

## Limited conversations about constrained futures

Bright, Felicity ; Kayes, Nicola M.; Soundy, Andrew; Drown, Juliet

DOI:

[10.1071/IB23067](https://doi.org/10.1071/IB23067)

License:

Creative Commons: Attribution-NonCommercial-NoDerivs (CC BY-NC-ND)

*Document Version*

Publisher's PDF, also known as Version of record

*Citation for published version (Harvard):*

Bright, F, Kayes, NM, Soundy, A & Drown, J 2024, 'Limited conversations about constrained futures: Exploring clinicians' conversations about life after stroke in inpatient settings', *Brain Impairment*, vol. 25, no. 1, IB23067. <https://doi.org/10.1071/IB23067>

[Link to publication on Research at Birmingham portal](#)

### General rights

Unless a licence is specified above, all rights (including copyright and moral rights) in this document are retained by the authors and/or the copyright holders. The express permission of the copyright holder must be obtained for any use of this material other than for purposes permitted by law.

- Users may freely distribute the URL that is used to identify this publication.
- Users may download and/or print one copy of the publication from the University of Birmingham research portal for the purpose of private study or non-commercial research.
- User may use extracts from the document in line with the concept of 'fair dealing' under the Copyright, Designs and Patents Act 1988 (?)
- Users may not further distribute the material nor use it for the purposes of commercial gain.

Where a licence is displayed above, please note the terms and conditions of the licence govern your use of this document.

When citing, please reference the published version.

### Take down policy

While the University of Birmingham exercises care and attention in making items available there are rare occasions when an item has been uploaded in error or has been deemed to be commercially or otherwise sensitive.

If you believe that this is the case for this document, please contact [UBIRA@lists.bham.ac.uk](mailto:UBIRA@lists.bham.ac.uk) providing details and we will remove access to the work immediately and investigate.

# Limited conversations about constrained futures: exploring clinicians' conversations about life after stroke in inpatient settings

Felicity A. S. Bright<sup>A,\*</sup> , Nicola M. Kayes<sup>A</sup>, Andrew Soundy<sup>B</sup> and Juliet Drown<sup>A</sup>

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

**\*Correspondence to:**

Felicity A. S. Bright  
Centre for Person Centred Research,  
School of Clinical Sciences, Auckland  
University of Technology, Auckland,  
New Zealand  
Email: [felicity.bright@aut.ac.nz](mailto:felicity.bright@aut.ac.nz)

**Handling Editor:**

Jenny Fleming

**Received:** 9 May 2023

**Accepted:** 4 December 2023

**Published:** 17 January 2024

**Cite this:**

Bright FAS et al. (2024)  
*Brain Impairment* 25, IB23067.  
doi:[10.1071/IB23067](https://doi.org/10.1071/IB23067)

© 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](https://creativecommons.org/licenses/by-nc-nd/4.0/))

OPEN ACCESS

## ABSTRACT

**Background.** After a stroke, people can find it challenging to look forward to the future. Hope, a critical resource for recovery, can be threatened and can be supported or diminished through interactions with clinicians. As such, understanding *how* conversations can support people embarking on life after a stroke is critical. Our study explored how clinicians talk about the future with patients and considered what factors shape how these conversations occur.

**Methods.** This study drew on the Interpretive Description methodology, informed by principles of ethnographic inquiry. We conducted 300 hours of observations and 76 interviews with five people with stroke and 37 clinicians. Data were analysed using the reflexive thematic analysis.

**Results.** We constructed three themes that reflect how clinicians talk about the future with people in inpatient stroke services: (1) constrained temporal horizons, (2) limited talk controlled by clinicians, and (3) opening some doors while closing others. **Conclusions.** Conversations about the future after stroke were constrained and limited: constrained to short-term futures and limited in what aspects of life after stroke were discussed. Creating conversational and relational spaces where people are supported to look to the future with a sense of possibility, hope, and potential is vital for assisting people to move forward in their lives after their stroke. Given its role in supporting people to move forward in their lives, communication must be seen as a core clinical skill and a clinical intervention in its own right.

**Keywords:** ethnography, health communication, hope, life after stroke, patient-provider interaction, qualitative, quality of life, stroke.

## Introduction

Following a stroke, people can find it challenging to look forward to the future. Early after a stroke, people can experience hopelessness, uncertainty, and concern about what their future may look like (Bright *et al.* 2013; Lou *et al.* 2017; Loft *et al.* 2019). Notions of a disrupted life are common, reflecting a sense of 'biographical disruption' (Ellis-Hill and Horn 2000) in which the threads of one's life are metaphorically damaged or rearranged, making it harder to feel coherence and self-continuity (Ellis-Hill *et al.* 2008). One's assumptive future is often challenged by stroke (Hjelmblink and Holmstrom 2006). Hope for the future and a broad sense of possibility are key to adapting and living well following a stroke. Luker and colleagues (2015) describe hope as a critical but 'fragile feature of stroke recovery' (p. 1705). Hope can include *broad* hopes that the future will be alright and *specific* hopes for particular outcomes (Bright *et al.* 2011, 2013). However, hope can be challenged by uncertainty about what the future will look like and what might be possible (Alaszewski *et al.* 2006) and may make it harder to re-envision life after a stroke.

Interactions with healthcare professionals, family, and broader social networks are critical in supporting hope and possibility. People living with stroke describe how clinicians' words can help people perceive their life 'with a renewed sense of positivity

and possibility' (Rixon 2022, p. 3), or clinicians' words can diminish hope and disempower people (Bright et al. 2013; Luker et al. 2015). Future-focused conversations have the potential to provide a sense of reassurance and encouragement and can maintain and support hope (Bright et al. 2013; Soundy et al. 2014; Loft et al. 2019). Yet, people with stroke and family members report that future-focused conversations can cause distress and not support hope (Maddern and Kneebone 2019). They identified an *absence* of conversations and missed opportunities for conversations when staff were not available to talk about people's concerns, which contributed to people and families having unmet needs (Loft et al. 2019; Burton et al. 2021). Given that interactions with health professionals can have detrimental impacts, it is critical to explore how interactions can best support people embarking on life after a stroke.

Clinicians can struggle to have these pivotal conversations. They identify that these conversations are difficult to have (Burton et al. 2021), reporting difficulty conveying prognoses (Peel et al. 2020), concerns about promoting false hope (Soundy et al. 2010; Burton et al. 2021), and indicating that future-focused conversations are emotionally challenging (Peel et al. 2020; Burton et al. 2021). Previous work suggests conversations might instead focus on what is possible within an episode of care, remediation of impairments, and addressing activity limitations (Evans et al. 2017; Loft et al. 2019). However, even though such conversations can be considered difficult by clinicians, these conversations about the future are important, as they help people make peace with uncertainty and maintain hope and possibility (Soundy et al. 2014; Cheng et al. 2022). Recognising that hope and possibility are co-constructed through interactions and relationships with others (Bright et al. 2020; Rixon 2022) means it is essential we understand how clinicians talk about the future with people and consider how such conversations can support people's journeys of hope and recovery.

