

2023

Is learning being supported when information is provided to informal carers during inpatient stroke rehabilitation? A qualitative study

Elizabeth A. Lynch

Jessica Nolan

Lemma N. Bulto

John Mitchell

Annette McGrath

See next page for additional authors

Follow this and additional works at: <https://ro.ecu.edu.au/ecuworks2022-2026>



Part of the [Rehabilitation and Therapy Commons](#)

10.1080/09638288.2023.2259307

Lynch, E. A., Nolan, J., Bulto, L. N., Mitchel, J., McGrath, A., Lane, S., . . . Godecke, E. (2023). Is learning being supported when information is provided to informal carers during inpatient stroke rehabilitation? A qualitative study. *Disability and Rehabilitation*. Advance online publication. <https://doi.org/10.1080/09638288.2023.2259307>

This Journal Article is posted at Research Online.

<https://ro.ecu.edu.au/ecuworks2022-2026/3097>

Authors

Elizabeth A. Lynch, Jessica Nolan, Lemma N. Bulto, John Mitchell, Annette McGrath, Simon Lane, Gill Harvey, Dominique A. Cadilhac, Rachel Harling, and Erin Godecke

Is learning being supported when information is provided to informal carers during inpatient stroke rehabilitation? A qualitative study

Elizabeth A. Lynch, Jessica Nolan, Lemma N. Bulto, John Mitchell, Annette McGrath, Simon Lane, Gill Harvey, Dominique A. Cadilhac, Rachel Harling & Erin Godecke

To cite this article: Elizabeth A. Lynch, Jessica Nolan, Lemma N. Bulto, John Mitchell, Annette McGrath, Simon Lane, Gill Harvey, Dominique A. Cadilhac, Rachel Harling & Erin Godecke (25 Sep 2023): Is learning being supported when information is provided to informal carers during inpatient stroke rehabilitation? A qualitative study, *Disability and Rehabilitation*, DOI: [10.1080/09638288.2023.2259307](https://doi.org/10.1080/09638288.2023.2259307)

To link to this article: <https://doi.org/10.1080/09638288.2023.2259307>



© 2023 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group



[View supplementary material](#)



Published online: 25 Sep 2023.



[Submit your article to this journal](#)



Article views: 303




[View related articles](#)



[View Crossmark data](#)

Is learning being supported when information is provided to informal carers during inpatient stroke rehabilitation? A qualitative study

Elizabeth A. Lynch^a , Jessica Nolan^{b,c}, Lemma N. Bulto^a, John Mitchell^d, Annette McGrath^d, Simon Lane^d, Gill Harvey^a, Dominique A. Cadilhac^{e,f}, Rachel Harling^g and Erin Godecke^{c,h}

^aCaring Futures Institute, College of Nursing and Health Sciences, Flinders University, Adelaide, Australia; ^bSchool of Health Sciences and Physiotherapy, University of Notre Dame Australia, Fremantle, Australia; ^cSir Charles Gairdner and Osborne Park HealthCare Group, Perth, Australia; ^dLived Experience Contributor, Australia; ^eStroke and Ageing Research, Department of Medicine, School of Clinical Sciences at Monash Health, Monash University, Clayton, Australia; ^fStroke Theme, the Florey Institute of Neuroscience and Mental Health, University of Melbourne, Heidelberg, Australia; ^gPhysiotherapy Department, Central Adelaide Local Health Network, Adelaide, Australia; ^hSchool of Medical and Health Sciences, Edith Cowan University, Joondalup, Australia

ABSTRACT

Purpose: To explore how health professionals provide information to informal carers during inpatient stroke rehabilitation and whether these practices align with adult learning principles.

Methods: Informal carers and survivors of stroke who had completed inpatient rehabilitation, and health professionals working in inpatient stroke rehabilitation were interviewed. Directed qualitative content analysis was conducted using an adult learning model, to determine how closely reported practices aligned to adult learning principles.

Results: 14 carers, 6 survivors of stroke and 17 health professionals participated. Carers (79% female, 57% spouse/partner) reported having incomplete knowledge during rehabilitation, lacking information about mechanisms of stroke recovery, rehabilitation processes, long-term effects of stroke, and navigating post-discharge services. Health professionals supported carers to address their learning needs related to safety of caring for stroke survivors. Carers indicated they were responsible for their own non-safety related learning. Health professionals tended not to check carers' understanding of information provided nor offer learning opportunities beyond written or verbal information.

Conclusions: Health professionals consistently provide certain information to carers during inpatient rehabilitation, but adult learning principles are not routinely applied when information is provided. Fostering adult learning among informal carers may improve preparedness of carers to support stroke survivors after discharge from inpatient rehabilitation.

ARTICLE HISTORY

Received 18 January 2023
Revised 6 September 2023
Accepted 10 September 2023

KEYWORDS

Stroke rehabilitation; carer; adult learning

> IMPLICATIONS FOR REHABILITATION



- Carers reported often being in a state of shock in the early post-stroke period, and may need extra support to remember, understand, and apply information.
- Carers are often highly motivated to acquire immediate and relevant information tailored to their situation.
- Interactions between health professionals and carers are learning opportunities that can assist the carer to commence their unexpected and significant learning journey.
- Health professionals should apply adult learning principles when communicating with carers on all topics, not just topics important to the healthcare team such as patient safety and requirements for discharge.


Introduction

Stroke is a leading global cause of death and disability; one in four people globally will have a stroke in their lifetime [1]. In Australia, more than half of all community-dwelling survivors of stroke require assistance for daily activities [2], which is frequently provided by an informal carer, defined as a spouse, partner, family member, friend or significant other [3]. The nature of caring roles is variable and depends on the survivor's needs; carers may provide physical assistance or cognitive, communication and

emotional support to the survivor of stroke [3, 4]. The burdens and unmet needs faced by informal carers of stroke survivors are becoming increasingly recognised [5], leading to awareness of the need for initiatives to support carers in their caring role.

