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Stroke survivors’ perspective on recovering in rural and remote Australia: A systematic mixed studies review

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Abstract

Introduction: Stroke survivors recovering in rural and remote locations often have little or no access to rehabilitation services. The purpose of this study was to review the literature on recovering in rural and remote Australia, from the perspective of stroke survivors. Use of technology to support recovery was also explored.

Methods: A systematic mixed studies review was conducted and reported according to the ENTREQ and PRISMA statements. MEDLINE (Ovid), CINAHL (EBSCOhost), Scopus, PsycINFO (ProQuest), Cochrane Library and Google Scholar were searched from inception to May, 2021 for studies investigating stroke survivors' perspectives on recovering in rural or remote Australia. Qualitative, quantitative, or mixed methods studies were included. Methodological quality was assessed using the Mixed Methods Appraisal Tool. Studies were not excluded or weighted according to methodological quality. To review the perspective of stroke survivors on recovering, findings of included studies were mapped to the *Living My Life* framework and integrated using a convergent qualitative synthesis. The review protocol was registered on PROSPERO (CRD42017064990).

Results: Eight studies met the inclusion criteria: six qualitative; one quantitative; and one mixed-methods. Methodological quality of the small number of studies ranged from low to high, indicating further high-quality research is needed. Included studies involved 152 stroke survivors in total. Review findings indicated that recovering was driven by working towards what mattered to stroke survivors, in ways that matched their beliefs and preferences, and that worked for them in their world, including use of technology.

Conclusion: Stroke survivors recovering in rural and remote locations want to live their life by doing what matters to them, despite the challenges they face. They want support in ways that work for them, in their environment. Further research is required to tailor support for stroke survivors that is specific to their life in rural and remote locations.

Keywords: Rural and Remote health; Rehabilitation services; Stroke; Assistive Technology; Client-centred practice.

Key points for Occupational Therapy

- Rural and remote stroke survivors' perspective offers insights into supporting their recovery.
- Further research is required to tailor services, focusing on what matters to and works for stroke survivors.
- Progress needs to be measured according to what matters to the stroke survivor using self-report measures.

Introduction

Stroke remains a leading cause of long-term disability in Australia (Australian Institute of Health and Welfare, 2020), and with each decade, the disabling effects of stroke are lasting longer due to improved survival rates, longer life expectancy (Australian Institute of Health and Welfare, 2020) and increased stroke rate among younger Australians (Stroke Foundation, 2020). Thus, a good recovery from stroke is not guaranteed. To optimise recovery, rehabilitation is recommended for stroke survivors along the recovery continuum.

In rural and remote locations, stroke survivors cannot rely on access to rehabilitation services, and hence must draw on different avenues for recovering from stroke (Mairami et al., 2020). Most acute stroke and rehabilitation units are located in major cities (Stroke Foundation, 2020), typically requiring rural and remote stroke survivors to be dislocated from their home and support systems to participate (Armstrong et al., 2019; Quigley et al., 2019). On returning home from a major city after stroke rehabilitation, ongoing rehabilitation may be unavailable or difficult to access (State of Queensland (Queensland Health), 2016). Yet, minimal attention has been given to how stroke survivors in rural and remote Australia approach their ongoing recovery from the disabling consequences of stroke. Even with the advent of stroke telerehabilitation, little research has been conducted investigating the application and value of telerehabilitation to stroke survivors recovering in rural and remote Australia (Laver et al., 2020).

Health professionals seeking to support stroke survivors in rural and remote Australia need to have a comprehensive understanding of the process of recovering, from the stroke survivor's perspective. This approach honours the insiders' view of recovering and their right to determine what for them, is a meaningful recovery (Brown, 2010). Furthermore, it is important to not only hear the perspective of stroke survivors but also to try to view recovering through the eyes of the stroke survivors rather than a health professional lens. In so doing, it is possible to privilege the voices of remote stroke survivors and to challenge the dominance of the traditional urban-centric biomedical model that underpins the western health system (Farre & Rapley, 2017), a sentiment that echoes the principles of Indigenist research methodology (Rigney, 1999).

Recently, the *Living My Life* framework (Jackson et al., 2021) emerged from the views on recovering shared by stroke survivors in remote northwest Queensland (NWQ). This framework was explicitly developed to provide a stroke survivor lens to guide development of stroke services for people living in rural and remote locations. Accordingly, the purpose of this study was to review the literature on recovering from the perspective of stroke survivors in rural and remote Australia, by viewing the findings through the lens of the *Living My Life* framework.

Methods

A systematic mixed studies review (SMSR) (Pluye & Hong, 2014) was undertaken to evaluate and integrate studies of diverse design and methodological quality. A broad search strategy sought to gather all studies investigating recovering in rural and remote locations across Australia from the perspective of stroke survivors. Data from included studies were mapped to the *Living My Life* framework (Jackson et al., 2021). This framework was explicitly developed to provide a stroke survivor lens through which to view recovering in a remote area of Australia. To construct the framework, 15 stroke survivors were interviewed using elements of constructivist grounded theory for data collection and analysis. The credibility of the framework was confirmed through member checking. The framework was then used in the current study to ensure the review held true to the perspective of stroke survivors. This is the first time the framework has been used. Individual study findings were then integrated in a convergent qualitative synthesis (Pluye & Hong, 2014). The systematic review was registered on PROSPERO (CRD42017064990). The protocol evolved to focus exclusively on the perspective of stroke survivors. The protocol was not prepared for publication. The review was reported using the Enhancing transparency in reporting the synthesis of qualitative research (ENTREQ) statement (Tong et al., 2012) and the Preferred Reporting Items for Systematic Reviews and Meta-analysis (PRISMA) Statement (Page et al., 2021).