To date, our understanding of how conversations unfold is limited and often based on interviews, which privilege people's recall, perceptions, and experiences of interactions (Sandelowski 2002). Examining conversations *as they occur* in naturally occurring conversations can offer new insight into what is discussed, when, and by whom (Thorne 2016); the specifics of which might be forgotten or mis-recalled after the fact and the complexity of which may not be fully realised by the participants (Ajajawi and Higgs 2012). This exploratory qualitative study aimed to examine how clinicians talk about the future with people with stroke in acute and inpatient rehabilitation services. Our research questions were:

1. How do clinicians talk about the future with people in inpatient stroke services?
2. What aspects of the future do they discuss?
3. What shapes the ways that clinicians discuss the future?

## Methods

### Qualitative approach and research paradigm

Our study used the Interpretive Description methodology (Thorne 2016), an applied qualitative approach, with a relativist ontology, holding that multiple realities exist and are equally valid. These realities are constructed through interaction and language (Thorne 2016). Interpretive Description generates new knowledge into the 'subjective, experiential, tacit and patterned aspects' (Thorne 2016, p. 41) of healthcare practice, addressing practice-based questions and generating useful, meaningful, and applicable information for everyday practice (Thorne 2016).

### Research context

This research occurred in three stroke services across two urban District Health Boards in Aotearoa New Zealand, including (1) an organised acute stroke unit providing hyperacute and acute stroke care, (2) an integrated hyperacute/acute/inpatient rehabilitation stroke unit where people are transferred between 'acute' and 'inpatient' beds once they were medically stable, and (3) an inpatient rehabilitation ward providing stroke and general rehabilitation services. Each service was overseen by a medical consultant (neurologist, geriatrician and/or rehabilitation specialist) and staffed by a multidisciplinary team. Before developing the research protocol, the first author met with staff in each locality to identify their priorities for the research and sought their perspectives on how it could be conducted to be meaningful but minimally obtrusive for patients and clinicians. Ethical approval for this research was granted by the Health and Disability Ethics Committee (13NTB103) and the Auckland University of Technology Ethics Committee (19/303); approval was gained from all research localities.

### Participants and sampling

The research centred on interactions occurring within clinical dyads – the person with stroke and their treating clinician. We first recruited the person with stroke, then recruited staff members working with them. People with stroke were eligible for inclusion if they were over 18 years of age, English-speaking, able to communicate with the researcher (with the use of supported communication if aphasic) (Kagan 1998), and able to provide informed consent. Sampling was purposive, seeking variation in stroke severity and impairments. Potential participants were screened by stroke service staff. If they appeared eligible and were interested, the staff member provided their details to the research team. We then met the person, explained the study, and completed informed consent. We identified two people who did not meet the eligibility criteria and one person declined. All staff were made aware of the study prior to its commencement and had the option to

opt-out from being approached to participate. Once people with stroke were recruited, we directly contacted staff working with them, re-orientating the clinicians to the study and seeking consent. Only one staff member opted out. Two staff members declined to be participants. All staff members working with the person with stroke were eligible, but we drew on purposive sampling to prioritise which staff were approached. In this, we sought variation in discipline. Principles of information power (Malterud *et al.* 2016) informed our decisions about sample size. We obtained information power by having a specific and somewhat narrow aim, participants with a depth of experience, variability among participants (patient and staff), and rich data constructed and analysed by a research team with significant clinical and research expertise.

## Data construction

Data construction was multi-faceted and differed depending on the physical setting. Observations centred on interactions between the person with stroke and clinicians. These were recorded on a voice recorder and detailed field notes were taken during and after observations. In acute services, we observed every interaction between 7 am and 7 pm during their episode of care, unless any person indicated this was not appropriate or wanted. In inpatient rehabilitation, we conducted episodic observations, completing at least six 4-h observation periods during each person's length of stay. We used event sampling to purposefully sample events (e.g. ward rounds). We conducted informal interviews with participants with stroke during observations, seeking their

reflections on their stroke, its impact, their care, and their future hopes and goals. We completed short ethnographic interviews immediately after observations where possible, seeking reflections on the interaction. These lasted between 5 and 30 mins. After each patient was discharged, we conducted semi-structured interviews with purposefully selected clinicians, aiming to interview at least two clinicians who had worked with each patient participant and with whom we had completed several observations. We sought to explore their reflections on their interactions with patients (including those not observed by the researcher) and their reasoning behind their ways of talking about the future. Examples of questions are provided in Table 1. These interviews were dynamic and responsive to what was observed, and as such, most short ethnographic questions were very specific to observed features of interaction. Interviews were audio-recorded and transcribed.

## Data analysis

We used reflexive thematic analysis (Braun and Clarke 2021). We familiarised ourselves with the data by listening to recordings, reviewing fieldnotes and transcripts, and creating analytic memos. Through coding, we extracted data relating to the idea of 'the future', or indeed, reflecting anything time-related, including references to the past. What constituted the 'future' was broad; we included data about any point in time beyond the immediate situation. Semantic codes stayed close to the data (e.g. 'focusing on the immediate present') whereas latent codes reflected a deeper interpretation (e.g. 'waiting in a holding zone'). Initial

**Table 1.** Focus of each interview type.

		Examples of questions
Short ethnographic interviews: people with stroke	<ul style="list-style-type: none"> <li>• Impressions of the interaction</li> <li>• What they recalled</li> <li>• What remaining questions they had</li> <li>• What they would have liked to discuss</li> <li>• How they felt during the discussion</li> </ul>	<ul style="list-style-type: none"> <li>• How did that conversation go?</li> <li>• Do you feel you have a sense of what life will look like after you leave here?</li> <li>• What questions do you still have?</li> </ul>
Short ethnographic interviews: clinicians	<ul style="list-style-type: none"> <li>• Reasoning behind the conversation</li> <li>• Perceptions of the needs, priorities, and future of the person with a stroke</li> <li>• Areas that had not been addressed</li> <li>• Plans for future interactions</li> </ul>	<ul style="list-style-type: none"> <li>• I noticed that conversation focused on [topic]. Can you tell me more about why that was the main thing discussed?</li> <li>• What are the most important things for you to be focused on at the moment? Why is this?</li> <li>• What other conversations about life after stroke will be had before [patient's name] leaves here? Who will have them and when?</li> </ul>
Semi-structured interviews: clinicians	<ul style="list-style-type: none"> <li>• Perspectives about how the future had been discussed throughout the person's episode of care (including in interactions, which we may not have observed)</li> <li>• Exploring what was and was not discussed throughout the episode of care</li> <li>• Clinical reasoning behind these interactions</li> <li>• Reflections on how these were received</li> </ul>	<ul style="list-style-type: none"> <li>• Were there any conversations that I <i>didn't</i> observe where you talked about life after stroke with this person? Can you describe some of those conversations to me?</li> <li>• What do you think [patient's name] is expecting and/or wanting [their] future to look like? What makes you think this?</li> <li>• One thing I wondered if I would observe was conversations about [topic]. Did you or the team have any conversations with [patient] about this? (If no) Can you tell me more about why that wasn't discussed?</li> </ul>

themes were generated by grouping codes, although many reflected topic summaries (Braun and Clarke 2021), for instance, ‘context of care’. We then engaged more deeply with the data, attending to features of conversation and paying particular attention to the data from observed interactions. Through this, the temporal aspects of conversation became more apparent. Analytic questioning furthered the analysis, for example, ‘How is the notion of ‘possibilities’ evident in interactions?’ These areas of focus were influenced by our previous research and positioning (see below). We re-coded the interviews with clinicians to better understand their (self-identified) rationale for their conversational approaches. This helped us attune to different notions, such as the agendas of services. Themes were developed and refined through mapping and team discussions. Through this iterative process, three themes were constructed.

