for the enduring impact of living with disability. Biester et al. (2016) surveyed people with TBI and close others of people with TBI to gauge their satisfaction with the information they were given about the consequences of TBI. Overall, only 30.1 and 30.0% of people with TBI and close others, respectively, felt that they were provided adequate information about the consequences of TBI. Only 41.1% of people with TBI reported being told about the possible cognitive effects of TBI, and what these might mean for post-discharge life, despite 71% undergoing some form of cognitive assessment. Approximately half (55.2%) reported being provided feedback from cognitive assessments, with only 43.8% reporting understanding what these results meant. Forty-six percent of people with TBI reported being told of possible psychological sequalae of brain injury such as irritability, poor frustration tolerance, depression and anxiety. Similar patterns emerged for close others: 27.3% reported being satisfied with the information provided about possible cognitive effects of TBI and 52% reported having the results of cognitive assessment explained in a way that was understandable. Only 57.3% of close others reported being told that irritability and frustration were a possible consequence of TBI and 60% reported being told about anxiety and depression after TBI.

Moving home was a highly anticipated goal for people with acquired disability and close others. People with acquired disability often thought that life would return to a sense of normality when they were back at home; however, returning home sometimes represented the beginning of a new understanding of living with disability: 'I thought it was going to be a lot easier ... I thought I was back to normal, yes. And I was nowhere near' (person with ABI; Abrahamson *et al.* 2017). Some people with acquired disability said that they would have liked support to be more fully prepared for life after discharge: 'Nobody prepared me for home. Nobody said, 'Well, what are you going to do when you get there?' ... I just needed a bit more guidance on how it was going to be' (person with ABI; Abrahamson *et al.* 2017).

#### Adjustment support

Psychological distress emerged as an important unmet need across a number of studies (Abrahamson *et al.* 2017; Dwyer and Mulligan 2017; Fitts *et al.* 2019), sometimes with serious outcomes: 'I actually took an overdose ... because I didn't think that it was worth going on ... because everything that I wanted was taken away: my work, my driving, my ... normality, if you like' (person with ABI; Abrahamson *et al.* 2017). Some close others felt that there was insufficient psychological support: 'I also think that greater support should be provided for us psychologically' (niece of person with SCI; Conti *et al.* 2016). Some close others felt unsupported by health providers and informal support networks when they were taking full responsibility for supporting the person with disability at home: 'I feel abandoned by everybody, not only by institutions but also friends' (spouse of person with SCI; Conti *et al.* 2016).

#### Tangible supports on hospital discharge

Many people experienced delays in tangible supports needed for discharge such as assessments by health professionals (Redfern *et al.* 2016), housing (Redfern *et al.* 2016; Houston *et al.* 2020), equipment (New 2015; Abrahamson *et al.* 2017; Houston *et al.* 2020), and home modifications (Hodson *et al.* 2016; New 2015, Redfern *et al.* 2016; Dwyer and Mulligan 2017). Prevalence of barriers to discharge was high, with many people spending unnecessary time in hospital due to delays with these supports being implemented (New 2015; Houston *et al.* 2020).

#### Housing

It was important that discharge planning encompassed a comprehensive plan for where a person could live in the long term if they could not return to their previous home. Housing emerged across some studies (Redfern et al. 2016; Houston et al. 2020) as a barrier to discharge. Redfern et al. (2016) highlighted the complexities of the health, disability and housing interface, whereby lengthy assessment times, allocation of suitable funding and lack of housing options resulted in delays to discharge that could be compounded by hospital acquired infections and iatrogenic injuries acquired while awaiting assessments and funding. Fitts et al. (2019) highlighted the consequences of secure housing not being obtained prior to discharge, with one person being unaware of this until after their discharge: 'I want an accommodation of my own, see ... And it's going from bad to worse, getting to worse. Like, I've been sleeping in the parks, couple of nights' (person with TBI; Fitts et al. 2019).

# Home modifications, equipment and disability supports

For some people with acquired disability, successful discharge was contingent on home modifications, equipment and disability supports. Quantitative data revealed that assistive technology and equipment (New 2015; Houston *et al.* 2020), home modifications (New 2015; Houston *et al.* 2020) and disability supports (including Positive Behaviour Support) were the most common reasons for discharge delay. Redfern *et al.* (2016) cited uncertainty around prognosis as a contributing factor to delays in planning for community housing and supports. Houston *et al.* (2020) identified that funding applications for people with ABI were often not instigated until a median of 72 days into their admission. It was then a median of 77 days until funding was approved. In contrast, similar funding applications were initiated for people with SCI a median of 35 days into admission.

