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ORIGINAL ARTICLE

Recovering is about *living my life, as it evolves*: perspectives of stroke survivors in remote northwest Queensland

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ABSTRACT

Purpose: Recovering from stroke in remote Australia has rarely been considered, even though rehabilitation services are generally scarce. The primary purpose of this study was to explore stroke recovery, from the perspective of stroke survivors in remote northwest Queensland (NWQ), to explicate the lens through which they view recovering. The secondary purpose was to explore the role of technology to support stroke survivors in remote locations along their recovery journey.
Methods: A qualitative study was undertaken using elements of constructivist grounded theory for data collection and analysis. Semi-structured interviews were conducted with fifteen stroke survivors and two partners living, working or travelling in remote NWQ.
Results: From the participants' perspective, recovering in a remote area after stroke is about *living my life, as it evolves* by *endeavouring to recover my way* and *navigating my recovery in my world*. Technology was only considered helpful when it supported participants to recover their way in their world.
Conclusion: Recovering from stroke from the perspective of stroke survivors in remote NWQ is about living their life, as they want it to be, and as it unfolds within their own context. Technology only has a place when it can support them to recover their way in their world. These findings reinforce the importance of health professionals listening, learning about, and enabling stroke survivors along their recovery journey, within their remote context and support network.

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Australia; qualitative; recovery; rural and remote; stroke; technology

➤ IMPLICATIONS FOR REHABILITATION

- Recovering from the perspective of stroke survivors is about living their life as it evolves.
- To support stroke survivors from remote areas, health professionals need to listen to and learn from each stroke survivor about what matters to them, what works for them, and about their world; including the challenges (e.g., switching between services) and enablers (e.g., community support) as the stroke survivor perceives them.
- Finding ways to utilise the strengths within and around them, may improve the recovery process for the stroke survivor in a remote area, ensuring they can access care that meets their needs in their world.
- Working together with stroke survivors, health professionals need to consider how technology could help them to live their life, while recovering their way and in their world.

Introduction

Recovering from stroke in rural and remote areas in any part of the world may disadvantage stroke survivors [1]. Limited access to rehabilitation services [2], uneven terrain, limited public transport and large distances to travel [1] are just some of the potential challenges for recovering in a rural and remote context. In Australia, the burden of stroke is growing for stroke survivors, their family and society with increased stroke survival rates [3]. The burden of stroke is greater in rural and remote communities [4], particularly Aboriginal and Torres Strait Islander communities [5], where access to health and community services is poorer [6] when compared to the general Australian population. Despite the inequities faced [6,7], little is known about stroke survivors' experiences of recovering in remote communities in Australia [8,9].

Strategies that enhance recovery, as provided in the current stroke guidelines [10], rely on skilled, multidisciplinary teams working in dedicated facilities [11]. Accordingly, translating current evidence-based recommendations into practice is challenging in remote Australia [12,13]. Stroke rehabilitation services are overwhelmingly located in urban areas, requiring stroke survivors from remote communities to stay far away from their home and community for extended periods to attend rehabilitation [14,15]. Close to home, access to a small health workforce often servicing a vast region [5] and with limited skills in rehabilitation [15] may restrict long-term opportunities for stroke survivors in remote communities to maximise their recovery.

Innovative approaches, such as the use of technology, may overcome some of the challenges to recovery faced by stroke survivors in remote Australia [11]. Interactive and communication

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technologies have been offered to stroke survivors to enhance physical and cognitive function, emotional well-being, communication, case management, community reintegration, secondary prevention, and access to services [16–18]. Individual studies have demonstrated patient satisfaction [19–22] and acceptability [23–25] of this approach. As telehealth services are growing across rural Australia [26], the role of technology in supporting stroke recovery in remote areas is yet to be explored [18].

The purpose of this study therefore, was to explore:

a. the stroke survivors' perspective on recovering in remote northwest Queensland (NWQ), to explicate the lens through which they view recovering; and,
b. opportunities for the use of technology to support their recovery.

Methods

Design

A qualitative study using the five key actions of grounded theory (GT) [27] was chosen to gain insight into the stroke survivors' perspective on recovering in NWQ [28], which could then be used as a lens for further research, rather than to develop a theory [29]. Constructivism, the epistemology that aligns with the primary researcher's (SJ) interpretative view, assumes that people construct their knowledge of reality, shaped by the context of their experiences [27]. Adopting constructivist grounded theory (CGT) methods enabled exploration of the perspectives of a diverse group of stroke survivors on their experience of recovering, in a way that was empowering for them to share their story [30,31]. The CGT approach recognises that data are generated and shaped through the interaction of the participants and researchers, and the context in which the interaction occurs [27,31]. In this way, CGT provides researchers with flexibility to explore topics that emerged and that were most meaningful to the participant, while taking care to avoid pre-defining concepts such as recovering and technology from existing literature or the researchers' assumptions [27]. This approach resulted in a construction itself [27] of the stroke survivors' perspective on recovering in remote NWQ.