Research credibility was achieved through multiple strategies (Thorne 2016). Integrating multiple forms of data from across multiple participants and contexts, integrating raw data into analytic representation, and situating findings within the broader practice context aid the reader in interpretation and support *representative credibility*. Detailed descriptions of data construction and analysis processes, accompanied by thick descriptions, demonstrate *analytic logic*. Team discussions regarding analysis and discussions about the findings with experienced clinicians provide *interpretive authority*.

### Researcher characteristics and positionality

The research team is experienced in conducting clinically orientated health research. We bring clinical and research

experience in speech-language therapy (F.B.), health psychology (N.K.), physiotherapy (A.S.) and pharmacy (J.D.), and over many years, we have conducted research in patient-provider communication, hope, and well-being in the context of living with long-term neurological conditions. We view the relationship between the person with a stroke and their clinician as integral in care, providing a platform for engagement and helping people as they move forward after a significant diagnosis or health event. This informed our decision to focus on the communication between the dyad; our combined interests in communication hope and well-being likely influenced how we constructed the analysis.

The research was led by F.B., an experienced ethnographer. She completed all data collection, while all authors contributed to data analysis. Although she had previous clinical experience in the localities, she had not worked in them for over 10 years; through professional networks, she was known to many of the clinician participants. In this research, she was an ‘outsider’ with some familiarity with the setting. She took the role of observer-as-participant (Gold 1958), observing interactions but not taking part unless a participant directly addressed her.

## Results

Our study included 42 people: five people with stroke and 37 clinicians. Table 2 contains details of people with stroke. They presented with a variety of impairments, and there was variation in age and severity. All were New Zealanders of European or Asian descent. Demographic information was

**Table 2.** Participants with stroke.

Pseudonym	Gender	Age range (years)	Service used	Stroke presentation Barthel range 0–20, 0 being fully dependent	Number of dyads participating
Catherine	F	65–74	Inpatient rehabilitation	Moderate non-fluent aphasia Barthel: 19	8
Gary	M	55–64	Inpatient rehabilitation	Severe non-fluent aphasia Severe left hemiparesis Incontinent Barthel: 0	12
Arthur	M	75–84	Acute	Mild cognitive impairments Mild right hemiparesis Barthel: 8	10
Bruce	M	55–64	Acute	Minimal residual impacts Barthel: 20	4
Alison	F	45–54	Inpatient rehabilitation	Moderate left hemiparesis Mild dysarthria Barthel: 5	3

**Table 3.** Clinician participants.

Clinical experience	<5 years	18
	>5 years	19
Profession	Doctor	7
	Nurse	13
	Healthcare or rehabilitation assistant	4
	Physiotherapist	4
	Occupational therapist	5
	Speech-language therapist	4
Workplace	Acute	14
	Inpatient rehabilitation	23
Gender	Female	32
	Male	5
Ethnicity	New Zealand European	15
	Samoan	1
	Chinese	3
	Other	18

reported from the person's clinical records, and the Barthel Index (a measure of dependence on daily activities) (Mahoney and Barthel 1965) was completed on admission. Clinicians, detailed in Table 3, represented most healthcare disciplines, except social work and psychology. They varied in clinical experience. Data were gathered through over 300 h of observations and 76 interviews.

We constructed three themes that reflect how clinicians talk about the future with people in inpatient stroke services: (1) constrained temporal horizons, (2) limited talk controlled by clinicians, and (3) opening some doors while closing others. Within the analysis, we present quotes taken from observations and interviews. The context of the data is identified, along with the pseudonym of the person with stroke and the clinician's discipline.

### Theme one: constrained temporal horizons

This theme describes the constrained nature of temporal horizons – the expanse of time constructed and made visible within people's interactions. Interactions about the future focused on the short-term future. This reflected specific temporal horizons, which arguably shaped clinicians' actions, informing what was prioritised. Care focused on the short-term future, with limited discussion observed about life beyond the hospital or first days at home. Disciplinary trends were evident, with nurses focusing on activities within their shift or the next 24 h. Completing required 'cares' (Interview, Arthur's nurse) – monitoring for deterioration, providing medications, and not leaving work undone – was a core drive for nurses in acute care. Doctors discussed what needed to happen before discharge

from their service, problem-solving issues so that people could be discharged. In acute care, there was a 'day-by-day' focus (Interview, Arthur's physiotherapist), which co-existed for allied health with a focus on discharge preparations and was reflected in quotes, such as 'we've got the family meeting on Monday to talk about home, what we need to aim for, what needs to be done' (Observation, Alison's occupational therapist; OT). They also looked to the immediate time beyond discharge, discussing physical equipment needed and advising on community follow-up. These timescapes appeared to reflect what clinicians considered they needed to prioritise and what the care context *required* them to prioritise to ensure patient throughput and management of high, and often acute, caseloads.

As people moved toward discharge from rehabilitation, timescapes in conversation and action reflected a stronger focus on discharge and beyond, which one clinician called the 'agenda of discharge' (Interview, Catherine's OT), such as 'meal prep assessment, social supports, rehabilitation referral' (Clinical notes, Catherine's OT) and 'showering, walking around her home, and getting in and out of the toilet' (Alison's family meeting records). Interactions centred on assessing, treating, and problem-solving to maximise people's abilities at home. Within conversations, clinicians intimated about the future beyond discharge. For instance, people with stroke were told that 'rehabilitation is something that happens when you come into hospital. Here (inpatient rehabilitation) is where we step it up and get more aggressive with it. But it continues once you leave hospital, at home or where you go' (Observation, Gary's doctor). This was reiterated in a family meeting: 'We're just the first part of the rehab journey. [The community rehabilitation service] picks up where we leave off once you go home. Not many people who come to us with your needs finish completely when you leave us' (Observation, Gary's physiotherapist). Conversations about life beyond discharge centred around services that would be provided, with few conversations appearing to attend to the person's emotions, identity, meaningful activities or roles, or other areas literature suggests are important for life after stroke. Although longer-term rehabilitation and recovery were discussed by staff in interviews, task-focused care and discharge planning were privileged within interactions. This reinforced the focus on short-term futures.

Throughout the continuum of care, some clinicians made active decisions to not talk about a more distant and unknown future. This appeared to reflect assumptions about what inpatient clinicians considered they could and should talk about:

[We are] trying to focus on the transition home and what that would look like because the [community rehabilitation] team are in a much better place to talk about what happens after them ... [The person] will always have their [general practitioner] GP and the community

team will go through this with [the person], so [we're] trying, in a way, I suppose, to not to get too far into the future. (Interview, Alison's OT).