In Australia, 39% of people who survive their stroke participate in inpatient rehabilitation [6]. Typically these survivors of stroke are alert but need assistance to walk or have pronounced language or cognitive changes from their stroke [6, 7]. Accordingly, many stroke survivors in inpatient rehabilitation (where the average length of stay is 22 days) [8] require assistance from a carer

CONTACT Elizabeth A. Lynch  elizabeth.lynch@flinders.edu.au  Caring Futures Institute, College of Nursing and Health Sciences, Flinders University, GPO Box 2100, Adelaide 5001, SA, Australia.

 Supplemental data for this article can be accessed online at <https://doi.org/10.1080/09638288.2023.2259307>.

© 2023 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group

This is an Open Access article distributed under the terms of the Creative Commons Attribution License (<http://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited. The terms on which this article has been published allow the posting of the Accepted Manuscript in a repository by the author(s) or with their consent.

when they are discharged to the community. For the safety and wellbeing of both survivors of stroke and carers, new carers must be supported to provide safe and competent care. Previous research with carers, researchers and health professionals has identified that preparing people before leaving the hospital setting for the complex, long-term role as carer of a survivor of stroke is of key importance [4].

The Australian New Zealand Clinical Guidelines for Stroke Management include strong recommendations about information provision and education for carers [9]. These recommendations fit within the National Safety and Quality Health Service Standard regarding partnering with consumers, which highlights the importance of involving patients in their own care and providing clear communication to patients and their carers [10]. Improving information provision to patients with stroke and carers has been identified as a top priority to address in Australia [11]. Stroke Foundation has cocreated written information resources about stroke with health professionals, stroke survivors and carers; these resources are available in different languages and for people with different literacy levels [12]. While 63% of carers or people with stroke receive written information from health professionals during the hospital stay [8], written information alone is unlikely to address the complex and varied learning requirements of people new to the caring role.

To be of benefit to carers, information must be provided in a way that addresses learning goals such as remembering, understanding or using information [13]. There is a vast array of knowledge on how to support adults to learn effectively. Accordingly, practices to address the information needs of adults new to the role of carer should be guided by the principles of adult learning. Adult learning includes both planned and incidental learning opportunities, that can occur in settings as far ranging from academic institutions to one's own home [14]. When using an adult learning lens to view information provision to novice carers, the diverse and extensive life experience of carers and their motivation to find out and use new information should be acknowledged in learning activities [15].

Providing effective and timely information to carers requires health professionals to recognise that carers are adult learners; accordingly health professionals must be aware of their role and that of the carer in this learning process [16]. Recommendations in the Clinical Guidelines implicitly acknowledge the need for health professionals to facilitate adult learning; it is strongly recommended that health professionals actively engage carers and survivors and provide them with individually tailored information, opportunities for follow-up and clarification, and reinforce information [9].

A model of adult learning specific for medical education was developed by Taylor and Hamdy [15], with roles assigned to educators and learners. In this model wherein health professionals act as educators, the educator roles include providing an environment that is conducive to learning, supporting learners to identify their learning needs, exploring learners' prior knowledge, and ensuring relevant learning experiences are available at the appropriate level for the learner. The learner roles include identifying their baseline knowledge, identifying their information needs, seeking possible explanations, articulating their knowledge and reflecting on their learning. Implicit in this model is the existence of a shared understanding of the learning goals, the learning needs and prior knowledge of the educator and the learner, and that these factors enhance the learning experience. Health professionals should gauge what carers already do and do not know, and what is of importance and relevance to the carer and their situation. Use of the Johari Window [17], which has quadrants representing information known and unknown by one party (the carer) and what is known and unknown by others

(health professionals) can guide the information content provided to carers.

Despite the existence of the body of knowledge about how adults learn and the importance of information to carers and people with stroke, little is known about how new carers are being supported to understand and use information required to care for survivors of stroke prior to discharge to the community. The aim of this study was to explore how health professionals provide information to carers in inpatient stroke rehabilitation and determine how these practices align with adult learning principles.

Methods

This was a co-designed qualitative study, co-authored by carers, people living with stroke, health professionals and academics. One carer on the team posed the question, "Why are hospitals not acting as learning institutions?", which led to the development of our research question and guided our analysis. We have used the COREQ reporting checklist ([Supplementary file](#)).

Design

This was a qualitative study, using semi-structured interviews with nominated carers of people with stroke who had completed inpatient rehabilitation (sometimes accompanied by the stroke survivor they supported), and health professionals working in the same inpatient rehabilitation settings. Ethics approval was received from Central Adelaide Local Health Network Human Research Ethics Committee (approval number: HREC/18/CALHN/755).

Setting

All participants were recruited from two inpatient rehabilitation centres in South Australia and Western Australia. Both facilities were stand-alone rehabilitation hospitals located separately from the acute hospitals. Patients with stroke were co-located on one ward, and care was provided by a multidisciplinary team with expertise in stroke rehabilitation.

Participants

Carer participants were spouses, partners, family members or friends of people with stroke who had completed inpatient rehabilitation at one of the participating sites. Carers were eligible to participate in the study if the person they supported had been discharged from the inpatient rehabilitation service within the last 12 months and were able to converse in English. A staff member from the rehabilitation service (Authors JN in Western Australia and RH in South Australia) reviewed lists of discharged patients to identify patients with carers who varied in terms of their stroke-related impairments, age, gender and social history. The staff member telephoned potential carer participants to inform them of the study, and if they expressed interest in participating, they received written information about the project *via* post or email.

Stroke survivor participants: When requested by carers, stroke survivors were also included in the same interview as the carer.