Context

In the current study, NWQ is defined as the remote and very remote (MM6 and 7) [32,33] region serviced by the North West Hospital and Health Service (NWHHS). NWHHS catchment area is 300,000 km^2 with an estimated population of 28,000, of which 23.3% identify as Aboriginal and/or Torres Strait Islander [34]. The main industries in the area include mining, agriculture and tourism [35]. People experiencing stroke in NWQ who are deemed eligible for rehabilitation are referred to the nearest tertiary facility, located ~900km by road from Mount Isa. North West Community Rehabilitation (NWCR), based in Mt Isa, offers a small ongoing public service, in addition to existing public and private allied health services within Mt Isa. Across the NWQ region outside of Mt Isa, allied health services are available intermittently. Difficulties recruiting and retaining a skilled health workforce to provide services coupled with a lower population health status contribute to the inequity of service accessibility in the region [36] compared to metropolitan areas. Use of telehealth to access services is growing in the region [36].

Participants

Recruitment strategies selected were those which were most likely to reach a diverse range of stroke survivors living, working or travelling in the remote setting [37]. Stroke survivors were invited to participate *via* print, radio and digital media, professional networks, word-of-mouth or written invitation. All stroke survivors with a postcode registered to NWQ who had accessed the main public hospital in the NWHHS or the nearest tertiary referral facility in the previous five years were posted a written invitation by an allied health professional. NWCR staff posted a written invitation to stroke survivors accessing their service at the time. Those stroke survivors who were interested in participating contacted the research assistant for further information and screening. Eligible stroke survivors: 1) were aged 18 years or older; 2) were at least 3 months post-stroke; 3) had spent 2 or more weeks in NWQ post-stroke; and 4) were able to communicate, either verbally or using augmented communication. Stroke survivors who were unable to provide consent to participate due to cognitive linguistic incapacity were excluded.

Purposive sampling [38] was used to ensure maximum variation in participants' age, gender, location, and naturally occurring population groups: Aboriginal and/or Torres Strait Islander peoples; people engaged in agricultural or mining industries; and people who lived, worked or travelled in the NWQ region. Efforts were made to include participants from as many communities in the region as possible and people who had left NWQ since having a stroke, recognising their experiences may differ. Thirty-three people contacted the research team, eleven of whom were: ineligible ($n = 3$); not interested ($n = 2$); unable to be interviewed ($n = 2$); or, unable to be re-contacted ($n = 4$). Fifteen stroke survivors were purposively selected from the pool of 22 people, ensuring diversity in participant demographics (Table 1). Two participants attended with their partners. One participant with aphasia declined having a speech language pathologist attend, preferring to have their partner act as their interpreter. All participants provided written consent.

Table 1. Participant characteristics.

Gender	Ethnicity	Age⁺	Living arrangements	Occupation	Location@	Time since stroke⁺	Affected side (body)	Technology use^
Male = 9	Non-indigenous = 12	Under 40yr = 3	House = 10	Employed = 6	MM2 = 1	Range: 6mo–22yr	Left = 10	Mobile = 13
Female = 6	Aboriginal = 3	40–59yr = 4	Unit = 2	Retired = 5	MM4 = 2	Mean: 6yr 1mo	Right = 4	Telephone = 11
		60yr and over = 8	RACF = 2	Interested in working = 2	MM6 = 10		Both sides = 1	Internet = 11
			Caravan = 1	Volunteer = 1	MM7 = 2			Computer = 9
				Homemaker = 1				Tablet = 5
								Wearables = 0

⁺At time of recruitment.
@Location at time of interview, classified by Modified Monash Model [32,33]: MM2 Regional centre; MM4 Medium rural centre; MM6 Remote; and, MM7 Very remote.
^Collected during screening.
Abbreviations: yr: years; mo: months; RACF: Residential aged care facility.

Data collection

Demographic, condition-specific, and technology familiarity data were collected during screening. One-off interviews were conducted in-person in a university office ($n = 8$), at the stroke survivor's residence ($n = 4$), or *via* phone ($n = 3$) by the primary researcher, affording participants the flexibility to participate regardless of their location. As the primary researcher was a novice researcher, the first five interviews were co-facilitated by a second researcher (RB, SS) in person or *via* web-based videoconferencing. A cultural mentor (SS) co-facilitated interviews with Aboriginal participants [39]. Assistance with transport to and from the interview was provided as needed ($n = 4$).