This quote reflects a perspective that other clinicians were better placed to discuss longer-term rehabilitation and recovery. It could also reflect that all parties experiencing uncertainty about the future, with the future outside the control of both the person with stroke and the clinician (e.g. the timing of when things might happen, such as transfer to rehabilitation, and actual outcomes, such as the degree of recovery). In the context of uncertainty, people with stroke sought and valued information, particularly from nurses as they were present around the clock. Yet nurses felt they had limited information about the short- or long-term futures, making it challenging for them to talk about the future. Across disciplines, many clinicians deferred conversations about the future. For example, in acute services, clinicians suggested that the patient and family have conversations in inpatient rehabilitation: 'You can have more discussions up there [the rehabilitation ward] about discharge and where he will go' (Observation, Arthur's OT). Yet inpatient rehabilitation clinicians also deferred conversations, saying '[we're] trying [to] not get too far into the future ... the community team are better placed to talk about [that]' (Interview, Alison's OT). By deferring these conversations until *others* could discuss the future, uncertainty was prolonged, and even reinforced, for the person with stroke and their whānau (family, or for Māori, people within wider network who are important to them). This had the unintended consequence of constraining patients' temporal horizons.

### Theme two: limited talk under the control of clinicians

Although discussions about the future were constrained, they occurred in the context of limited communication overall. Planned interactions – ward rounds, regular neurological observations, and therapy sessions – were the primary sites of interaction, with topics shaped by information that clinicians considered they needed to know or share. Medical and nursing interactions followed an unwritten script in which physical function was reviewed before actions that needed to be completed during their shift, or before discharge, were discussed. Clinicians wove discussions about the future throughout their interactions. Examples included a nurse commenting during her regular observations: 'Did you know the cardiologist is still reviewing you and you have a procedure tomorrow?' (Observation, Bruce's nurse) and an OT asking Arthur for his views of his impairments and coping during a session: 'Do you normally shave like this ... how do you think you'd get on at home?' (Observation). However, these interactions were still initiated by, and under the control of, clinicians.

The person's future was most overtly discussed in the context of goal-setting; however even then, the areas of life discussed and documented appeared constrained and shaped around the person's previous function and activities. This reflected an assumptive future in which clinicians appeared to assume *previous* functions and activities were *desired* future activities: 'What we like to do is talk to people about what they used to do and what they want to get back to' and 'we want to get people back to doing as much as what they used to do before.' (Observations, Catherine's speech-language therapist; SLT). In goal-setting, physical function, rehabilitation needs, and physical and home support needs were privileged, reinforcing the orientation toward discharge: 'Before we send you home ... [we are] making sure that the little things in life flow well. Things like medication.' (Observation, Catherine's SLT). When people with stroke identified goals outside of these areas, these were not often integrated into the structured goals of care. For example, Alison identified a goal to 'cook Christmas lunch' during a group education session on the ward (Interview), but this remained *her* goal; it was nowhere in the clinical notes. In an observed session, the OT told her 'We need a goal for the upper limb'; however, goals recorded in her clinical notes focused on what was needed for her to 'return home': 'to be able to walk independently, to be able to toilet independently, to be able to prepare meals, to be able to dress and shower independently'. The services' priority of moving people toward discharge was reflected in what was prioritised in conversations and care. Unintentionally, processes designed to identify what mattered could limit what was identified and what was then focused on.

What topics were *not* initiated by clinicians were notable. There was little observed discussion or attention to the emotional or psychosocial impacts of stroke. This is not to say that staff did not respond to issues when raised, but these were rarely observed to be pre-emptively raised by clinicians. In one instance, a family member initiated a conversation about Alison's emotions. The OT explained later:

[Her husband] was right, things could change down the line and there might be a realisation that things are different so we pinpointed them to like that there is a psychologist on the team ... and then we just talked about the GP as a contact ... and we discussed that it's very normal to happen after stroke and it could happen in the future. Just to be aware to keep an eye on it ... but it was really important because it could definitely, you know, once she gets home. (Interview).

Some clinicians reported a hesitation to 'open the door' and 'start those conversations too early' (Interview, Alison's OT) for areas that they did not feel equipped to address or they felt could be deferred. Other topics *not* talked about related to social roles beyond roles within the household,

relationships, and hobbies. Despite being recognised as important, these were not considered ‘essential’ in inpatient care. During a family meeting, Alison’s team said, ‘It is a good idea to think about the essential goals when you are an inpatient, and longer-term goals when you are with the community team’. Examples of ‘essential goals’ were given, such as ‘getting in and out of the toilet, bathroom and kitchen’. This was taken up by Alison’s husband, who suggested essential goals might be ‘walking within Alison’s home or perhaps 1 day, walking at [local park]’. Alison’s OT, in an interview, suggested the best place to support social roles and other domains was in the community, reflecting the process of deferral discussed above. There were explicit conversations about hobbies and emotions with only one person, Gary. This occurred in the context of a team who were highly attuned to people’s emotions, regularly considering them in team discussions, and where staff described working intentionally to build trust. That attention to areas beyond physical function is the exception rather than the rule reflects that particular functions and topics are privileged in conversation and may (not necessarily intentionally) limit what is considered in care.

Clinician control over interactions was particularly evident when communication was challenging. Two participants had significant aphasia, another was in infection control isolation, and another had significant fatigue. Interactions required greater intentionality, and sometimes skill, from the clinician. However, these people were rendered as somewhat forgotten patients, with whom staff had limited interactions. For Bruce in isolation, staff worked to do their face-to-face work ‘all at once’ (Interview, Bruce’s nurse), seeking maximum efficiency given the need for personal protective equipment (PPE), in the context of pandemic-related PPE shortages. There were few opportunities for incidental conversations. Catherine was another ‘forgotten patient’ because her communication impairments meant conversations took longer. One nurse commented:

I hope Catherine is not missing out because I’m spending time quickly with other patients to try and balance what I haven’t been able to do what I want to do with her because of the communication barrier. This morning, she just went off and had a shower because I didn’t have time to work out what she wanted. I couldn’t slow down and talk to her because my other ladies were demanding. (Interview, Catherine’s nurse).

Conversations about the future were limited; for many people, conversations *in general* were limited.

### **Theme three: opening some doors while closing others**

This theme shows that although future-focused conversations were limited and focused on particular temporal

horizons, clinicians did hold the door open to some possible futures, addressing the future beyond discharge.

New technologies facilitated different conversations about possible futures. Prognostic testing for upper limb recovery was routinely used in one service. Clinicians took the responsibility of determining and conveying prognoses seriously, mindful of the possible emotional ramifications, and were supported by evidence-based scripts for conveying prognosis. Alison received a ‘poor prognosis’. This was conveyed as:

We’ve had a good look and Alison, I wish we had a bit better news to give you. Unfortunately the tests have shown us the pathway isn’t working for you. What that means, if you remember, is that we would expect you to get some movement back. What that means for your rehab is two things. [We] will work on seeing how much strength you can get back in your arm and learning how to do the fine motor stuff with the left hand. (Observation, Alison’s OT).

The sense of certainty the test provided appeared attractive to Alison and her family. They sought the same information about her walking. Clinicians later commented on how Alison had taken the prognosis, considering it ‘probably skewed her perception early on ... she was asking a lot ‘is my leg gonna be like this? If my leg is like this then I’m not gonna walk and then I’m definitely not going home’ (Interview, Alison’s OT). This suggested that conveying prognoses could see people make determinations of what was possible, extrapolating to other areas of recovery, but also orientated them toward their bodily function.