Delays with home modifications meant that people often remained hospital inpatients or spent a long time in interim discharge destinations before returning home. One person with SCI had been living in a motel for 14 months: 'It's been 14 months now I guess, so long ... just have to be patient ... as they say no place like home, look forward to going home you know, do my thing' (person with SCI; Dwyer and Mulligan 2017). One person with acquired disability realised that his home modifications were not suitable after they had been installed. In this case, space was lost to accommodate an accessible bathroom and his house became too small to use a powered wheelchair (Dwyer and Mulligan 2017). Another person had a ramp built that he could use to exit the house, but not to re-enter: 'But I can't get back in with my wheelchair. Once I go out, I can't get back up the ramp' (person with stroke; Hodson et al. 2016).

#### **Accessing services**

Prior to discharge, some people worried that they would be discharged without supports for unidentified issues or unmet needs, including continence, pain management, concurrent injuries, and outpatient appointments (Abrahamson et al. 2017). Barriers such as lack of transportation, lack of phone credit or financial difficulties sometimes impacted peoples' ability to engage with community allied health services. People with acquired disability who were Aboriginal and/or Torres Strait Islander and lived in regional and remote areas of Northern Australia reported that they were better able to engage in rehabilitation and with support providers if transport was available: 'Oh like, if I need to go to the hospital, they'll pick me up and take me there. And if I need medication, they supply it, like they can get it for me' (person with TBI; Fitts et al. 2019). For others in a different study, the cost of therapies on top of day-to-day expenses was identified as a barrier to engaging with support: 'The speech pathologist [said] I had to pay \$110 for a disc ... but you know then you've got to pay \$53 a week which is OK ... I've got to budget and now I've got to look at getting cleaners in and I've got to get the money' (person with ABI; Hodson et al. 2016).

#### Support to manage unexpected challenges

In the community, novel issues arose which neither people with acquired disability nor close others knew how to solve. Kable *et al.* (2018) found that only 37% of people with stroke were provided a formal contingency plan to prepare for any post discharge complications. Dwyer and Mulligan (2017) reported that people with acquired disability and close others did not have enough information to be able to navigate services on discharge: 'I don't think there was enough introductions of the sorts of people that you would be dealing with you once you got home. I was totally lost, I remember having a bowel accident one night in the motel not knowing who I could get to help me, how to go about it and I remember having to get the moteliers in to help' (person with SCI; Dwyer and Mulligan 2017).

In the community, the rehabilitation centre remained an important reference for close others, as it could provide support and resources post discharge, especially when they did not know who to contact (Conti *et al.* 2016). Some people with acquired disability reported not knowing what support was available to them: 'I just found out yesterday that I could have requested an annual check-up of my chair that probably would have identified a lot of these problems. I could've asked for something six months ago but I had no idea at that time' (person with SCI; Dwyer and Mulligan 2017).

# People with acquired disability and close others as active participants

Dwyer and Mulligan (2017), reported that the involvement of people with acquired disability in the discharge plan reduced feelings of stress and allowed people to evaluate the pros and cons of the decisions being made. However, some people felt too overwhelmed by all of the new information that they were required to understand, which led to disengaging with planning, 'because you're so overwhelmed, they could be telling you these messages but you're just not perceiving them' (person with SCI; Dwyer and Mulligan 2017).

New (2015) found that negotiations with family members accounted for 12.8% of barriers to discharge in an SCI unit. Across qualitative studies, close others considered their involvement in the discharge planning process as crucial (Conti et al. 2016; Abrahamson et al. 2017; Hersh and Armstrong 2021). In two quantitative studies, people with acquired disability and close others were involved in the development and delivery of discharge plans and post discharge rehabilitation programs (Borg et al. 2020; Chu et al. 2020). These studies identified improvements in adaptability, physical recovery and participation as well as decreased self-reports of depression and anxiety for people with acquired disability over time when compared with control or comparison groups, highlighting benefits for consumer involvement in their discharge planning. Involvement in the decision making processes resulted in feelings of hope for the mother of a person with spinal cord injury: 'I felt integrated and fully participant in the decision making process, I loved the happiness and optimism of health care professionals' (mother of person with SCI; Conti et al. 2016).

In countries where discharge supports were under resourced, close others played a significant role in facilitating access to health care (Abdul Aziz *et al.* 2017). However, other studies identified that hospital teams could assume that close others would provide informal supports where gaps in funded supports existed, whereas not all close others were able to provide this level of support. As such it was crucial that hospital teams consulted closely with close others to ensure the person's care needs could be met. During the discharge process, close others acted as advocates to secure supports on discharge, but also to inform the clinical team of the realities of home life and the feasibility of certain support models (Conti *et al.* 2016; Abrahamson *et al.* 2017; Hersh and Armstrong 2021). Close others reported often having to persevere and routinely follow up with providers to secure required supports: 'I'm quite happy to badger the system until I get something sorted ... It just annoys me that I have to do that ... because I don't think we should have to, because I think things should be in place' (spouse of person with ABI; Abrahamson *et al.* 2017).