Health professional participants were members of the multidisciplinary stroke rehabilitation team, including rehabilitation physicians, nurses, physiotherapists, occupational therapists, speech pathologists, pharmacists, social workers, dieticians, clinical psychologists, neuropsychologists and exercise physiologists. Health

professional participants were eligible to participate if they worked on the inpatient rehabilitation ward at the participating sites. The lead investigator met staff at a team meeting and explained the project, seeking participation from one member of each health discipline, before providing written information and inviting staff to participate.

All people who agreed to participate, signed a written consent form.

Data collection

Interviews (30-60 min duration) were conducted using a semi-structured interview guide by the lead researcher or research assistants (interview guide available in [Supplementary file](#)). All interviewers are women with experience as allied health clinicians and as qualitative researchers. All interviews were audio-recorded and transcribed. Transcripts were not returned to participants. The interview guide for carers was pilot tested with two people without health professional training (but who were not carers) to ensure questions were understandable to lay people.

Individual interviews were conducted with carers, either face-to-face, *via* videoconferencing (Zoom) or *via* telephone, depending on participant preference and COVID-19 restrictions. Some carers preferred to have the survivor of stroke they cared for present during the interview, in which case, the survivor of stroke was provided written information and signed a consent form prior to data collection. Carers were asked to describe how information was provided and sourced following the stroke, what was helpful in finding and using the information and invited to share recommendations for improving information provision. Repeat interviews were not conducted. Two carers provided additional information *via* email following the interview when they remembered extra details they wanted to share.

Health professionals were interviewed individually or in groups, depending on participant availability and preference. Interviews were conducted in person or *via* Microsoft Teams, depending on COVID-19 restrictions. Health professionals were asked to describe how information was provided to carers and stroke survivors in their facility and what was being done well, and what needed to improve in terms of addressing carers' information needs.

Data analysis

Two models were used to guide data analysis. First, Taylor and Hamdy [15] described a model of adult learning in medical education settings, where the learner moves through five stages of learning. The concept of moving through these five stages is a reminder that learning, in this case for informal carers, is a journey not a one-off event: incomplete knowledge (learner's existing knowledge is challenged and found to be incomplete), refinement (learner refines new information into a series of concepts), organisation (learner restructures their ideas to account for the new information), feedback (learner tests their new knowledge) and consolidation (learner reflects on learning process). Second, the Johari Window [17] was used to map areas of information need in terms of whether information was known or unknown to carers and known or unknown to health professionals. The concept of known and unknown information is a reminder that carers commonly start their learning journey from different knowledge bases to health professionals.

Transcripts were imported into NVivo 12, for directed qualitative content analysis [18]. Two reviewers (JN and LB), read through

the interview transcripts and mapped data deductively to Taylor and Hamdy's proposed model of adult learning [15], using the pre-identified categories of *incomplete knowledge, refinement, organization, feedback, and consolidation*. When provision of information on specific topics was discussed, the topics were mapped to the Johari Window. Data within each category were coded inductively. The identified codes were reviewed and discussed among the coders, the senior researchers (EL and EG) and lived experience team members (JM, AMcG, SL) at regular meetings.

A final stage of analysis informed recommendations for clinical practice to support health professionals to use adult learning theory when providing new carers with information and education. The recommendations are provided from the perspectives of carers, survivors of stroke, adult educators, health professionals and academic researchers.

Results

Fourteen carers, 6 survivors of stroke (interviewed with their carer) and 17 health professionals participated in interviews. Carers were mostly female ($n=11$, 79%), spouses ($n=8$, 57%) or children ($n=4$, 29%) of stroke survivors. Nurse unit managers, medical leaders and allied health professionals were interviewed at both sites. Details of interview participants are provided in [Table 1](#). To maintain confidentiality, we have labelled health professionals' quotes to "health professionals" rather than identify each health professional participant's discipline. We judged data saturation to have been reached when no new themes were identified from the last 3 carer interviews.

Information needs

When carers and health professionals had a shared understanding of a topic, unmet information needs were not apparent. However, there was a clear disconnect between what was known to carers and known to health professionals, which tended to result in carers having ongoing unmet information needs in these areas. The themes of what was known to the different groups relevant

Table 1. Details of participants.

	Carer		Survivor of stroke		State
	Relationship to stroke survivor	Gender	Participated in interview	Gender	
1	Spouse	female	Yes	male	South Australia
2	Spouse	female	Yes	male	South Australia
3	Spouse	female	Yes	male	South Australia
4	spouse	male	yes	female	South Australia
5	spouse	male	yes	female	South Australia
6	friend	female	no	male	Western Australia
7	daughter	female	No	female	Western Australia
8	spouse	male	Yes	female	Western Australia
9	daughter	female	no	female	Western Australia
10	spouse	female	no	male	Western Australia
11	daughter	female	no	female	Western Australia
12	daughter	female	no	female	Western Australia
13	spouse	female	No	male	Western Australia
14	friend	female	No	male	Western Australia
Health professionals					
Interdisciplinary professional, nurse unit manager, neuropsychologist, occupational therapist, physiotherapist x 2, rehabilitation consultant, speech pathologist					South Australia
Nurse unit manager, occupational therapist, pharmacist, physiotherapist x 2, speech pathologist x 2, stroke consultant					Western Australia

Table 2. Themes of unmet information need mapped to the Johari Window.

	Known to carer	Unknown to carer
Known to health professional	Carer's learning needs regarding safety issues	Stroke-related information <ul style="list-style-type: none"> • Mechanisms of stroke recovery • Anticipated recovery, long-term effects of stroke Information about facility and processes <ul style="list-style-type: none"> • Location and availability of toilets, canteen, laundry etc • Rehabilitation process and expectations • Institutional processes Information for discharge <ul style="list-style-type: none"> • Discharge processes • How to navigate post-discharge services • Processes to organise equipment
Unknown to health professional	Individual carer-specific details <ul style="list-style-type: none"> • Carer's baseline knowledge/skills • Carer's (non-safety related) learning needs • Carer's preferred learning experiences Common barriers to meeting information needs <ul style="list-style-type: none"> • Impact of shock and emotional upheaval on carer's ability to learn • Carers often not confident to seek desired information 	Precise details of anticipated recovery

to addressing carers' information needs is presented in [Table 2](#), and discussed below in the text.