Another way in which clinicians opened doors to possible futures was evident when people appeared to be somewhat stuck in the present. Their temporal horizons were diminished; their sense of possibility appeared to be limited. In these instances, clinicians worked to hold the door open for hope. For Gary, they talked about the importance of keeping ‘aspirational goals’ alive (Observation, Gary’s OT). Clinicians recorded Gary’s dream of driving a specific, special car, but also recorded goals that might be possible in the shorter term, such as going for a drive in the car. Gary’s team tried to maintain an orientation to progress and possibility, keeping that particular door open for Gary and his family. They helped him see progress by focusing on taking one step at a time. Alison, another woman with significant physical impairment, actively problem-solved how she was going to manage at home based on her *current* level of function, not appearing to consider that this might change. However, her clinicians thought she would have more recovery, with her OT saying ‘It was part of our job to kind of instil that hope for her but still be realistic, but I guess we can see the potential in her’. The same therapist described trying to plant seeds as to what might be possible, opening up possibilities and warding off hopelessness: ‘She’s got it in her



mind about getting a wheelchair for longer distances but I'm just trying to show her that with time and with the community input, she probably will get back to walking' (Interview, Alison's OT). In this case, the door was held *conditionally* open to what clinicians considered was realistic. The two teams focused on different future possibilities: Gary's team on what brought joy and meaning, and Alison's team on specific activities, such as walking. Through their interaction, staff adopted 'holding the door open' as a therapeutic strategy, employing hope and possibility as strategies to achieve the goal of patient engagement in rehabilitation.

## Discussion

This is the first in-depth qualitative study to reveal how clinicians talk about the future of people in inpatient stroke care. Clinicians employed common timescapes within their interactions, framing the future as something short-term. There was limited talk about life beyond the four walls of the hospital or the first days at home. This represented the endpoint of the episode of care for the clinician but not the endpoint of recovery for the person with a stroke. Conversations were often linked to short-term physical and functional outcomes and within conversations; these outcomes were broken into smaller units considered achievable within the episode of care. The ways clinicians talked about the future reflected their challenges with managing uncertainty, their conceptualisation of their role in the person's journey after stroke, and broader organisational priorities of care. As a result, clinicians commonly did not advise beyond the horizons of their timescape of care. Taken in totality, this has implications for how people with stroke are supported to engage in thinking about their life after stroke. When people are supported to understand how their stroke has impacted them and when they are supported to look forward to their future, this can be reassuring and empowering (Kitzmüller et al. 2019). Therefore, understanding *how* clinicians support people to look forward to their future is imperative.

Understanding the context of stroke care gives some insight into *why* communication occurs as it does. The short-term, impairment-based focus is not uncommon (Bradley et al. 2021; Greenway et al. 2022). Communication can both *reflect* the broader context of care practice and *reproduce* this context of care. Other work in stroke has revealed some features of the context of care. These include focusing on physical function and impairments within goal-setting and care provision (Levack et al. 2011; Rosewilliam et al. 2016); focusing on short-term goals (Levack et al. 2011); privileging mandated activities, such as assessments and care processes, which have key performance indicators attached (Bright et al. 2018); and deferring different aspects of care, such as supporting self-management, until the next phase of

rehabilitation (Greenway et al. 2022). Communication also reflects another aspect of the care context: how clinicians construct their roles and the scope of their roles. This can be seen in nursing interactions that focus on the immediate future with interactions being primarily task-focused (Hersh et al. 2016). This likely reflects that core nursing roles in stroke are monitoring for deterioration and prevention of secondary complications (Theofanidis and Gibbon 2016), which requires close attunement to the here and now. Combined with high workloads, nurses organise their work around what they consider possible to achieve within their shift (Seneviratne et al. 2009). All of these factors can contribute to a time-limited, task-focused approach to care, which then is reflected in how clinicians talk about the future and the timescapes created through conversation.

Our study revealed an absence of conversation about some significant areas impacted by stroke, specifically the emotional and the broader psychosocial impacts of stroke and the more existential impacts of stroke, such as hope (Bright et al. 2011), self (Hutton and Ownsworth 2019; Schmidt and Ownsworth 2022), and meaning (Eilertsen et al. 2010). These wider impacts on self may be unseen and not discussed during inpatient care but can cause significant distress after discharge (Arntzen et al. 2015), leaving people to reconstruct a meaningful life after stroke with little support, and even with limited awareness that this is common and limited perspectives on what might be possible (Gallagher 2011). It is possible that by not talking about these aspects, clinicians have unintentionally restricted what people were informed about, felt able to talk about at the time, or felt comfortable talking about with others at a later point (Wenzel et al. 2021). Indeed, previous research has shown that people with stroke do not always know the stroke team can support them with psychosocial issues and so do not raise issues (Wenzel et al. 2021). This can be problematic given that the psychosocial impacts of stroke are recognised as an unmet need after stroke (Satink et al. 2013; Guo et al. 2021) and that depression and anxiety rates are significant after stroke (Barker-Collo et al. 2017; Arwert et al. 2018). Bradley and colleagues (2021) described how the focus on improving physical function and ensuring people are physically safe for discharge 'compromised the emphasis on wider cognitive, emotional and social needs' (p. 2300), akin to what we observed in this study. Having conversations that both acknowledge the existential impacts of stroke and also support people to have a sense of hope and possibility for the future, may help support people as they navigate life after stroke (Bright et al. 2013; Rixon 2022).

This study suggested that one factor impacting how clinicians talk about the future is uncertainty. Uncertainty is recognised as a key feature of the time post-stroke (Carlsson et al. 2009; Satink et al. 2013; Connolly et al. 2021) and is unavoidable (Connolly et al. 2021). Our study furthers understandings by identifying how clinicians

manage uncertainty through interactions by (1) giving certainty on what is known and focusing *only* on what is known; (2) avoiding what is not known; and (3) limiting conversations to what feels safe or known; that is, safe from possible emotional reactions from the patient and safe from the risk of predicting the wrong future. In other clinical contexts, uncertainty has been found to have a significant emotional sequelae for people (Costa *et al.* 2022; Nissen *et al.* 2022). However, clinicians in our study did not appear to attend to the emotional elements of uncertainty, instead managing it by deferring conversations to future time points and others. By failing to acknowledge or engage with the emotional aspects of uncertainty, and by actively limiting opportunities and depth of conversation about areas of uncertainty, we suggest this may exacerbate the distress felt by those with stroke (Connolly *et al.* 2021). Research has identified the importance of uncertainty being acknowledged, calling for open and honest conversation about areas of uncertainty (Connolly *et al.* 2021). We agree with Costa *et al.* (2022) that there is value in both acknowledging the uncertainty and exploring and supporting people's emotions about this uncertainty.