# Communication

Communication emerged as a central principle underpinning the implementation of all components of successful discharge planning. Although considered crucial, some unfavourable discharge outcomes were characterised by, or attributed to, poor communication (Conti *et al.* 2016; Biester *et al.* 2016; Abrahamson *et al.* 2017).

# Between person with acquired disability and health professionals

Lack of communication from health teams was experienced by people with acquired disability from their admission throughout the trajectory of their hospitalisation and discharge: 'There was no communication. No. From day one ... I was told nothing' (person with ABI; Abrahamson *et al.* 2017). For some people, lack of communication was perceived as a form of ableism and institutional racism. In Fitts *et al.* (2019), Aboriginal and/or Torres Strait Islander people were reportedly not told the details of their injuries, as doctors assumed that they would not understand the information provided. This experience resulted in a self-discharge for one person: '[The doctor] knew that I wouldn't understand, or I wouldn't get it what he was telling me. I thought well if no one is going to tell me that I'm supposed to be here I might as well go home' (person with ABI; Fitts *et al.* 2019).

Hersh and Armstrong (2021) highlighted the inappropriate use of medical terminology when communicating with a person with aphasia. This rendered the information inaccessible to the person and resulted in a missed opportunity for effective communication. In the community, some people reported that the roles, responsibilities and boundaries of community health providers were not explained clearly and suggested the use of a familiar structure like a 'family tree' to help the person better understand the system (Dwyer and Mulligan 2017).

#### Between close others and health professionals

Close others also often felt dissatisfied with communication across the trajectory of hospitalisation and discharge (Biester *et al.* 2016; Conti *et al.* 2016; Abrahamson *et al.* 2017; Fitts *et al.* 2019; Hersh and Armstrong 2021). A lack of communication was experienced by many close others regarding the diagnosis of the person with disability: 'A definite step forward should be made regarding the two basic steps of hospitalisation, that is, diagnosis communication and discharge management. I think that communication aspects should be more implemented by all professionals' (spouse of person with ABI; Conti et al. 2016). Others reported disorganised communication, which came in the form of multiple calls a day from different hospital-based health professionals: 'Every day ... they call me ... they are so unorganised' (wife of person with ABI; Abrahamson et al. 2017). This resulted in confusion for close others due to multiple conflicting narratives (Abrahamson et al. 2017; Hersh and Armstrong 2021). The theme of a lack of communication continued post discharge: 'Four weeks after discharge and we haven't heard a dickey bird' (spouse of person with ABI; Abrahamson et al. 2017).

# Discussion

A high quality discharge planning process is crucial for people with acquired disability and complex needs to leave hospital when they are medically ready to do so and to access housing and supports that align with their needs and preferences (Holloway et al. 2019). The 16 included studies highlighted principles of discharge planning that influence the transition from the inpatient setting to the community. Rather than a series of standalone principles, it was evident that these components were interrelated and interdependent such that if one was not done well, it could impact on the entire hospital stay and discharge trajectory. Importantly, multiple stakeholders across the continuum of care typically needed to work collaboratively to achieve satisfactory outcomes for people with acquired disability, prevent delays to discharge and reduce hospital readmissions. When principles of discharge were overlooked, the entire discharge trajectory could be impacted. This lack of oversight resulted in unsatisfactory outcomes for people with acquired disability, delayed discharges and, subsequently, unnecessary costs and pressure for the hospital system (New 2015; Conti et al. 2016; Redfern et al. 2016; Abrahamson et al. 2017; Hersh and Armstrong 2021). The findings of this review align with previous research and health-condition-specific guidelines, clinical practice emphasising the importance of continuity of care throughout the discharge trajectory (Turner et al. 2007, 2011; Foster et al. 2007; British Society of Rehabilitation Medicine 2009; NICE 2013; SIGN 2013; Stroke Foundation 2017; Barry et al. 2019).

Due to a combination of newly acquired disability, complex interfaces between health, disability and community and, in some cases, cognitive impairment, coordination and continuity of care emerged as a crucial principle of discharge planning. The complexity of coordination of care throughout the discharge continuum is acknowledged in clinical practice guidelines through the recommendation of strategies such as appointing a lead discharge planner to manage the transition into the community (British Society of Rehabilitation Medicine 2009; Stroke Foundation 2017). Excellent coordination and continuity of care was consistently identified as a necessity to ensure correct supports were provided, and all essential actions were completed in a timely manner for supports to eventuate on discharge. Despite this, continuity of care did not always occur throughout the discharge trajectory, resulting in delays to discharge and increasing the likelihood of readmission (Conti *et al.* 2016; Redfern *et al.* 2016; Abrahamson *et al.* 2017).