Carers were aware of the need to learn new information to assist them as they assumed the new role of carer of the person with stroke.

Because even though...your partner's life has changed, your life changes as well...because now I'm like a carer. (Carer 8)

Incomplete knowledge after stroke

When asked about information provision and addressing the information needs of carers, most data were mapped to the *Incomplete knowledge* category, as carers sought to find the information they needed, and health professionals strove to provide the information required by patients and carers.

Carers consistently identified and discussed their existing knowledge, skills and attitudes (including their professional experience), their knowledge of the stroke survivor, and their personal attributes such as organizational skills and the ability to seek information, that facilitated their learning. However, neither carers nor health professionals reported that health professionals explored carers' baseline knowledge, skills or experience, which was recognized as a concern by some participants.

The family members should be asked, do they want any more information, "What do you know so far, are there any questions you want answered?" (Carer 4)

There was one exception of a carer who perceived their medical background resulted in health professionals providing less

information, because they assumed the information was not needed. One health professional highlighted the importance of understanding the relationship between the person with stroke and the carer, and the need to obtain consent of the person with stroke before providing patient-related information to the carer.

Many carers acknowledged that their emotional state in the early post-stroke period affected their ability to absorb information. In contrast, health professionals showed little awareness that carers did not consistently understand or remember the information they provided.

Carer recognises what is unknown

Carers reported multiple instances of not having the information they wanted about the stroke journey, including acute care processes, mechanisms of recovery, anticipated prognosis, rehabilitation processes and preparing for discharge.

From that very first day when we were waiting for [husband] who was having surgery at that point...there were many times we didn't know what was going on. (Carer 1)

When first admitted to the rehabilitation hospital, carers frequently reported not being orientated to the site, and not having information provided about rehabilitation processes. Carers described not knowing how to address basic daily needs in the rehabilitation hospital, such as where to get a drink, purchase a meal or how to do laundry. Health professionals reported that the acute hospitals did not provide information to carers about rehabilitation, but no approach was described to routinely provide this information in the rehabilitation hospital.

I think what happens is people become a little bit complacent when they're doing that job day in, day out; they just actually forget for every new person that comes in, it's a whole new experience and that person hasn't understood or dealt with any of those experiences that you're going through, this is the first time. (Carer 9)

Yeah, look, I have no doubt that the therapists know where they're going, but for me personally, I would also like to know where they're going. (Carer 13)

Carers consistently expressed a need for information regarding prognosis. Some carers perceived prognostic information to be unknown to both the health professional and the carer, which was reiterated by some health professional participants. Other carers perceived that health professionals knew but withheld this information. Some health professionals indicated they were uncomfortable in delivering information about anticipated recovery, particularly if they were unsure or if they predicted a negative outcome.

There's a lot of answers I'd like to hear, and I'm not getting them. I don't think they actually know...I'd be asking a lot of questions and a lot of times they weren't answered...They don't know what...we'll get back, or if I'm going to be tired forever or if this tiredness is going to slowly disappear... "Every person's fingerprint is different, same with a stroke", "Every stroke is different", "There's no two strokes that are exactly the same". So, they couldn't...answer me. (Stroke Survivor 2)

When you go home and you're crying at night...the questions you want to ask... "How long is your husband going to live? How long is this rehab going to take? How far will he get?" Questions that can't be answered, but they're the questions that you want to know (Carer 2)

Sometimes the information is not provided at the time because it's not known at the time. (Health Professional)

If they say, "Will I get the use of my arm back?" I will say, "Every stroke is different so that's a great question to ask the medical team"... Some

of them it's very obvious and you might say something like, "Oh you may get some flickers of movement...but look, I think...you won't be able to use it in your everyday tasks. So let's focus on learning these one-handed strategies in the kitchen"...So I'll put it that way, I won't just say, "No, I don't think your arm is going to ever be useful or get motor and strength back." I don't know why I don't say it, I don't know, it just seems too mean. (Health Professional)

Services after discharge were a common unknown to carers. Carers reported that health professionals organized and provided information about referrals to ongoing services but did not provide advice about how to navigate the services, when to expect contact from service providers, or what to do if services did not make contact. Consequently, carers reported feeling inadequately prepared to navigate services after discharge from the hospital setting.

And I thought [when meeting service provider], "I don't get all of this, I don't understand who are you then, and why are you here?"...And so I'm still a bit confused about it all to be honest with you. (Carer 14)

I'm struggling with aged care at the moment. I've never had anything to do with aged care, and so now...we're sort of like fumbling our way through the aged-care system. (Carer 9)

Working to address information needs

Health professionals helped carers to identify their learning needs related to safety implications of caring for the stroke survivor, such as managing impaired swallow, risk of falling, or administration of medication. Outside of safety-related information, health professionals tended not to routinely explore carers' knowledge, understanding or unmet information needs. This left many carers in the position where they did not have information that would be beneficial, but they were unaware that this information was available or relevant to their situation, "I didn't know what I didn't know."

Carers indicated that they sourced information as required and were responsible for their own learning, which could be difficult at times. Health professionals acknowledged that carers often needed to initiate their own learning experiences.

Whatever I needed to know, I went and found out. (Carer 1)

I can definitely see that the certain kinds of people that are more extroverted and confident and used to being advocates, they just... figure this stuff out, but if you get anyone who's slightly more reserved or anxious then they would really struggle. They probably wouldn't take the step they need to take...to figure it out. (Health Professional)

The environment and interactions with staff influenced carers' ability to take on new information. Staff approachability, kindness, willingness to answer questions and to include carers in therapy contributed to carers being able to find and understand their required information.