There is a need for clinicians to open the door to different stories and pathways of recovery. We do not suggest that the sole responsibility for opening up different possibilities resides in clinical services. Our findings suggest that the absence of conversations about the future in stroke services not only limits the opportunity to engage with different possibilities but may work to actively counter a person's sense of possibility. We suggest that access to others with stroke, learning from their experiences and stories, normalising current experiences, and developing a sense of different possibilities can be key (Moss *et al.* 2022) and should be something supported within stroke services (Bright *et al.* 2011; Arntzen *et al.* 2015; Hutton and Ownsworth 2019). Although our research offers new insights into communicative practices in inpatient stroke services, it has some limitations. We sought the perspectives of people with stroke; however, future research could explore their perspectives later in recovery to understand how these time-limited conversations may have impacted their experience of recovery and gain their views of what they needed from those early conversations. From this work, we cannot determine that every person with stroke desires conversations about the future nor that every clinician must have these conversations. Gaining insights from those later in their journey may provide more understanding about what conversations about the future are needed, when, and with whom. Nor have we delved into the ways interactions may have been influenced by culture, gender, or socio-economic status, an area worthy of future investigation. The small number of stroke participants, albeit with significant observation periods and many clinician participants, may mean that we saw particular interactional patterns that reflected specific patient characteristics. Gathering a more diverse sample of

people with stroke may offer different insights. We also acknowledge that we did not see every conversation between clinicians and those with stroke. Different aspects of the future may have been addressed within other conversations, although we sought to identify other interactions through interviews with people with stroke and clinicians. However, gathering data across different patients, clinicians, and clinical contexts provides rich insight into common conversational patterns, and this study provides useful prompts for clinicians to reflect on in practice.

This research has a number of implications for practice. It can prompt clinicians to reflect on what timescapes are discussed and created in their interactions. Goal-setting processes, often thought to foster these conversations, instead reinforced a short-term, discharge-orientated focus and reflected tacit assumptions that people want to get back to 'normal' or to past activities. People need to be invited to share what is important and provided with opportunities and support to re-envisage their desired future life, as this can often change after a significant event, such as stroke (Bright *et al.* 2020). Being aware of what *aspects* of the future are discussed is critical in supporting people to navigate life after a stroke. Our finding that there are few conversations about emotions is not new (Satink *et al.* 2013; Burton *et al.* 2021). However, it remains deeply problematic that these areas of life remain unspoken. Emotions, adjustment, social relationships and interactions, and sexuality are all important in living well after a stroke (Hole *et al.* 2014; Wray and Clarke 2017; McGrath *et al.* 2019). It is essential that clinicians open the door to future-focused conversations that consider *all* the ways people can be impacted by stroke, normalising these impacts and giving people access to information (Shipley *et al.* 2020).

As our work has shown, opening the door for conversations about the future may be challenging for clinicians. Clinicians themselves experience uncertainty about people's future, resulting in the strategy of deferring conversations or anchoring to techniques that allow high levels of certainty (Burton *et al.* 2021). The emotional aspects of these conversations can be challenging but are not often discussed (Burton *et al.* 2021). Clinicians may benefit from having opportunities to reflect on their uncertainties regarding prognosis and exploring how, in light of this, they continue to prioritise conversations about this uncertain future. Such future-focused conversations may bring up aspects of adjustment and emotions that clinicians feel ill-equipped to support (Burton *et al.* 2021). Although specialist psychological support may be needed for some people with stroke (Kneebone 2016), these supportive conversations are a core component of good stroke practice and, as such, we suggest all clinicians in stroke should have the capacity for these and may benefit from improving their skills, consistent with a stepped care model (Kneebone 2016). Peer support, training, supervision, and coaching may build their skills and ability to hold open the door for people to reflect on

what is happening (e.g. Thomson *et al.* 2013; Pedersen *et al.* 2021). This is not to say clinicians are the sole sources of information; however, connecting people to other information sources may also be valuable. Information from trusted online sources or support organisations and provision of peer support can be vital in helping people make sense of their experience (Morris and Morris 2012; Finch *et al.* 2022). Our work has also demonstrated that conversations may be more limited when there are communication challenges, with patient isolation and aphasia being just two examples we encountered. We encourage clinicians to reflect on how some people may face communicative isolation (Bright and Reeves 2020), rendering them more vulnerable to being excluded from conversations about the future.

Although we have focused on the clinicians' communicative acts in this research, we acknowledge that clinicians' conversational practices likely reflect wider organisational and professional priorities and discourses. Inpatient services face significant pressures and discharge is a common organisational priority that then gets passed to clinicians and may shape what they prioritise (Suddick *et al.* 2019; Heenan 2023). Similarly, it is not uncommon for professional practice in stroke care to prioritise body structures and functions and activity restrictions (Foster *et al.* 2014; Evans *et al.* 2017). Previous work has detailed how this can sideline important care that supports people to reconstruct their identity and life after stroke (Brown *et al.* 2014; Foster *et al.* 2014). Our findings highlight that this is evident in interactions, which has implications for supporting people as they navigate life after a stroke. It is imperative that any moves to improve clinician communication explicitly address the wider context that shapes their practice, attending to systemic factors that privilege particular aspects of care, as well as supporting clinicians to reflect on their practice and build their knowledge, skills, and confidence.

## Conclusion

This observational study of communication practices reveals that conversations about the future after stroke are constrained and limited: constrained to short-term futures and limited in what aspects of life after stroke are discussed. Creating conversational and relational spaces where people are supported to look to the future with a sense of possibility, hope, and potential is vital for assisting people to move forward in their lives after their stroke. It is essential that we attend to how communication invites conversations about the future and assists people to consider what a good and meaningful life with stroke can look like for them. Given its role in supporting people to move forward in life, communication must be seen as a core clinical skill and a clinical intervention in its own right.

## References

- Ajjawi R, Higgs J (2012) Core components of communication of clinical reasoning: a qualitative study with experienced Australian physiotherapists. *Advances in Health Sciences Education* 17(1), 107–119. doi:10.1007/s10459-011-9302-7
- Alaszewski A, Alaszewski H, Potter J (2006) Risk, uncertainty and life threatening trauma: analysing stroke survivor's accounts of life after stroke. *Forum: Qualitative Social Research* 7(1), 1–18.
- Arntzen C, Hamran T, Borg T (2015) Body, participation and self transformations during and after in-patient stroke rehabilitation. *Scandinavian Journal of Disability Research* 17(4), 300–320. doi:10.1080/15017419.2013.868823
- Arwert HJ, Meesters JJJ, Boiten J, Balk F, Wolterbeek R, Vliet Vlieland TPM (2018) Poststroke depression: a long-term problem for stroke survivors. *American Journal of Physical Medicine and Rehabilitation* 97(8), 565–571. doi:10.1097/phm.0000000000000918
- Barker-Collo S, Krishnamurthi R, Witt E, Theadom A, Starkey N, Barber PA, Bennett D, Rush E, Arroll B, Feigin V (2017) Depression and anxiety across the first year after ischemic stroke: findings from a population-based New Zealand ARCOS-IV study. *Brain Impairment* 18(3), 265–276. doi:10.1017/BrImp.2017.12
- Bradley G, Baker K, Bailey C (2021) The meaning of rehabilitation: a qualitative study exploring perspectives of occupational therapists and physiotherapists working with older people in acute care. *Disability and Rehabilitation* 43(16), 2295–2303. doi:10.1080/09638288.2019.1697762
- Braun V, Clarke V (2021) 'Thematic analysis: a practical guide.' (SAGE Publications)
- Bright FAS, Reeves B (2020) Creating therapeutic relationships through communication: a qualitative metasynthesis from the perspectives of people with communication impairment after stroke. *Disability and Rehabilitation* 44, 2670–2682. doi:10.1080/09638288.2020.1849419
- Bright FAS, Kayes NM, McCann CM, McPherson KM (2011) Understanding hope after stroke: a systematic review of the literature using concept analysis. *Topics in Stroke Rehabilitation* 18(5), 490–508. doi:10.1310/tsr1805-490
- Bright FAS, Kayes NM, McCann CM, McPherson KM (2013) Hope in people with aphasia. *Aphasiology* 27(1), 41–58. doi:10.1080/02687038.2012.718069
- Bright FAS, Kayes NM, McPherson KM, Worrall LE (2018) Engaging people experiencing communication disability in stroke rehabilitation: a qualitative study. *International Journal of Language & Communication Disorders* 53(5), 981–994. doi:10.1111/1460-6984.12409
- Bright FAS, McCann CM, Kayes NM (2020) Recalibrating hope: a longitudinal study of the experiences of people with aphasia after stroke. *Scandinavian Journal of Caring Sciences* 34(2), 428–435. doi:10.1111/scs.12745
- Brown M, Levack W, McPherson KM, Dean SG, Reed K, Weatherall M, Taylor WJ (2014) Survival, momentum, and things that make me "me": patients' perceptions of goal setting after stroke. *Disability and Rehabilitation* 36(12), 1020–1026. doi:10.3109/09638288.2013.825653
- Burton L-J, Forster A, Johnson J, Crocker TF, Tyson SF, Wray F, Clarke DJ (2021) Experiences and views of receiving and delivering information about recovery in acquired neurological conditions: a systematic review of qualitative literature. *BMJ Open* 11(4), e045297. doi:10.1136/bmjopen-2020-045297
- Carlsson GE, Möller A, Blomstrand C (2009) Managing an everyday life of uncertainty – a qualitative study of coping in persons with mild stroke. *Disability and Rehabilitation* 31(10), 773–782. doi:10.1080/09638280802638857
- Cheng BBY, Ryan BJ, Copland DA, Wallace SJ (2022) Prognostication in post-stroke aphasia: perspectives of people with aphasia on receiving information about recovery. *Neuropsychological Rehabilitation* 31, 773–782. doi:10.1080/09602011.2022.2051565
- Connolly T, Coats H, DeSanto K, Jones J (2021) The experience of uncertainty for patients, families and healthcare providers in post-stroke palliative and end-of-life care: a qualitative metasynthesis. *Age and Ageing* 50(2), 534–545. doi:10.1093/ageing/afaa229