In preparation for discharge, individuals with acquired disability required that hospital health professionals: liaised with community-based service providers, including GPs (Redfern et al. 2016; Abrahamson et al. 2017); provided quality discharge summaries (Qian et al. 2019; Irgens et al. 2020); facilitated caregiver training for close others and support workers (Conti et al. 2016; Dwyer and Mulligan 2017); organised psychosocial supports for people with acquired disability and close others (Conti et al. 2016; Abrahamson et al. 2017; Dwyer and Mulligan 2017; Hersh and Armstrong 2021); and arranged home visits that adequately exposed them to challenges that would be faced upon returning home (Abrahamson et al. 2017). Support was also required for people with acquired disability and close others to understand how to navigate challenging situations in the community. This was an important and often overlooked aspect of discharge planning despite being recommended in existing clinical practice guidelines (Conti et al. 2016; Abrahamson et al. 2017; Dwyer and Mulligan 2017).

Essential supports for a safe transition home were often a key contributing factor to lengthy discharge delays. The length of time taken to acquire home modifications, equipment and disability supports often resulted in extended lengths of stay (New 2015; Redfern et al. 2016; Houston et al. 2020). A possible contributing factor to this was the time taken between admission to hospital and initiation of funding applications (Houston et al. 2020). This delay was especially evident for people with ABI, whereas funding applications for those with SCI were initiated much earlier in the discharge trajectory. A possible explanation for this is health professionals' perceptions that a prognosis for ABI is too uncertain early in the hospital admission. Nevertheless, these delays in initiating funding applications can contribute to discharge delays at the end of the admission. Delays to sourcing housing and home modifications can lead to delayed discharge, prolonged periods of stay in unsuitable interim accommodation or hospital readmission (Abrahamson et al. 2017; Dwyer and Mulligan 2017).

Although clinical practice guidelines continuously state the significance of communication in the discharge planning process (British Society of Rehabilitation Medicine 2009; SIGN 2013; Stroke Foundation 2017), the delivery of selective or inaccessible communication by the clinical team was prevalent throughout and led to feelings of exclusion for people with acquired disability and close others (Biester *et al.* 2016; Abrahamson *et al.* 2017; Hersh and Armstrong 2021). Limited evidence was available around the involvement of people with acquired disability in discharge planning; however, when included, it had a positive impact on discharge outcomes (Borg *et al.* 2020; Chu *et al.* 2020). The lack of involvement of people with acquired disability in discharge planning presented a missed opportunity to increase the accuracy of the match between support needs and provision and develop a sustainable discharge plan and effective transition to the community.

Despite the existence of disability-specific clinical practice guidelines, the discharge experience of people with acquired disability and complex needs remains suboptimal, resulting in delays to discharge, poor participant outcomes, and hospital readmissions (Marks 1994; Shepperd *et al.* 2013; Biester *et al.* 2016; Abrahamson *et al.* 2017; Houston *et al.* 2020). Based on the relevant literature, clinical practice guidelines and the findings of this review, six recommendations regarding hospital discharge for people aged under 65 with acquired disability and complex needs are presented below:

- 1. Comprehensive discharge planning should commence as soon as a need for discharge supports is identified and remain a focal point of service delivery throughout the admission (British Society of Rehabilitation Medicine 2009; Redfern *et al.* 2016; Abrahamson *et al.* 2017; Stroke Foundation 2017; Holloway *et al.* 2019).
- 2. Expert coordination and continuity of care should be provided throughout the entire discharge process. This coordination should involve a designated point of contact to facilitate the many moving components of a person's inpatient and discharge trajectory (New 2015; Conti *et al.* 2016; Abrahamson *et al.* 2017; Hersh and Armstrong 2021).
- 3. The involvement of the person with acquired disability and their close others in all discharge discussions and decisions is essential to enhance the likelihood of successful discharge (British Society of Rehabilitation Medicine 2009; NICE 2013; SIGN 2013; Abrahamson *et al.* 2017; Stroke Foundation 2017; Borg *et al.* 2020; Conti *et al.* 2016; Chu *et al.* 2020; Hersh and Armstrong 2021).
- 4. Required assessment and application for tangible supports, such as equipment or home modifications, should be made as soon as possible during the hospital admission to mitigate the risk of discharge delays due to tangible supports not being in place (British Society of Rehabilitation Medicine 2009; New 2015; Redfern *et al.* 2016; Houston *et al.* 2020).
- 5. People with acquired disability, close others and support workers need education and practical opportunities to explore skills required at home and in the community through home or community visits. Information provision should be tailored to people's cognitive and

communication needs. This may include repeated provision of information, visual aids, involving close others and aphasia-friendly resources (NICE 2013; SIGN 2013; Biester *et al.* 2016; Conti *et al.* 2016; Abrahamson *et al.* 2017; Dwyer and Mulligan 2017; Stroke Foundation 2017; Kable *et al.* 2018).