Both the teams at the [acute hospital and rehabilitation hospital], never shunned our questions or made us feel like we have asked too many or silly or inappropriate questions, in fact, they answered them all with great understanding of our distress and need for information. (Carer 1)

I was just there, I didn't have any real interface with the doctors at all, sometimes I was asking "When's the doctor coming, I'd like to speak to him, ask him a couple of questions" ...That was difficult to do for me... to make that contact with the doctor... If you sort of button-hole a doctor while he's on the ward...they sort of look...[like]" I've got a time-limit here"...They've got to sort of realise [providing information to carers] has got to be fitted...into their agenda, somewhere. (Carer 5)

Carers reported that family meetings, where family members met the multidisciplinary team and discussed the consequences

of the stroke and rehabilitation plans approximately two or three weeks after admission to the rehabilitation facility, were very beneficial for finding relevant information. However, many carers expressed a desire for family meetings to occur earlier in the admission and to have a second family meeting before discharge. Staff were aware of families' desires for more opportunities for structured information provision and recognized this as an area that needed to be addressed.

Occasionally a patient will have two family meetings but most patients only have one, so that's at the two week mark as a rule, and a lot can change then after that two weeks...There may be a lot of things that come out following the initial family meeting and the ongoing therapy that then are not really discussed unless it's a one-on-one conversation with a therapist or a nurse. (Health Professional)

Other strategies highlighted by carers as being useful for finding and understanding information were information displays such as noticeboards and timetables. While some carers found accessible handouts about stroke helpful for their learning, many also reported feeling overwhelmed with the amount of written information that was provided. Further, carers reported that the information provided was not always relevant to their situation. Staff reported awareness of the overwhelming amount of written information provided and the lack of opportunities for carers to receive and discuss information. Health professionals provided in-principle support for the idea of having a key team member who would be responsible for coordinating information, but when discussing how this would work in practice, did not know who would have capacity to take on this additional role.

I think we were bombarded with information. (Carer 7)

It's totally daunting, you don't understand the process...even though people give you lots of paperwork. (Carer 3)

I do think that there are not enough opportunities for patients and families to get the information they need...You do need an expert bringing it all together really for other people to bounce off and yeah, that's not my role so it's difficult. (Health Professional)

We also have a lot of brochures and that on the ward on different aspects post-stroke, but again, sometimes they're pitched a little high and I think the information needs to be simplified, so that people can understand what's happening, what they can do, how they can be involved. (Health Professional)

Carers' primary concern was the welfare of the survivor of stroke. Carers needed to know that the survivor was safe and receiving adequate care, before they could focus on seeking or taking in new information. Carers reported that emotions and uncertainty during the acute and rehabilitation hospital stays hindered their ability to process and organise information.

After the stroke when it makes you super upset because your life is in turmoil, everything that is emotional, I think it is...it's just like magnified, because of that. And...so, for the carer, I particularly think that whatever the patient's going through, it's magnified because of your own emotional state, and it's not 'til later that you can understand that. (Carer 3)

I mean, you're not really interested in paperwork, you're just interested in her welfare. (Carer 6)

Everything just becomes hard when you've got the worry of "what is happening to my beloved man?", you know? (Carer 2)

Carers routinely discussed how busy the staff were. This led to some carers not asking the questions they wanted to ask. Restricted visiting hours were an additional barrier to finding the required information. Other carers described using various

strategies to approach staff to ask their questions, and reported that staff provided information willingly. Health professionals were aware of the perception that they are too busy to answer questions, but reiterated they were always willing to provide information when asked.

I thought you can't ring nurses and doctors, because you don't know where they are, how busy they are...I don't think they get time to scratch themselves. (Carer 7)

So, we would organise with [treating doctor] that... "whatever time it suits, because we're here all day, we'll make sure we're here and we'll fit in with you...if we could just have a small time of your busy day, we know you're busy, just to go through...a couple of the questions". (Carer 1).

[There is] a perception that [families] have that [health professionals] are busy, but every time I see family members asking staff members anything, staff are more than happy to answer the questions. (Health Professional)

Both carer and health professional interviews suggested a power imbalance between the health professional team and the patient and carer network. Carers at one facility spoke about needing to obtain permission to be present during ward rounds and to speak with the medical team. Carers at both sites reported being 'allowed' to attend therapy, rather than being encouraged or invited. One carer described putting extra time into their appearance before travelling to the rehabilitation centre, to ensure they were taken seriously by the health professionals. Some participants perceived that this power imbalance would lead to missed opportunities for learning.

Many carers expressed a self-driven motivation to learn about how to support the survivor of stroke.

I wanted to do my very, very, very best for [husband]. If there was ever going to be one job that I was going to be the best in my whole life, it was going to be this. (Carer 2)

Health professionals considered that carers who actively sought information and learning experiences were motivated. However, carers' motivation to learn was not always supported; some health professionals described enforcing boundaries to ensure that the presence of a carer did not disrupt therapy sessions.

Refinement

Carers reported proactively seeking learning experiences, asking questions, and attending therapy sessions.

I was trying to learn as much as I could so that when you came home I would be able to, and on weekends when the physios weren't there, that I would be able to do...some extra work with [stroke survivor]. (Carer 3)

One carer in our interviews reported wanting to understand the mechanisms of the survivor's impairment so they could help the survivor overcome the impairment. No other carer or health professional interviews provided evidence that carers sought to explain what was happening or create solutions during the inpatient rehabilitation stay. However, some indicated they wanted to do as good a job as possible as a carer and implicitly were willing to meet any challenges that might arise.

Carers drew on various resources for information, including staff members, online materials, social media, and family members and friends with experience of living with stroke or working in healthcare. Many carers expressed a need to discuss and talk through relevant information and have these discussions on more

than one occasion. Knowledge of support organisations varied among carers, with some reporting that they sought out and contacted the Stroke Foundation, Australian Aphasia Association, and carer support organisations, while others were unaware of these organisations. Some carers reported sharing information with other carers during rehabilitation, whereas others expressed no interest in interacting with other carers.