Audio and visual clarity were checked for phone and online interviews prior to commencing. Each semi-structured interview [40] followed the topic guide, which was piloted by the primary researcher [38] and assessed by an experienced qualitative methodologist, prior to the study commencing. The topic guide was comprised of four main questions: 1) Can you tell me about your stroke recovery journey? 2) How could your experience have been better? 3) How could your experience have been worse? and 4) Is there anything that you think technology could help with? The interview followed a conversational style, with probes used only as needed to dig deeper into participants' experiences in NWQ (e.g., transitioning home to NWQ). At the end of the interview the discussion was summarised by the primary researcher before participants were provided with the opportunity to clarify or add further thoughts. Interviews ranged in duration from 25 to 127 min, averaging 70 min. Data generation ceased once a diverse sample had been interviewed and the emerging analysis revealed no new information [38].

Interviews for fourteen participants were audio-recorded [27], and documented in writing for one participant as per the participant's wishes. Interview context, non-verbal communication and debrief by the researchers were recorded as field notes which were used to contextualise data during analysis [38]. Interviews were transcribed verbatim [27], de-identified and imported into NVivo v12 for ease of data management [41]. Transcripts were cross-checked for accuracy and inaudible segments (SS, FY).

Ethical approval was obtained from the Human Research Ethics Committee of the Townsville Hospital and Health Service (HREC/16/QTHS/203) and acknowledged by James Cook University (H6853). Public Health Act approval (RD006710) was given by Queensland Health.

Data analysis

Analysis occurred continuously throughout the study with interpretations generated from initial interviews used to inform questioning in subsequent interviews. In-depth analysis commenced after all recordings were transcribed. Transcripts were first read in full to understand the narrative [42] of the participant's recovery journey, then analysed using CGT techniques [27] by the primary researcher in discussion with co-researchers (RB, SS). Initial coding [27] began with line-by-line analysis, progressing to coding meaningful segments, using gerunds that stayed close to the text [27]. During subsequent readings, focused coding [27] drew together initial codes to build emerging categories. Constant comparative methods within and between transcripts were used to refine codes and develop categories, with analysis gradually reaching higher levels of abstraction that reflected the participants' perspectives by staying grounded in the data [27]. For example, codes *getting sick of repeating myself* and *travelling for specialist care* merged in *interacting with health services*, under *navigating my recovery in my world*. Three categories (Table 2) emerged from this process, with a core category identified as central to the process of recovering, explaining variability in the data and the interaction between the categories. Discussions with co-researchers, memo-writing and diagramming [27] supported category development, including detailing the properties, variation within and relationships between categories. To check the fit of the categories, the primary researcher reviewed all transcripts and a second researcher (RB) reviewed two transcripts for contradicting cases. Member checking [27] with three participants of varying age, gender, occupation, location and ethnicity, confirmed the model reflected their experiences, with one participant suggesting a change in description of the core category to reflect the extent of variation they personally experienced. A plain-language English summary of the results was offered to all participants. To minimise the likelihood of drawing preconceived ideas from the literature into the analysis [27], review of the literature occurred following commitment to categories. Instead, review of the literature on recovering from stroke in rural and remote Australia, through the stroke survivors' lens, served to situate the findings of this study.

Trustworthiness

Strategies used specifically to ensure trustworthiness included engaging in reflexivity and maintaining an audit trail [27]. The primary researcher (SJ) is a Physiotherapist who has lived and worked in NWQ for over 10 years. The secondary researcher (RB) is a physiotherapist and researcher with expertise in stroke rehabilitation and service delivery in remote and indigenous communities. Two experienced Aboriginal health researchers (SS, CFB) living and working in Mt Isa, with cultural and family connections across northern Queensland provided cultural and research support. The cultural mentor (SS) involved in data collection and analysis, identifies as an Aboriginal man whose cultural values and beliefs around social justice and empowering research participants, inform his position. An experienced researcher (FY) living in NWQ assisted with screening and data checking. All of the researchers involved in the study, shared a common motivation to see people living and ageing well in the region, through culturally secure research and clinical practice. They were all aware of challenges in accessing services in remote areas (e.g., large distances to specialist services, limited local services, high staff turnover, and limited expertise in stroke rehabilitation), and of increasing use of technology to access specialist healthcare in the region.

Table 2. Summary of categories.