6. Accessible and consistent communication throughout transition is recommended. This includes listening to a person's needs and preferences and providing clear and regular updates on medical, allied health and disability support matters (British Society of Rehabilitation Medicine 2009; NICE 2013; SIGN 2013; Biester *et al.* 2016; Conti *et al.* 2016; Abrahamson *et al.* 2017; Stroke Foundation 2017; Fitts *et al.* 2019; Hersh and Armstrong 2021).

# Limitations and directions for future research

The findings of this review should be considered within its limitations: (1) non-peer reviewed studies and studies not in English were excluded, and their inclusion might have yielded additional insights, particularly in relation to clinical guidance on discharge planning; (2) the defined daterange might have excluded studies that could add additional insights on the experience of hospital discharge in earlier studies; (3) the protocol for this review was not published prior to being conducted; and (4) additional search terms relating to 'early readmission' to hospital following discharge might have yielded studies with relevant insights relating to problems with hospital discharge.

Notwithstanding these limitations, this scoping review has highlighted important gaps in research on hospital discharge for people with acquired disability and complex needs. Apart from the work of Houston et al. (2020), there was a lack of quantitative data on the health and disability sector timeframes. There is a dearth of data on receipt of equipment, home modifications, community services and longitudinal outcomes post-discharge. Future research should collect quantitative data on these timeframes, and on service utilisation and post-discharge outcomes from multiple sites to better identify barriers and facilitators to successful hospital discharge. Most studies did not specifically seek to explore the characteristics of successful discharge, meaning that much reported data focused on the negative aspects of hospital discharge, or when things did not work well. Hence, an opportunity remains to seek further qualitative information on what people found helpful in their hospitalisation and discharge trajectory. Although some included studies explored the experiences of allied health professionals, their perspective was somewhat lacking within this scoping review. To achieve more balanced findings representative of all stakeholder perspectives, the experiences of allied health professionals and service providers should be included in future reviews where possible. Although included studies were conducted in eight different countries, studies from Australia accounted for half of the studies, resulting in over representation of the Australian experience on these findings. Together, these factors highlight the need for further international research into contemporary discharge planning and practice across health and disability systems and sociocultural settings.

# Conclusion

The findings of this scoping review highlight the complex, and at times competing, environment in which hospital discharge occurs, wherein the needs of the person with acquired disability can often conflict with the priorities of the hospital. In hospitals, time-efficient discharges are valued, yet complex support needs are typically associated with prolonged lengths of stay and high financial costs (Hendy et al. 2012; Buist et al. 2014; Kritikou et al. 2016; Landeiro et al. 2016). The six recommendations presented in this review are by no means novel as standalone principles; vet it is evident that implementation of these components of successful discharge remains challenging in practice. Future intervention research is needed to explore the impact of implementation of the abovementioned six principles in hospitals to evaluate whether these can lead to reduced discharge delays and improved long-term outcomes related to independence, community integration and quality of life.

#### References

- Abdul Aziz AF, Mohd Nordin NA, Ali MF, Abd Aziz NA, Sulong S, Aljunid SM (2017) The integrated care pathway for post stroke patients (iCaPPS): a shared care approach between stakeholders in areas with limited access to specialist stroke care services. *BMC Health Services Research* **17**(1), 35. doi:10.1186/s12913-016-1963-8
- Abrahamson V, Jensen J, Springett K, Sakel M (2017) Experiences of patients with traumatic brain injury and their carers during transition from in-patient rehabilitation to the community: a qualitative study. *Disability and Rehabilitation* **39**(17), 1683–1694. doi:10.1080/09638288.2016.1211755
- Ådnanes M, Cresswell-Smith J, Melby L, Westerlund H, Šprah L, Sfetcu R, Straßmayr C, Donisi V (2020) Discharge planning, selfmanagement, and community support: Strategies to avoid psychiatric rehospitalisation from a service user perspective. *Patient Education* and Counseling **103**(5), 1033–1040. doi:10.1016/j.pec.2019.12.002
- Altfeld SJ, Shier GE, Rooney M, Johnson TJ, Golden RL, Karavolos K, Avery E, Nandi V, Perry AJ (2013) Effects of an enhanced discharge planning intervention for hospitalized older adults: a randomized trial. *The Gerontologist* 53(3), 430–440. doi:10.1093/geront/gns109
- Arksey H, O'Malley L (2005) Scoping studies: towards a methodological framework. *International Journal of Social Research Methodology* **8**(1), 19–32. doi:10.1080/1364557032000119616
- Barry S, Knox L, Douglas JM (2019) "Time's Up": The Experience of Entering Residential Aged Care for Young People with Acquired Neurological Disorders and Their Families. *Brain Impairment* 20(1), 37–48. doi:10.1017/BrImp.2018.13
- Biester RC, Krych D, Schmidt MJ, Parrott D, Katz DI, Abate M, Hirshson CI (2016) Individuals with traumatic brain injury and their significant others' perceptions of information given about the nature and possible consequences of brain injury: analysis of a national survey. *Professional Case Management* 21(1), 22–33. doi:10.1097/NCM. 000000000000121
- Borg DN, Nielsen M, Kennedy A, Drovandi C, Beadle E, Bohan JK, Watter K, Foster MM, Fleming J (2020) The effect of access to a designated interdisciplinary post-acute rehabilitation service on

participant outcomes after brain injury. *Brain Injury* **34**(10), 1358–1366. doi:10.1080/02699052.2020.1802660