- Costa N, Olson R, Mescouto K, Hodges PW, Dillon M, Evans K, Walsh K, Jensen N, Setchell J (2022) Uncertainty in low back pain care – insights from an ethnographic study. *Disability and Rehabilitation* 45, 784–795. doi:10.1080/09638288.2022.2040615
- Eilertsen G, Kirkevold M, Bjørk IT (2010) Recovering from a stroke: a longitudinal, qualitative study of older Norwegian women. *Journal of Clinical Nursing* 19(13–14), 2004–2013. doi:10.1111/j.1365-2702.2009.03138.x
- Ellis-Hill CS, Horn S (2000) Change in identity and self-concept: a new theoretical approach to recovery following a stroke. *Clinical Rehabilitation* 14(3), 279–287. doi:10.1191/026921500671231410
- Ellis-Hill C, Payne S, Ward C (2008) Using stroke to explore the Life Thread Model: an alternative approach to understanding rehabilitation following an acquired disability. *Disability and Rehabilitation* 30(2), 150–159. doi:10.1080/09638280701195462
- Evans M, Hocking C, Kersten P (2017) Mapping the rehabilitation interventions of a community stroke team to the extended International Classification of Functioning, Disability and Health Core Set for Stroke. *Disability and Rehabilitation* 39(25), 2544–2550. doi:10.1080/09638288.2016.1239763
- Finch E, Minchell E, Cameron A, Jaques K, Lethlean J, Shah D, Moro C (2022) What do stroke survivors want in stroke education and information provision in Australia? *Health & Social Care in the Community* 30(6), e4864–e4872. doi:10.1111/hsc.13896
- Foster A, O'Halloran R, Rose M, Worrall L (2014) "Communication is taking a back seat": speech pathologists' perceptions of aphasia management in acute hospital settings. *Aphasiology* 30(5), 585–608. doi:10.1080/02687038.2014.985185
- Gallagher P (2011) Becoming normal: a grounded theory study on the emotional process of stroke recovery. *Canadian Journal of Neuroscience Nursing* 33(3), 24–32.
- Gold RL (1958) Roles in sociological field observations. *Social Forces* 36(3), 217–223. doi:10.2307/2573808
- Greenway A, Gustafsson L, Bower K, Walder K (2022) Exploring self-management within hospital-based stroke care: current and future opportunities. *Disability and Rehabilitation* 44(11), 2340–2346. doi:10.1080/09638288.2020.1833092
- Guo Y, Zhang Z, Lin B, Mei Y, Liu Q, Zhang L, Wang W, Li Y, Fu Z (2021) The unmet needs of community-dwelling stroke survivors: a systematic review of qualitative studies. *International Journal of Environmental Research and Public Health* 18(4), 2140. doi:10.3390/ijerph18042140
- Heenan D (2023) Hospital social work and discharge planning for older people: challenges of working in a clinical setting. *Ageing & Society* 43(6), 1333–1350. doi:10.1017/S0144686X21001124
- Hersh D, Godecke E, Armstrong E, Ciccone N, Bernhardt J (2016) "Ward talk": nurses' interaction with people with and without aphasia in the very early period poststroke. *Aphasiology* 30(5), 609–628. doi:10.1080/02687038.2014.933520
- Hjelmlink F, Holmstrom I (2006) To cope with uncertainty: Stroke patients' use of temporal models in narratives. *Scandinavian Journal of Caring Sciences* 20(4), 367–374. doi:10.1111/j.1471-6712.2006.00415.x
- Hole E, Stubbs B, Roskell C, Soundy A (2014) The patient's experience of the psychosocial process that influences identity following stroke rehabilitation: a metaethnography. *The Scientific World Journal* 2014, 349151. doi:10.1155/2014/349151
- Hutton L, Ownsworth T (2019) A qualitative investigation of sense of self and continuity in younger adults with stroke. *Neuropsychological Rehabilitation* 29(2), 273–288. doi:10.1080/09602011.2017.1292922
- Kagan A (1998) Supported conversation for adults with aphasia: methods and resources for training conversation partners. *Aphasiology* 12(9), 816–830. doi:10.1080/02687039808249575
- Kitzmüller G, Mangset M, Evju AS, Angel S, Aadal L, Martinsen R, Bronken BA, Kvigne K, Bragstad LK, Hjelle EG, Sveen U, Kirkevold M (2019) Finding the way forward: the lived experience of people with stroke after participation in a complex psychosocial intervention. *Qualitative Health Research* 29(12), 1711–1724. doi:10.1177/1049732319833366
- Kneebone II (2016) Stepped psychological care after stroke. *Disability and Rehabilitation* 38(18), 1836–1843. doi:10.3109/09638288.2015.1107764
- Levack WMM, Dean SG, Siegert RJ, McPherson KM (2011) Navigating patient-centered goal setting in inpatient stroke rehabilitation: how clinicians control the process to meet perceived professional responsibilities. *Patient Education and Counseling* 85(2), 206–213. doi:10.1016/j.pec.2011.01.011
- Loft MI, Martinsen B, Esbensen BA, Mathiesen LL, Iversen HK, Poulsen I (2019) Call for human contact and support: an interview study exploring patients' experiences with inpatient stroke rehabilitation and their perception of nurses' and nurse assistants' roles and functions. *Disability and Rehabilitation* 41(4), 396–404. doi:10.1080/09638288.2017.1393698
- Lou S, Carstensen K, Jørgensen CR, Nielsen CP (2017) Stroke patients' and informal carers' experiences with life after stroke: an overview of qualitative systematic reviews. *Disability and Rehabilitation* 39(3), 301–313. doi:10.3109/09638288.2016.1140836
- Luker J, Lynch E, Bernhardtsson S, Bennett L, Bernhardt J (2015) Stroke survivors' experiences of physical rehabilitation: a systematic review of qualitative studies. *Archives of Physical Medicine and Rehabilitation* 96(9), 1698–1708.e1610. doi:10.1016/j.apmr.2015.03.017
- Madden R, Kneebone II (2019) Receiving Bad News: A Thematic Analysis of Stroke Survivor Experiences. *Journal of Patient Experience* 6, 271–277. doi:10.1177/2374373518803613
- Mahoney FI, Barthel D (1965) Functional evaluation: the Barthel Index. *Maryland State Medical Journal* 14, 56–61.
- Malterud K, Siersma VD, Guassora AD (2016) Sample size in qualitative interview studies: guided by information power. *Qualitative Health Research* 26(13), 1753–1760. doi:10.1177/1049732315617444
- McGrath M, Lever S, McCluskey A, Power E (2019) How is sexuality after stroke experienced by stroke survivors and partners of stroke survivors? A systematic review of qualitative studies. *Clinical Rehabilitation* 33(2), 293–303. doi:10.1177/0269215518793483
- Morris R, Morris P (2012) Participants' experiences of hospital-based peer support groups for stroke patients and carers. *Disability and Rehabilitation* 34(4), 347–354. doi:10.3109/09638288.2011.607215
- Moss B, Behn N, Northcott S, Monnelly K, Marshall J, Simpson A, Thomas S, McVicker S, Goldsmith K, Flood C, Hilari K (2022) "Loneliness can also kill." a qualitative exploration of outcomes and experiences of the SUPERB peer-befriending scheme for people with aphasia and their significant others. *Disability and Rehabilitation* 44(18), 5015–5024. doi:10.1080/09638288.2021.1922519
- Nissen N, Lemche J, Reestorff CM, Schmidt M, Skjærbæk AG, Skovgaard L, Stenager E, Søgaard IG, la Cour K (2022) The lived experience of uncertainty in everyday life with MS. *Disability and Rehabilitation* 44(20), 5957–5963. doi:10.1080/09638288.2021.1955302
- Pedersen K, Brennan TMH, Nance AD, Rosenbaum ME (2021) Individualized coaching in health system-wide provider communication training. *Patient Education and Counseling* 104(10), 2400–2405. doi:10.1016/j.pec.2021.06.023
- Peel R, Jones S, Miller C, Gibson J (2020) Great expectations? A qualitative study of health professionals' perspectives on breaking bad news about rehabilitation potential after traumatic brain injury or spinal injury. *Disability and Rehabilitation* 42, 3209–3214. doi:10.1080/09638288.2019.1589586
- Rixon C (2022) Connection: stories not statistics. *Brain Impairment* 23, 4–8. doi:10.1017/BrImp.2021.37
- Rosewilliam S, Sintler C, Pandyan AD, Skelton J, Roskell CA (2016) Is the practice of goal-setting for patients in acute stroke care patient-centred and what factors influence this? A qualitative study. *Clinical Rehabilitation* 30(5), 508–519. doi:10.1177/0269215515584167
- Sandelowski M (2002) Reembodying qualitative inquiry. *Qualitative Health Research* 12(1), 104–115. doi:10.1177/1049732302012001008
- Satink T, Cup EH, Iloft I, Prins J, de Swart BJ, Nijhuis-van der Sanden MW (2013) Patients' views on the impact of stroke on their roles and self: a thematic synthesis of qualitative studies. *Archives of Physical Medicine and Rehabilitation* 94(6), 1171–1183. doi:10.1016/j.apmr.2013.01.011
- Schmidt J, Ownsworth T (2022) Special issue editorial: the self after brain injury. *Neuropsychological Rehabilitation* 32(8), 1669–1675. doi:10.1080/09602011.2022.2120504
- Seneviratne CC, Mather CM, Then KL (2009) Understanding nursing on an acute stroke unit: perceptions of space, time and interprofessional practice. *Journal of Advanced Nursing* 65(9), 1872–1881. doi:10.1111/j.1365-2648.2009.05053.x