Core category	Category	Sub-category
Living my life, as it evolves	Endeavouring to recover my way	Working out what matters to me, and works for me
		Finding and keeping the right mindset
	Navigating my recovery in my world	Being supported by those around me
		Adapting in my world
		Interacting with health services

Figure 1. Participants' perspective on recovering in remote NWQ.

Results

Fifteen stroke survivors participated in the study. Participants ranged in age from 32 to 75 years. All participants except one had previously attended inpatient rehabilitation, at either the tertiary referral facility closest to Mt Isa ($n = 12$), a facility closer to their location at the time of stroke ($n = 2$), or a regional facility closer to their home in remote NWQ ($n = 1$).

Living my life, as it evolves

Living my life, as it evolves is the core category which describes how study participants viewed the process of recovering in remote NWQ, according to what matters to them, amidst the ups and downs of life moving forward (Figure 1). Participants were *endeavouring to recover my way*, by drawing on their personal motivations and strengths, while *navigating my recovery in my world*, by working with the people and the properties of their environment. Like two cogs working together in a set of gears, *endeavouring to recover my way* and *navigating my recovery in my world* describe how participants were typically *living my life, as it evolves.*

Living my life, as it evolves reflects the participants' view that recovering is about doing what matters to them, now and as they move forward into the future. 'What matters' varied amongst participants, often centred around activities that made up their daily lives such as driving, working or caring for family.

> the things in that person's life that spun their tyres. That brought a sparkle to their eyes. [Female, 40–59 years, 22 years post-stroke]

'Doing' what matters often meant working with and around their changed capacity and circumstances after stroke. Some found different ways of doing what mattered independently; while others did less of what mattered to them, due to limitations such as pain, or a lack of manual dexterity to accomplish the tasks required.

> I've always been good with my hands … fixing things up. I can't even fix up a tap now these days [Male, 60 years and over, 5 years post-stroke]

Doing what mattered could induce feelings of pride, success and confidence; in contrast, feeling they were going nowhere led some to feel useless.

> I was able to do it … . I was able to sit there and for 4 hours … a day, and do [data entry], voluntary! [Male, 60 years and over, 7 years post-stroke]

> Just a whole change of lifestyle … from being a worker to just being nobody. Just sitting around watching TV. [Male, 60 years and over, 5 years post-stroke]

Yet life and what matters in life, was continually evolving, changing with time, with their changing capacity (e.g., returning to driving), circumstances (e.g., introduction of the National Disability Insurance Scheme (NDIS)), or stage of life (e.g., becoming a parent). The evolving nature of their life gave them both hope and uncertainty regarding their future and influenced how they approached recovering their way in a remote community.

> it's a whole new way of life, and it just evolves [Male, 60 years and over, 8 years post-stroke]

> I can do so much more with [my second son] … that I just wasn't able to do with [my first son] (sniffs) [Female, under 40 years, 3 years post-stroke]

Participants shared how their lives were evolving following the sudden changes brought about by stroke. Taking a detour on life's path, without knowing how long, wide or bumpy the detour could be until life was back on track, was depicted by some participants. Others described feeling like the bottom had dropped out of their world, that their future was lost and completely unknown, drastically altering their life's path.

> it's big! (short laugh) It's quite big. It's quite devastating. It's quite … bombastic. It's like a little Hiroshima in your life [Female, 40–59 years, 22 years post-stroke]

Some were working towards a new version of their life, accepting the differences they were experiencing; yet others felt stuck, despite trying to adapt their lifestyle (e.g., downsizing the farm), because their limited capacity persisted. Conversely, needing some normality and stability in their world (e.g., going home) enabled some participants to get on with living their life, particularly in the early period after stroke.

Endeavouring to recover my way

For participants, *endeavouring to recover my way* involved *working out what matters to me, and what works for me*, as well as *finding and keeping the right mindset* to continue persevering with recovery.

> now that I've got the thumb squarely out of my arse and I'm moving in the right direction [Male, 40–59 years, 3 years post-stroke]

Working out what matters to me, and what works for me: meant believing in and working towards the life that each individual wanted for themselves. Participants described weighing up what they wanted to gain against what they were willing to forgo as their way of prioritising now and for their future. Sometimes this meant finding new ways to achieve what mattered.