- British Society of Rehabilitation Medicine (2009). BSRM Standards for Rehabilitation Services, Mapped on to the National Service Framework for Long-Term Conditions. BSRM, London.
- Buist MD, Jaffray L, Bell E, Hanna L, Weinstein P, Kumar S, Grimmer K (2014) Utilisation of beds on the general medical unit by 'non-acute medical'patients: a retrospective study of incidence and cost in two T asmanian regional medical hospital units. *Internal Medicine Journal* 44(2), 171–177. doi:10.1111/imj.12335
- Chu K, Bu X, Sun Z, Wang Y, Feng W, Xiao L, Jiang F, Tang X (2020) Feasibility of a Nurse-Trained, Family Member-Delivered Rehabilitation Model for Disabled Stroke Patients in Rural Chongqing, China. *Journal* of Stroke and Cerebrovascular Diseases **29**(12), 105382. doi:10.1016/j. jstrokecerebrovasdis.2020.105382
- Collings S, Dew A, Dowse L (2016) Support planning with people with intellectual disability and complex support needs in the Australian National Disability Insurance Scheme. *Journal of Intellectual & Developmental Disability* **41**(3), 272–276. doi:10.3109/13668250. 2016.1151864
- Conti A, Garrino L, Montanari P, Dimonte V (2016) Informal close others' needs on discharge from the spinal cord unit: analysis of perceptions and lived experiences. *Disability and Rehabilitation* 38(2), 159–167. doi:10.3109/09638288.2015.1031287
- Covidence Systematic Review Software (2022) Veritas Health Innovation, Melbourne, Australia. Available at www.covidence.org.
- Destino L, Bennett D, Wood M, Acuna C, Goodman S, Asch SM, Platchek T (2019) Improving patient flow: analysis of an initiative to improve early discharge. *Journal of Hospital Medicine* **14**(1), 22–27. doi:10.12788/jhm.3133
- DeVivo MJ, Hawkins LVN, Richards JS, Go BK (1995) Outcomes of post-spinal cord injury marriages. Archives of Physical Medicine and Rehabilitation 76(2), 130–138. doi:10.1016/S0003-9993(95)80022-0
- Duncan PW, Zorowitz R, Bates B, Choi JY, Glasberg JJ, Graham GD, Katz RC, Lamberty K, Reker D (2005) Management of Adult Stroke Rehabilitation Care: a clinical practice guideline. *Stroke* **36**(9), e100–e143. doi:10.1161/01.STR.0000180861.54180.FF
- Durocher E, Kinsella EA, Gibson BE, Rappolt S, Ells C (2019) Engaging older adults in discharge planning: Case studies illuminating approaches adopted by family members that promote relational autonomy. *Disability and Rehabilitation* **41**(25), 3005–3015. doi:10.1080/ 09638288.2018.1483430
- Dwyer K, Mulligan H (2017) The experiences of individuals with a spinal cord injury following discharge from inpatient rehabilitation. *International Journal of Therapy And Rehabilitation* **24**(8), 353–359. doi:10.12968/ijtr.2017.24.8.353
- Fitts MS, Bird K, Gilroy J, Fleming J, Clough AR, Esterman A, Maruff P, Fatima Y (2019) A Qualitative Study on the Transition Support Needs of Indigenous Australians Following Traumatic Brain Injury. *Brain Impairment* **20**(2), 137–159. doi:10.1017/BrImp.2019.24
- Foster M, Fleming J, Tilse C (2007) Council of Australian Governments'(COAG) Initiative for Young People With Disability in Residential Aged Care: What Are the Issues for Acquired Brain Injury? *Brain Impairment* 8(3), 312–322. doi:10.1375/brim.8.3.312
- Gonçalves-Bradley DC, Lannin NA, Clemson L, Cameron ID, Shepperd S (2022) Discharge planning from hospital. *Cochrane Database of Systematic Reviews* 2022(2), CD000313. doi:10.1002/14651858. CD000313.pub6
- Gronda H, Ware V-A, Vitis L (2011) 'What makes a difference? Building a foundation for nationally consistent outcome measures.' Australian Housing and Urban Research Institute (AHURI), Australia.
- Haselden M, Corbeil T, Tang F, Olfson M, Dixon LB, Essock SM, Wall MM, Radigan M, Frimpong E, Wang R, Lamberti S, Schneider M, Smith TE (2019) Family involvement in psychiatric hospitalizations: associations with discharge planning and prompt follow-up care. *Psychiatric Services* **70**(10), 860–866. doi:10.1176/ appi.ps.201900028
- Hendy P, Patel JH, Kordbacheh T, Laskar N, Harbord M (2012) In-depth analysis of delays to patient discharge: a metropolitan teaching hospital experience. *Clinical Medicine* **12**(4), 320–323. doi:10.7861/ clinmedicine.12-4-320
- Hersh D, Armstrong E (2021) Information, communication, advocacy, and complaint: how the spouse of a man with aphasia managed his

discharge from hospital. Aphasiology 35, 1067–1083. doi:10.1080/02687038.2020.1765304