When safety was a consideration, health professionals organized learning experiences that were relevant and appropriate to the carers' needs, beyond simply providing information verbally or in writing. Health professionals and carers described providing (and receiving) education and training on the administration of insulin and other medication, and training and supervised practice in assisting the stroke survivor with activities of daily living and home visits.

This person may have a swallowing problem...and the nurse actually shows the family what strategies are important to keep the patient safe, so that when they take them out over the weekend, the family have that knowledge and they know what to do. (Health Professional)

Feedback

No interview participant reported activities where carers' learning was checked, or feedback on the carer's understanding of information that was provided. Carers expressed a need for the opportunity to test their knowledge and understanding, and to check in with staff about required information on multiple occasions.

Organising and consolidating learning

It was only on discharge from hospital that carers and stroke survivors reported progressing to the organisation and consolidation phases of learning. Carers reported being able to make sense of the information they had received during the hospital stay through trial and error, daily practice and accumulating experience of what life is really like after a stroke (experiential learning).

All the other stuff was just all the fine-tuning which will take years from now. I've worked out it will take years whereas, before, no one told me that. (Stroke Survivor 2)

We left [inpatient rehabilitation]...and we went on to Rehab in the Home for six weeks...and then "Oh, that's the end of your six weeks, you're on your own". And we were in the wilderness for a while. Fortunately, because we'd all been so hands-on, we continued with some of her exercises. (Carer 5)

Unless you experience it, you can't learn it from any books. (Carer 1)

Discussion

In the early post-stroke period, carers of people with stroke have a vital need for information they can remember and understand, to prepare for their new role as a carer. During rehabilitation and in life after discharge from hospital, carers need to identify what it is they need to know (either independently or with support from healthcare staff), then source, remember and understand this new information and be able to apply it in the real-world setting. The inpatient rehabilitation period (average length of stay 22 days) when the patient with stroke is medically stable but is not yet independent, allows time for health professionals to work with nominated carers and survivors of stroke to set individualised goals and tailored rehabilitation, including understanding the carer's information needs and supporting the carer to gain the

knowledge and skills required to care for the survivor of stroke after discharge. In line with the strong recommendation from the Stroke Clinical Guidelines that “All stroke survivors and their families/carers should be offered information tailored to meet their individual needs” [9], learning objectives such as identifying information needs and being able to remember, understand and use information [15] should be monitored and addressed by the health care team delivering care to the person with stroke. However, the findings from our study indicate that adult learning principles are not routinely applied in the rehabilitation setting, leaving carers sub-optimally informed and inadequately prepared for life as a carer when the person with stroke is discharged home. Accordingly, we have generated a list of recommendations for clinical practice to support health professionals to use adult learning theory when providing new carers with information and education, which are provided from the perspectives of carers, survivors of stroke, adult educators and health professionals (Box 1).

Different strategies may be required to support health professionals improve how they deliver different types of information. To educate carers about known, clearly delineated topics such as ward orientation or staff contact details, health professionals must be cognizant that carers need this information, and then provide this information ideally in more than one format on more than one occasion, checking in with carers that they have the information they need. Topics that are unclear to health professionals, such as anticipated recovery from stroke, may require health professionals to communicate uncertainty, which is more complex and challenging. Barriers to clear communication when the topic is uncertain include low levels of health literacy in the general population which can make these conversations more difficult [19], cultural challenges within healthcare settings where health professionals have traditionally assumed the role of all-knowing expert [20], and health professionals’ fear of negative repercussions such as loss of trust [20]. To overcome these barriers and convey the required information effectively, it is even more imperative for health professionals to determine a carer’s background knowledge base and preferred format for information delivery, so the content can be tailored appropriately. Information should be provided in the desired format/s, and health professionals should seek clarification from carers about what they have understood about the topic to promote learning [20]. Health professionals may need training to enhance their skills and confidence to communicate uncertainty, and if the topic is an emotional one (for instance poor anticipated recovery after stroke), health professionals may also need to develop skills in providing emotional support [21]. Contrary to some health professionals’ opinions, patient-health professional relationships tend to be strengthened when health professionals effectively share what is known and what is unknown; these discussions can also facilitate carers and patients to make better informed decisions about their healthcare [22].

Tailoring information to the individualised needs of each carer requires health professionals to recognise the multiple, different and changing information needs of carers and each carer’s different learning styles and preferences. Tailoring the content, level of detail, format, timing and delivery of information for individuals is far from straightforward, and supporting carers to learn in the early post-stroke period is particularly challenging. In contrast to formal adult education settings, where the educators and learners both choose their role voluntarily and enter the institution for the express purpose of teaching or learning new knowledge, the primary function of healthcare settings is to provide healthcare, and the people involved are health professionals, patients and

Box 1. Tips for health professionals when providing information to people new to the caring role

Tips for health professionals when providing information to people new to the caring role