> I come back to the fact that we are fairly independent … And we tend to try to do things ourselves so other people may have kept a contact … whereas … I didn't. We went back home. [Partner of female participant, 60 years and over, 11 years post-stroke]

> the best way I can do it, is I've achieved what I want to achieve … I probably cheat a lot of times and do things that I shouldn't do, but … I get done, what I wanna get done [Male, 60 years and over, 8 years post-stroke]

Finding support to achieve what mattered depended on what was available to them in their remote community. Choosing their way could mean balancing their individual and cultural needs and preferences with those of the people close around them, finding the support they needed without others' help, or conversely, fighting for the support they needed even when it disrupted the status quo.

> it took me two months of refusing to [fly to regional city], that they then decided that "Alright … we'll do [the consultation] over the phone" [Male, 60 years and over, 3 years post-stroke]

Similarly, participants expressed individual preferences relating to technology, and how they used it. Mainstream (e.g., mobile phone, audio books) and rehabilitation specific (e.g., SMART Arm [43]) technologies that supported participants to live their lifestyle in their environment, or to improve physically seemed most popular. Technology that did not work for them or failed to do what it was supposed to was disregarded. Some participants were hesitant to use technology on their own, yet keen to try it with support from others.

> I got the IT guy to give me a new mouse and … he setup the computer so I could do it with my left hand and … he would practise with me to make sure I, you know? [Female, under 40 years, 3 years post-stroke]

> you weren't feeling like you're getting the full story across [on videoconference] because they couldn't actually grab your arm and feel you and do this, that and the other [Male, 60 years and over, 7 years post-stroke]

Finding and keeping the right mindset: by being open to their future potential was considered by participants as critical to their recovery, particularly in overcoming feelings like wanting to give up. Yet, developing this attitude could take time. Drawing inspiration from not only survivors of stroke but also other disabling conditions helped participants persevere. For some, their own experience was motivating them to help improve the recovery journey for others. Believing that they were working towards their future life and finding ways of transforming exercises into their daily activities helped some participants persevere.

> I don't see improvement for months and months now, but I do the exercises everyday because it will improve it one day [Female, under 40 years, 3 years post-stroke]

Finding enjoyment in their life and being grateful for what they could do helped some participants in staying positive. Making the most of opportunities that crossed their path propelled some participants forward. Having success at a new task or relearning to do something could boost their confidence and inspire persistence. In contrast, failing repeatedly could diminish hope for the life they wanted, with participants feeling restricted by their own abilities, know-how or supports in their environment.

> Here they [staff] busy all the time … I'd love to have a [walk], I want to. You know just take that steps to walk. [Female, 60 years and over, 5 years post-stroke]

Navigating my recovery in my world

For participants, *navigating my recovery in my world* meant *being supported by those around me, adapting in my world,* and *interacting with health services*. Being able to do what matters meant working out what they needed in and from their world, and what they needed to give to their world, now and into the future. This could involve cultural and social support, equipment, technology, financial assistance or access to health services in their remote community.

Being supported by those around me: including partners and family was especially critical to many participants in the early period after stroke when they described feeling at their most vulnerable, often when far from home. Connecting with the people important in their lives could relieve feelings of isolation, kick-start rebuilding their life and keep them moving forward.

> just after I had my stroke, my world became incredibly small … so I only really needed to see my husband and my son … My world expanded a little bit when I came home, because … I wanted to socialise with people [Female, under 40 years, 3 years post-stroke]

Personal and family relationships evolved as a result of the stroke and recovering experience. Some participants described taking on the stroke as a couple, while others shared how their relationships had changed or ended. Some grieved for the loss of intimacy they once shared and the burden now borne by those closest to them.

> they'd always just say to [wife], "When you're home, you should do this and do that for him … And have him doing that", but … she's not getting paid to do all this [Male, 60 years and over, 5 years post-stroke]

Recovery came more easily to some participants when connecting with their family, home or community. For some, connecting was about living a normal life (e.g., being with other mums), while others were finding connections as a result of stroke (e.g., linking with other stroke survivors). Feeling culturally connected to people and place was particularly important for Aboriginal participants. Socialising became part of moving forward, with some participants finding the support they needed amongst friends and community, while others described feeling alone or unable to get around without assistance. Making the most of friendships and community resources helped some participants in achieving the life they wanted while reducing the burden on those closest to them. Yet, being known in a small town also meant lacking privacy.

> Everybody knows [partner] so she's got safety, security … if I was somewhere and she bogged her scooter or something like that, they'd stop and get her out or call me [Partner of female participant, 60 years and over, 11 years post-stroke]

> they made sure I was in my driveway and made sure I was OK … Then I found out they knew [wife] and it wasn't too long before the news of the world had reached her. [Male, 60 years and over, 7 years post-stroke]

Adapting in my world: describes participants adapting their usual ways and finding equipment to suit their needs, which helped some participants overcome obstacles in their home and remote community (e.g., scooter to navigate uneven terrain; changing daily routines to avoid hot weather). Others felt forced to relocate to another community to find the help they needed, typically moving within the first year after stroke. Participants choosing to move on for family reasons or changing employment often came later after stroke, as part of their evolving life.