- Hodson T, Aplin T, Gustafsson L (2016) Understanding the dimensions of home for people returning home post stroke rehabilitation. *British Journal of Occupational Therapy* **79**(7), 427–433. doi:10.1177/ 0308022615619420
- Holloway M, Orr D, Clark-Wilson J (2019) Experiences of challenges and support among family members of people with acquired brain injury: a qualitative study in the UK. *Brain Injury* **33**(4), 401–411. doi:10.1080/02699052.2019.1566967
- Houston V, Foster M, Borg DN, Nolan M, Seymour-Jones A (2020) From hospital to home with NDIS funded support: Examining participant pathway timeframes against discharge expectations. *Australian Social Work* **73**(2), 175–190. doi:10.1080/0312407X.2019.1684530
- Irgens EL, Henriksen N, Moe S (2020) Communicating information and professional knowledge in acquired brain injury rehabilitation trajectories–a qualitative study of physiotherapy practice. *Disability and Rehabilitation* **42**(14), 2012–2019. doi:10.1080/09638288.2018. 1544295
- Kable A, Pond D, Baker A, Turner A, Levi C (2018) Evaluation of discharge documentation after hospitalization for stroke patients discharged home in Australia: A cross-sectional, pilot study. *Nursing* & *Health Sciences* 20(1), 24–30. doi:10.1111/nhs.12368
- Kritikou P, Spengos K, Zakopoulos N, Tountas Y, Yfantopoulos J, Vemmos K (2016) Resource utilization and costs for treatment of stroke patients in an acute stroke unit in Greece. *Clinical Neurology* and Neurosurgery 142, 8–14. doi:10.1016/j.clineuro.2015.12.013
- Landeiro F, Leal J, Gray AM (2016) The impact of social isolation on delayed hospital discharges of older hip fracture patients and associated costs. Osteoporosis International 27 (2), 737–745. doi:10.1007/ s00198-015-3293-9
- Langhorne P, Widen-Holmqvist L (2007) Early supported discharge after stroke. *Journal of Rehabilitation Medicine* **39**(2), 103–108. doi:10.2340/16501977-0042
- Langhorne P, Baylan S, Early Supported Discharge Trialists (2017) Early supported discharge services for people with acute stroke. *Cochrane Database of Systematic Reviews* 2017(7), CD000443. doi:10.1002/14651858.CD000443.pub4
- Levac D, Colquhoun H, O'Brien KK (2010) Scoping studies: advancing the methodology. *Implementation Science* 5(1), 69. doi:10.1186/ 1748-5908-5-69
- Levack WM, Kayes NM, Fadyl JK (2010) Experience of recovery and outcome following traumatic brain injury: a metasynthesis of qualitative research. *Disability and Rehabilitation* **32**(12), 986–999. doi:10.3109/09638281003775394
- Lisby M, Klingenberg M, Ahrensberg JM, Hoeyem PH, Kirkegaard H (2019) Clinical impact of a comprehensive nurse-led discharge intervention on patients being discharged home from an acute medical unit: randomised controlled trial. *International Journal of Nursing Studies* **100**, 103411. doi:10.1016/j.ijnurstu.2019.103411
- Manikandan M, Kerr C, Lavelle G, Walsh M, Walsh A, Ryan JM (2022) Health service use among adults with cerebral palsy: a mixed-methods systematic review. *Developmental Medicine & Child Neurology* **64**(4), 429–446. doi:10.1111/dmcn.15097
- Marks L (1994) 'Seamless Care Or Patchwork Quilt?: Discharging Patients from Acute Hospital Care.' (King's Fund Institute London)
- Mayo NE, Wood-Dauphinee S, Côté R, Gayton D, Carlton J, Buttery J, Tamblyn R (2000) There's no place like home: an evaluation of early supported discharge for stroke. *Stroke* **31**(5), 1016–1023. doi:10.1161/01.str.31.5.1016
- McHugh ML (2012) Interrater reliability: the kappa statistic. *Biochemia Medica* **22**(3), 276–282.
- Nalder E, Fleming J, Foster M, Cornwell P, Shields C, Khan A (2012) Identifying factors associated with perceived success in the transition

from hospital to home after brain injury. *The Journal of Head Trauma Rehabilitation* **27**(2), 143–153. doi:10.1097/HTR.0b013e3182168fb1