- Shiple J, Luker J, Thijs V, Bernhardt J (2020) How can stroke care be improved for younger service users? A qualitative study on the unmet needs of younger adults in inpatient and outpatient stroke care in Australia. *Disability and Rehabilitation* 42(12), 1697–1704. doi:10.1080/09638288.2018.1534278
- Soundy A, Smith B, Butler M, Minns Lowe C, Helen D, Winward CH (2010) A qualitative study in neurological physiotherapy and hope: beyond physical improvement. *Physiotherapy Theory and Practice* 26(2), 79–88. doi:10.3109/09593980802634466
- Soundy A, Sayers J, Stubbs B, Roskell C (2014) Don't take my hope away: understanding the patient's hope in neurological rehabilitation. *International Journal of Therapy and Rehabilitation* 21(6), 257–258. doi:10.12968/ijtr.2014.21.6.257
- Suddick KM, Cross V, Vuoskoski P, Stew G, Galvin KT (2019) The acute stroke unit as a meaningful space: the lived experience of healthcare practitioners. *Health & Place* 57, 12–21. doi:10.1016/j.healthplace.2019.02.004
- Theofanidis D, Gibbon B (2016) Nursing interventions in stroke care delivery: an evidence-based clinical review. *Journal of Vascular Nursing* 34(4), 144–151. doi:10.1016/j.jvn.2016.07.001
- Thomson L, Schneider J, Wright N (2013) Developing communities of practice to support the implementation of research into clinical practice. *Leadership in Health Services* 26(1), 20–33. doi:10.1108/17511871311291705
- Thorne S (2016) 'Interpretive Description: qualitative research for applied practice', 2nd edn. (Routledge)
- Wenzel RA, Zgoda EA, St Clair MC, Knecht-Sabres LJ (2021) A qualitative study investigating stroke survivors' perceptions of their psychosocial needs being met during rehabilitation. *The Open Journal of Occupational Therapy* 9(2), 1–16. doi:10.15453/2168-6408.1691
- Wray F, Clarke D (2017) Longer-term needs of stroke survivors with communication difficulties living in the community: a systematic review and thematic synthesis of qualitative studies. *BMJ Open* 7, e017944. doi:10.1136/bmjopen-2017-017944

**Data availability.** The data is not available to access.

**Conflicts of interest.** The authors declare no conflicts of interest.

**Declaration of funding.** This study was supported by the Laura Fergusson Rehabilitation Trust (F.B.), and an AUT Faculty of Health and Environmental Sciences Emerging Researcher award (F.B.).

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

#### Author affiliations

<sup>A</sup>Centre for Person Centred Research, School of Clinical Sciences, Auckland University of Technology, Auckland, New Zealand.

<sup>B</sup>School of Sport, Exercise and Rehabilitation Sciences, University of Birmingham, Birmingham, United Kingdom.