> It wasn't a sudden decision, it was a slow, just a slow awareness … Because if anything happened to me, then [partner] being in [remote community] was going to present a difficulty all round. [Partner of female participant, 60 years and over, 11 years post-stroke]

> Eventually … we'll move close to family because I, I'd like to bring … our boys up, with family … But at the moment, being out here … suits us because I can get back some of my physical capacity and some of my communication skills … Everyday I wake up and I wanna be here or I wanna be somewhere else. It's a fine line. [Female, under 40 years, 3 years post-stroke]

Participants expressed the view that technology could be a useful resource when it enabled them to live their life. Having trouble accessing or using technology, however, made it difficult for participants to make the most of technology available in their world.

> That is what helped her speech recover more than anything, was audio books … You go to the library … all the tapes and discs but none of the books match! [Partner of female participant, 60 years and over, 11 years post-stroke]

Participants expressed how other people's perceptions of their abilities could be crippling, knocking their confidence and leaving them feeling less valued, even in a modern world that they saw as more accepting of disability. While returning to work was important to several participants, younger and older alike, they felt success in their work depended on not only their recovery but also how supportive their workplace would be.

> Because you're a liability. If you've got a disability you're a liability! [Male, 60 years and over, 7 years post-stroke]

Tapping into government funding allowed a few participants to reduce their reliance on family or friends, ease financial pressures or participate in return-to-work programs. Knowing about and accessing funding, however, could be a difficult and lengthy process.

> NDIS's going to change my whole concept of being independent [Male, 60 years and over, 7 years post-stroke]

Interacting with health services: could be frustrating, however participants appreciated the role health professionals played in supporting their recovery, particularly in the early period. The typical stroke journey involved multiple service providers across multiple locations and changing with time, often beginning with a trip to the local emergency department in a remote community, being transferred to a regional hospital for inpatient rehabilitation and then back home to yet another service.

> We had so much trouble because the flying doctor doesn't go from [remote city] to [small regional city]. He goes [remote city] to [large regional city] … And I said "[large regional city] is useless to us. We know nobody. It's even further from home … In [small regional city], we have friends. We know people. I can connect from there back to [home community]" [Partner of female participant, 60 years and over, 11 years post-stroke]

Participants described the uneasy experience of staying in hospital and being away from home for an extended period.

> I did six weeks the first time. I spent my first wedding anniversary, my birthday, my daughter's birthday and they almost made me spend Christmas there [Male, under 40 years, 2 years post-stroke]

Changing locations meant switching between services that did not always communicate well, leaving participants waiting for someone to contact them or being unsure about what was happening next. Some participants described getting sick of repeating themselves when starting with a new service provider.

> And I thought, "Now, here we go again, no communication!" … I asked them if I had to take any paperwork or email, "No, no, we sent all that over on the computers" … I got there and they asked me, "Did I bring any paperwork with me?" [Male, 60 years and over, 6 months post-stroke]

On returning home, some continued receiving outpatient care in person or over the phone from metropolitan services, others were accessing local providers in their remote community, while others were going it alone, by their choosing or being unable to find a service that could meet their needs. Accessing outpatient specialist services in regional cities could be costly, despite travel subsidies and public health services, and disruptive to participants' and families' lives. These costs and disruptions were later weighed up against potentially dissatisfying appointments, leading some participants to look for opportunities to make best use of the resources around them according to their own needs.

> It was only 10 minutes! … She just looked at the screen … "Oh, no change" … They were gonna fly me out just to do that … Ohhhh so *wild*! [Male, 60 years and over, 3 years post-stroke]

> "I refuse to go to [regional city] to get an MRI." I said, "There's an MRI machine here … I want to get it done [here]" [Male, 60 years and over, 3 years post-stroke]

> you fly down on a plane … so you pay for the taxi to get you to the airport … So that's $50 before you've even got to the [hospital]. Then you sit there for 4 hours, and the consult is very haphazard … you'd go and see the neuro at 2[pm]. And then you'd fly back that afternoon … . so a neuro consult costs you 75 bucks … Plus a day's lost wages if you have to work. [Male, under 40 years, 2 years post-stroke]

While some participants benefited from a growing community rehabilitation service in their town, others described uncertainty about whether health professionals closer to home had the specialist skills, capacity or cultural sensitivity to support their recovery. Accessing allied health services was particularly challenging for participants in the most remote communities or in aged care facilities.