- NDIS (2021) What is the NDIS? NDIS. Retrieved from https://www.ndis.gov.au/understanding/what-ndis
- New PW (2015) Prospective study of barriers to discharge from a spinal cord injury rehabilitation unit. *Spinal Cord* **53**(5), 358–362. doi:10.1038/sc.2014.166
- NICE (2013) Stroke rehabilitation in adults (NICE guidelines). National Institute for Health and Care Excellence, UK.
- Oliver S, Gosden-Kaye EZ, Jarman H, Winkler D, Douglas JM (2020) A scoping review to explore the experiences and outcomes of younger people with disabilities in residential aged care facilities. *Brain Injury* **34**(11), 1446–1460. doi:10.1080/02699052.2020.1805124
- Popejoy LL, Moylan K, Galambos C (2009) A review of discharge planning research of older adults 1990-2008. Western Journal of Nursing Research 31(7), 923–947. doi:10.1177/0193945909334855
- Qian C, Zhong D, Shen Y, Du Q (2019) Evaluation of clinical efficacy of transitional care mode for patients with strokes. *International Journal of Clinical and Experimental Medicine* **12**(1), 981–988.
- Rankin J, Regan S (2004) 'Meeting complex needs in social care.' (Housing, care and Support)
- Redfern H, Burton J, Lonne B, Seiffert H (2016) Social work and complex care systems: the case of people hospitalised with a disability. *Australian Social Work* 69(1), 27–38. doi:10.1080/ 0312407X.2015.1035295
- Rojas-García A, Turner S, Pizzo E, Hudson E, Thomas J, Raine R (2018) Impact and experiences of delayed discharge: A mixed-studies systematic review. *Health Expectations* **21**(1), 41–56. doi:10.1111/ hex.12619
- Shepperd S, Lannin NA, Clemson LM, McCluskey A, Cameron ID, Barras SL (2013) Discharge planning from hospital to home. *Cochrane Database of Systematic Reviews* 2013(1), CD000313. doi:10.1002/ 14651858.CD000313.pub4
- SIGN (2013) Brain injury Rehabilitation in adults. Available at https:// www.sign.ac.uk/
- Smith TE, Haselden M, Corbeil T, Wall MM, Tang F, Essock SM, Frimpong E, Goldman ML, Mascayano F, Radigan M, Schneider M, Wang R, Dixon LB, Olfson M (2021) Factors Associated With Discharge Planning Practices for Patients Receiving Inpatient Psychiatric Care. Psychiatric Services 72, 498–506. doi:10.1176/ appi.ps.202000021
- Stroke Foundation (2017) Clinical Guidelines for Stroke Management. Available at https://informme.org.au/guidelines/living-clinicalguidelines-for-stroke-management. Accessed 21 June 2021.
- Taha AS, Ibrahim RA (2020) Effect of a Design Discharge Planning Program for Stroke Patients on Their Quality of Life and Activity of Daily Living. *International Journal of Studies in Nursing* 5(1), 64. doi:10.20849/ijsn.v5i1.724
- Turner B, Fleming J, Cornwell P, Worrall L, Ownsworth T, Haines T, Kendall M, Chenoweth L (2007) A qualitative study of the transition from hospital to home for individuals with acquired brain injury and their family caregivers. *Brain Injury* **21**(11), 1119–1130. doi:10.1080/02699050701651678
- Turner BJ, Fleming JM, Ownsworth TL, Cornwell PL (2008) The transition from hospital to home for individuals with acquired brain injury: a literature review and research recommendations. *Disability and Rehabilitation* **30**(16), 1153–1176. doi:10.1080/09638280701532854
- Turner BJ, Fleming J, Ownsworth T, Cornwell P (2011) Perceived service and support needs during transition from hospital to home following acquired brain injury. *Disability and Rehabilitation* **33**(10), 818–829. doi:10.3109/09638288.2010.513422
- Victor CR, Vetter NJ (1988) Preparing the elderly for discharge from hospital: A neglected aspect of patient care? Age and Ageing 17(3), 155–163. doi:10.1093/ageing/17.3.155

Data availability. Data sharing is not applicable as no new data were generated or analysed during this study.

Conflicts of interest. The authors declare that they have no conflicts of interest.

Declaration of funding. This research received no specific grant from any funding agency, commercial or not-for-profit sectors.

Acknowledgements. We wish to acknowledge the contribution of Libby Witts to this paper. Libby provided valuable consultation on the results and findings of this review based on her experience of living with disability.

#### Author affiliations

<sup>A</sup>Summer Foundation Ltd., PO Box 208, Blackburn, Melbourne, Vic. 3130, Australia.

<sup>B</sup>Living with Disability Research Centre, La Trobe University, Melbourne, Australia.