1. Check in on carer baseline knowledge: Have you any experience with/what have you been told about [stroke, orientation to facility, rehabilitation process, anticipated recovery]? Tell/show me what you understand about...?
2. Assist carers to identify their information needs: *What is on your mind? What are you unsure about? What matters to you most right now?*
3. Ask carers about their information needs: *What questions have come to mind as we have talked about...? What would you like to know more about?*
4. Ask carers about their preferred ways of learning and learning supports: *How do you tend to take in information best? (face-to-face discussions, looking at images, reading documents or websites, hands-on activities)? Do you prefer to learn alone or in a group?*
5. Provide the right context for learning:
 - Be friendly and approachable: Introduce yourself and others with you, identify that education is a priority and suggest making a time to run through carers’ questions
 - Prepare carer for a learning experience: *I want to talk through some important things to do with X*
 - Identify that education is everyone’s responsibility: *My role is to teach you how to...; Your role is to teach me how to...*
 - Clarify why the information is important to know
 - Support for the carer: *Is there anyone you would like to come along to help ask questions or remember this information?*
6. When providing information:
 - Provide on more than one occasion: *We spoke about [topic] yesterday, have you had a chance to think things through? Is there anything you’d like to discuss about [topic]?*
 - Use more than 1 format: *Talk through information AND supplement with links to useful websites, written information, follow-up practice sessions etc.*
 - Seek feedback on carers’ understanding: *Does that make sense to you? Can you share with me what you have understood?*
7. Ensure relevant learning experiences are available at appropriate level for carer: *Follow-up information provided with further discussions, training/practice sessions, provide appropriate level of detail to suit individual carer*
8. Provide structure to frame carer’s learning: *Be as clear as possible (even if uncertain) about anticipated support required from carer on discharge. This way, the health professional team and carer can identify unmet learning needs and nominate learning strategies.*
9. Encourage reflection: *How are things going with supporting stroke survivor? Are you and [stroke survivor] managing to work things out together? [If unmet learning needs] What has helped you to learn the knowledge or skills required to support the stroke survivor adequately?*
10. Remember that preparing/educating carers to support the person with stroke long-term in the community is an integral part of in-hospital care. Simply providing written or verbal information does not usually equate to educating carers for their ongoing role beyond the hospital setting.

carers. Patients and carers have not chosen their roles and an added complexity is that many carers do not yet see themselves as carers [23], or comprehend the long-term nature of stroke and the stroke survivor’s need for long-term assistance and support [24]. Further, carers are busy dealing with the shock of the stroke and their potentially changing life roles [3], when they are being presented with important information. Health professionals receive extensive training on providing high quality healthcare, yet many do not receive explicit training or assessment on provision of adult education or strategies to improve health literacy [25];

previous authors have reported that Australian health and education environments operate as silos [26].

Carers in our study often reported they struggled to take in information easily in the early post-stroke period, but their actions (such as identifying what information they wanted, approaching staff with questions and seeking additional learning opportunities such as asking to attend therapy sessions) largely fulfilled previously described “learner roles.” [15] In contrast, health professionals largely failed to fulfil their role in facilitating the carers’ learning. No participants discussed health professionals helping carers to identify what information was important to the carer. When information needs were identified by carers, health professionals routinely provided written or verbal information, but this was usually provided only once, carers’ understanding of the information was not checked, and carers were not invited to discuss the presented information. Reinforcement of material is important to enhance adult learning [27], and in our study where information was not reinforced, carers reported receiving information that they did not remember, and written information that they did not read.

The interactions between health professionals and carers in our study contrast with how health professionals behave when they recognise clear educational objectives. For instance, when working with students in clinical settings, learning opportunities are commonly governed by learning contracts that outline learning goals and how the learning will take place [28, 29]. Students are supported to identify their learning objectives, health professionals traditionally provide verbal or written information, ask students to feedback what they have understood from the information provided, and explain how that information can be applied in clinical scenarios [15]. Demonstrating, practicing, and performing clinical tasks under supervision are also commonly used to support skill development in health professionals [30]. Interestingly, in our study, health professionals did employ a comprehensive range of strategies to teach carers skills that were identified by staff as being important for safety or essential for discharge from hospital, such as how to transfer into a car or how to administer medications. In these instances, health professionals initiated meeting and discussing the topic with the carer and survivor of stroke and asked the carer to practice the task under supervision until the carer could perform it competently. Therefore, health professionals possess the skills and have capacity to effectively facilitate learning when they are mindful of learning goals. We would argue that health professionals should be mindful that all interactions with carers and people with stroke are potential learning opportunities, and if viewed as such (i.e. by acknowledging the existing knowledge and skills held by carer, checking in with carers about their information needs, providing the right context for learning and gauging carers’ understanding when information is provided) could lead to better learning outcomes for people new to the caring role.

Limitations to this study are that the model used to guide analysis of the data was designed for medical education, rather than patient or carer education. We chose this model, because we wanted to compare how closely carer education aligned with the practices recommended for educating adults in healthcare settings; we consider that people who provide care to a person with stroke 24h a day, seven days a week, should receive as much high-quality education as possible. Limitations to use of the Johari window include that unmet information needs where information was unknown to both carers and health professionals may have been present, but were not identified by interview participants and thus not mapped in this study. Another limitation was that we asked participants about how information was provided (and asked carers about things they had learned), rather than how learning was facilitated, because we wanted our questions to align

with the recommendations about information provision in the Clinical Guidelines for Stroke Management. This may have contributed to the high proportion of data that were mapped to the incomplete knowledge category.

Conclusion

This study provides important new insights into how information is being provided to people with stroke and carers, through applying an adult learning lens to processes in healthcare settings. Information provision and education of patients and carers is a top priority to address to improve stroke care in Australia, yet in the stroke rehabilitation settings involved in this research, health professionals appeared to be inadequately supporting people new to the caring role to learn. At a minimum, health professionals should apply adult learning principles to support carers to remember, understand and apply information relevant to supporting someone with stroke. Further, health professionals could benefit from learning more about what they and the carers know and don’t know about carers’ information needs. Asking carers about their information needs, checking in on carers’ learning and providing carers with appropriate learning experiences are within the skillset of health professionals working in stroke rehabilitation and will enhance learning opportunities for carers.

Acknowledgement

We acknowledge the input of carers, people with stroke and health professionals who participated in interviews. Thank you also to Rachel Bridle for her role in coordinating data collection.

Disclosure statement

No potential conflict of interest was reported by the authors.

Reporting guidelines checklist

The consolidated criteria for reporting qualitative studies (COREQ) was used to guide the reporting of this study.