> they used to fly up about every six weeks or something … But every time they came, was new people … So they'd have to do an assessment. Speech therapists we had at least six! … And all that ever happened was that they did assessments on her! [Partner of female participant, 60 years and over, 11 years post-stroke]

> we had a lady come in to [residential aged care facility] and do physio on me. But she went overseas … They get you going for awhile, you feel good, and then they- … all of a sudden, they gone. [Female, 60 years and over, 5 years post-stroke]

Participants highlighted benefits of telehealth, such as minimising disruption in their lives, as well as challenges, such as missing the hands-on approach of in-person care.

> I think telehealth … I'm not saying that it's gonna be a great way of delivering health, but it's an alternative … I can't get the whole two days off work … . "can I take my lunch [early] because I've got a telehealth?" … And most managers … are pretty happy with that sort of solution. [Male, under 40 years, 2 years post-stroke]

Participants described feeling well cared for when a health professional saw them as a whole person with a life ahead of them, a person whose situation was unique, requiring care that matched their individual and cultural needs, now and into the future. Conversely, some participants described feeling like they were a number on a production line at times, while others remembered particular health professionals for devastating participants' dreams and casting doubt about being able to live their life their way.

> I felt like we were all wanting to get me back on the road and if [my son] came along, then that was quite good [Female, under 40 years, 3 years post-stroke]

In brief, *living my life, as it evolves* reflects how participants were moving forward with their lives, as they changed. *Endeavouring to recover my way* and *navigating my recovery in my world* helped them to keep moving forward, like two cogs working together in a set of gears. While the cogs work together, each cog may contribute more or less over time and in turn, influence the motion of the other: if one cog falters, so too may the other, slowing the stroke survivor's momentum e.g., for one participant, without the support of his workplace, he is unable to return to work, which influences how he sees himself and his future. Drawing more heavily on one cog for a period may help the stroke survivor keep moving forward e.g., having follow-up appointments by telehealth to avoid travelling and disrupting life again. Furthermore, as life evolves, changes can affect how both cogs function e.g., moving towns for family reasons could alter the opportunities and obstacles faced by a stroke survivor in navigating their recovery.

> we left and tried to go back home, out to [cattle station] to see if we were any good … but after a little while, we knew I wouldn't [get over it]. Not straight away. So, we had to leave. Retire. [Male, 60 years and over, 5 years post-stroke]

Discussion

This study explored stroke survivors' perspectives on recovering in remote NWQ, to explicate the lens through which they viewed recovering. To the best of our knowledge, this is the first study focused on the experience of recovering after stroke in remote Australia. Central to their perspective on recovering, *living my life, as it evolves* encapsulates how stroke survivors are working towards the life they want, by *endeavouring to recover my way* and by *navigating my recovery in my world*. Technology was considered helpful by stroke survivors but only when it supported them to recover their way in their world. *Living my life, as it evolves* and *endeavouring to recover my way* share similarities with findings from studies investigating urban stroke survivors' experiences. *Navigating my recovery in my world* does, however, highlight some of the unique challenges and strengths of recovering in a remote context, from the perspective of stroke survivors.

The importance of each stroke survivor living the life that matters to them, and as it unfolds, is central to recovering, according to the findings of this current study. Similar to previous studies, stroke survivors from urban and rural areas alike, viewed their recovery as personal, unique and an ongoing part of their life [44–47]. Moreover, they were adjusting and readjusting to their evolving lives, and to changes occurring within and around them [28,48]. Although there were common threads in each survivor's story, their unique circumstances, the direction in which their life was heading and the ways they responded to challenges varied. Their ability to live their life was affected by the state of their body and mind, by personal and environmental contextual factors, consistent with the International Classification of Functioning, Disability and Health (ICF) [49] and the experience of stroke survivors in underserved communities worldwide [50,51]. By contributing the remote stroke survivors' perspective, the findings of the current study confirm the value of a person-centred approach [52] to rehabilitation in rural Australia [8,9,53], similar to stroke survivors worldwide [54,55] and in line with current national and international stroke guidelines [10,56]. Accordingly, health professionals need to listen to stroke survivors, and work with them to recognise and draw on their individual strengths, both personal and environmental, to help them overcome challenges as they move on with living their life.

A key challenge for stroke survivors in NWQ was the lack of services that met their individual needs, in their world, when they needed them. Limited access to stroke services has been frequently reported as an issue for rural stroke survivors in Australia and worldwide [2,8,9,15,44,50,51]. Even so, recovery for stroke survivors in rural and urban areas has been reported to be similar [57,58], possibly due to different expectations towards recovery [44], degree of self-reliance [51], or the power of an enriched environment [9,59]. The current study highlighted that in remote NWQ, even when available, difficulties arise for stroke survivors when trying to access services as they are often changing, fragmented, and lack the specific expertise required for stroke rehabilitation. Furthermore, switching between services and health professionals means establishing new relationships and losing the old. Nearly all stroke survivors leave their remote community as a result of the stroke: sometimes temporarily disrupting their lives and support networks when accessing specialist services in metropolitan areas; while for others, the move reflects a permanent change in their lifestyle. While little is known about the impact of inequitable health services on recovery in remote [8,9] compared to urban Australia, innovative strategies are being developed to improve quality and continuity of care in NWQ through such strategies as collaborative practice [60,61], transition services [14] and telehealth [25].

Stroke survivors in remote NWQ who participated in this current study relied on their own personal assets and the resources within their world to continue recovering. Likewise, stroke survivors in rural areas worldwide have reportedly continued recovering in the absence of services, by drawing on their own strengths, such as resilience [51] and spiritual beliefs [62], as well as the strengths in their world, such as family [9] and complementary and alternative medicines [50,63]. Making the most of opportunities in their world, and utilising the resources available to them, enabled stroke survivors in the current study to continue their recovery their way in their world, rather than being constrained by it. These insights highlight the circumstances of stroke survivors recovering in remote areas. Health professionals need to recognise and work *with* stroke survivors to recover their own way, by creating opportunities to draw on their personal strengths and the strengths in their remote world.

Technology, in the context of this study, was seen to be helpful, yet only when it supported stroke survivors to recover their way in their world. Individual preferences for how and when to use technology varied according to perceived benefits (e.g., minimising disruption, returning to work) and barriers (e.g., self-confidence, lack of physical contact), consistent with existing literature [24,64–66]. These findings further support the importance of stroke survivors themselves, choosing how they use technology in their lives [24,66]. The impact of stroke survivors' choices around the use of technology, including when accessing services [18,67], needs to be investigated further particularly with the increase in the use of communication technology in work, education and healthcare associated with the worldwide response to the COVID-19 outbreak. This may increase the confidence and skill of health professionals in using technology to provide services, and that of stroke survivors to access services. Furthermore, the Person-Environment-Tool model [68] could support use of technology in remote areas as this approach is directed by the person, their needs and applied in their context. Such a model provides health professionals with a framework for considering how stroke survivors in remote areas could use technology to support them to live their life.

Strengths and limitations

Use of purposive sampling, adopting CGT methods for data collection and analysis, and strategies to enhance trustworthiness (e.g., engaging in reflexivity, member checking) revealed the perspectives of a diverse group of adult stroke survivors recovering in remote NWQ. In turn, the stroke survivors' perspective provided new insights to the researchers particularly with respect to the degree of disruption experienced by stroke survivors as a result of fragmented services. As the researchers (SJ, RB, SS) shared connections with several participants, through clinical, community and cultural links, it is possible that participants moderated their responses, or conversely, were more open in expressing their views, feeling they would be understood by researchers familiar with their situation [31]. It is important to acknowledge that participants were asked to recall specific details when reflecting on their recovery journey, the accuracy of which may have faded over time, however, hindsight has led them to share what they feel impacted most on their recovery. Having partners present also helped recall their shared experience of the recovery journey. Also, while findings reflect the views of those who participated, they may not reflect the views of others such as families with children who have survived a stroke. Including stroke survivors who have experience in the rural and remote context and with local health services, as co-researchers could strengthen their voice in research while maximising the relevance of research outcomes to them [69]. Overall, the findings reinforce the need for a person-centred approach to stroke rehabilitation in remote NWQ and may be transferable [70] to other rural and remote settings where there are similar contextual challenges to stroke recovery.

Conclusion

Recovery for stroke survivors in remote NWQ means getting on with living their life, as they want it to be and as it unfolds. Through endeavouring to recover their own way, stroke survivors are working towards the life they want and all the while, navigating their recovery within the physical, social and attitudinal environment around them. Technology that helps the stroke survivor to recover their way in their world may have a place in their recovery. These findings highlight strengths and challenges, as seen by stroke survivors, to recovering in a remote context with limited access to rehabilitation services. Health professionals need to listen, learn about and enable stroke survivors along their recovery journey, within their remote context and all that it can bring to the stroke survivor.

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