Funding

The work as described in this manuscript was funded as part of an Early Career Seed Grant from Stroke Foundation (Australia). The funding body was not involved in the design of the study, data collection, analysis or interpretation of the data. The following authors hold/held research fellowships: National Health and Medical Research Council: EA Lynch (APP1138515), DA Cadilhac (APP1154273), Raine Foundation: J Nolan. DA Cadilhac has received educational grants from industry unrelated to this research paid to her institution: Amgen, Boehringer Ingelheim, Bristol Myers Squibb, Moleac.

ORCID

Elizabeth A. Lynch  <http://orcid.org/0000-0001-8756-1051>

Data availability statement

The data used in this study will be available from the corresponding author on reasonable request.

References

- [1] Feigin VL, Nguyen G, Cercy K, et al. Global, regional, and country-specific lifetime risks of stroke, 1990 and 2016. *N Engl J Med*. 2018;379(25):2429–2437.
- [2] Deloitte Access Economics. The economic impact of stroke in Australia; 2013.
- [3] Luker JA, Murray C, Lynch EA, et al. Carers' experiences, needs and preferences during inpatient stroke rehabilitation: a systematic review of qualitative studies. *Arch Phys Med Rehabil*. 2017;98(9):1852–1862.e13.
- [4] Hall JF, Crocker TF, Clarke DJ, et al. Supporting carers of stroke survivors to reduce carer burden: development of the preparing is caring intervention using intervention mapping. *BMC Public Health*. 2019;19(1):1408.
- [5] Denham AMJ, Wynne O, Baker AL, et al. The long-term unmet needs of informal carers of stroke survivors at home: a systematic review of qualitative and quantitative studies. *Disabil Rehabil*. 2022;44(1):1–12.
- [6] Lynch EA, Mackintosh S, Luker JA, et al. Access to rehabilitation for patients with stroke in Australia. *Med J Aust*. 2019;210(1):21–26.
- [7] Lynch EA, Luker JA, Cadilhac DA, et al. Inequities in access to rehabilitation: exploring how acute stroke unit clinicians decide who to refer to rehabilitation. *Disabil Rehabil*. 2016;38(14):1415–1424.
- [8] Stroke Foundation. National stroke Audit - Rehabilitation services report 2020. Melbourne (Australia): Stroke Foundation, 2020.
- [9] Stroke Foundation. Clinical guidelines for stroke management; 2022, Available from: <https://informme.org.au/guidelines/clinical-guidelines-for-stroke-management#>
- [10] Australian Commission on Safety and Quality in Health Care. The NSQHS standards; 2022. Available from: <https://www.safetyandquality.gov.au/standards/nsqhs-standards>
- [11] Lynch EA, Lassig C, Turner T, et al. Prioritizing guideline recommendations for implementation: a systematic, consumer-inclusive process with a case study using the Australian clinical guidelines for stroke management. *Health Res Policy Syst*. 2021;19(1):85.
- [12] Stroke Foundation. Stroke journey resources; 2022. Available from: https://strokefoundation.org.au/what-we-do-for-survivors-and-carers/stroke-journey-resources?_id=69A2C473888847CBB2ACEAE589FE2FDA&_z=z
- [13] Armstrong P. Bloom's taxonomy. Nashville (TN): Vanderbilt University Center for Teaching; 2010.
- [14] Jarvis P. Adult education and lifelong learning. Theory and practice. 4th ed. London: Routledge Taylor & Francis Group; 2010.
- [15] Taylor DCM, Hamdy H. Adult learning theories: implications for learning and teaching in medical education: AMEE guide no. 83. *Med Teach*. 2013;35(11):e1561–e1572.
- [16] Marcus C. Strategies for improving the quality of verbal patient and family education: a review of the literature and creation of the EDUCATE model. *Health Psychol Behav Med*. 2014;2(1):482–495.
- [17] Luft J, Ingham H. The JoHari window, a graphic model of interpersonal awareness. In: Proceedings of the Western Training Laboratory in Group Development. Los Angeles (CA): UCLA; 1955.
- [18] Hsieh H-F, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res*. 2005;15(9):1277–1288.
- [19] Liu C, Wang D, Liu C, et al. What is the meaning of health literacy? A systematic review and qualitative synthesis. *Fam Med Community Health*. 2020;8(2): e000351
- [20] Simpkin AL, Armstrong KA. Communicating uncertainty: a narrative review and framework for future research. *J Gen Intern Med*. 2019;34(11):2586–2591.
- [21] Han PK. Conceptual, methodological, and ethical problems in communicating uncertainty in clinical evidence. *Med Care Res Rev*. 2013;70(1 Suppl):14s–36s.
- [22] Gordon GH, Joos SK, Byrne J. Physician expressions of uncertainty during patient encounters. *Patient Educ Couns*. 2000;40(1):59–65.
- [23] Carers WA. Who are carers?; 2022. Available from: <https://www.carerswa.asn.au/resources/who-are-carers/>
- [24] Lutz BJ, Young ME, Cox KJ, et al. The crisis of stroke: experiences of patients and their family caregivers. *Top Stroke Rehabil*. 2011;18(6):786–797.
- [25] Saunders C, Palesy D, Lewis J. Systematic review and conceptual framework for health literacy training in health professions education. *Health Professions Educ*. 2019;5(1):13–29.
- [26] Morony S, Lamph E, Muscat D, et al. Improving health literacy through adult basic education in Australia. *Health Promot Int*. 2018;33(5):867–877.
- [27] Knox AB. Proficiency theory of adult learning. *Contemp Educ Psychol*. 1980;5(4):378–404.
- [28] Brambleby P, Coates R. Learning contracts in higher professional training: a user's guide. *Postgrad Med J*. 1997;73(859):279–282.
- [29] Bailey ME, Tuohy D. Student nurses' experiences of using a learning contract as a method of assessment. *Nurse Educ Today*. 2009;29(7):758–762. 20090509.
- [30] Snowdon DA, Sargent M, Williams CM, et al. Effective clinical supervision of allied health professionals: a mixed methods study. *BMC Health Serv Res*. 2019;20(1):2.