Search strategy

MEDLINE (Ovid), CINAHL (EBSCOhost), Scopus, PsycINFO (ProQuest), Cochrane Library and Google Scholar were systematically searched using a strategy combining MeSH terms and keywords (Supplement 1). The strategy was developed and adapted for each database in consultation with an experienced librarian and peer-reviewed (BN, RB) without using an established checklist. No limits were applied to the search. A preliminary search conducted in March 2017 (SJ, BN) was repeated by the primary reviewer (SJ) on 11-12 May 2021. Reference lists and citations (indexed by Google Scholar) of eligible studies were hand-searched (SJ) most recently on 7 June 2021.

Broad search terms (e.g., ‘acquired brain injury’ and ‘neurological conditions’) were intentionally used to capture studies that included stroke survivors in the sample, as reviewers anticipated that studies solely sampling stroke survivors in rural areas would be rare, given the smaller population. ‘Recovery’ and ‘rehabilitation’ were included to capture studies that investigated factors influencing recovery. ‘Regional’, ‘rural’ and ‘remote’ were included in the search as these terms are commonly used to describe rural and remote areas in the literature (Stroke Foundation, 2020).

Study selection process

All references were extracted from each database with the exception of Google Scholar, with only the first 310 (of 256,000) references retrieved, as those of greatest relevance and consistent with the maximum references retrieved from other databases searched (i.e., Scopus identified 309 references). References were imported into Endnote X9. After removing duplicates, reviewers (SJ, BN) independently screened the references for eligibility. Studies were included in this review if they met each of the following criteria: qualitative, quantitative or mixed methods studies; the sample included ≥ 50% participants from rural, remote or regional Australia as described by the author or classified by the Modified Monash Model (Commonwealth of Australia (Department of Health), 2019) using the location of participants; the sample included ≥ 50% stroke survivors; investigated the perspective of stroke survivors on recovering in rural or remote Australia; and the full-text manuscript or conference proceeding was published in a peer-reviewed journal and available in English. Protocols, commentaries, or editorials were excluded along with studies investigating acute care or inpatient rehabilitation, medical or pharmacological management.

Reviewers (SJ, BN) followed a stepwise approach to screening, excluding studies that did not appear to meet the criteria at each step. Titles were screened initially, followed by abstracts and then the full text of articles that appeared to meet the criteria or where more information was required. To confirm rurality, in the absence of participant location or rurality index, the primary reviewer attempted to contact authors. The study from which the *Living My Life* framework emerged (Jackson et al., 2021) was excluded during title screening given its role as the lens for analysis. Studies included in reviews identified in the search were screened for eligibility (SJ). Differences in opinion between reviewers were resolved by consensus or referred to a third reviewer (RB).

Data extraction

Study and participant characteristics were extracted independently by both reviewers (SJ, BN) using a customised Excel spreadsheet containing: author/s; publication year; purpose; study design, methodology, data collection and analysis; sample size; participant demographics including health condition; location; rurality; intervention (if applicable); outcomes; and biases and limitations. Characteristics were extracted for stroke survivors only, when reported separately to the rest of the sample. Inpatient experiences were omitted from analysis when reported in conjunction with outpatient experiences, unless stroke survivors acknowledged these experiences as affecting their recovery journey in their rural or remote location. The full text of included studies was imported into NVivo 12 (QSR International, Cambridge, MA) for data management (SJ).

Data analysis and synthesis

Data were firstly mapped (Carr et al., 2019) to the categories of the *Living My Life* framework (Jackson et al., 2021): Recovering is about *living my life, as it evolves*; by *endeavouring to recover my way*; and by *navigating my recovery in my world*. A convergent qualitative synthesis (Pluye & Hong, 2014) was used to integrate, organise and review findings according to each category, then presented in a narrative form (SJ). Moving back and forth between the data and the categories, and discussing the findings between co-researchers (SJ, RB) helped to explore any variation emerging within the categories and to enhance rigor in the analysis (Pluye & Hong, 2014).

Quality appraisal

Methodological quality of included studies was assessed independently (SJ, BN) using the revised Mixed Methods Appraisal Tool (MMAT) (Hong et al., 2018). Five methodological criteria are assessed as ‘Yes’, ‘No’, or ‘Cannot tell’ according to the qualitative, quantitative, or mixed methods study design. Mixed methods studies are assessed against mixed methods criteria as well as the qualitative and quantitative criteria. Differences in opinion between reviewers were resolved by consensus. Studies were not excluded or weighted based on methodological quality.

Results

Database searching yielded 1051 references (Figure 1). Following duplicate removal and screening of titles and abstracts, the full text of 114 articles were reviewed for eligibility. Hand searching yielded a further two articles. Eight studies were included in the review (Table 1): six qualitative, one quantitative and one mixed methods study.

Methodological quality

Methodological quality of included studies (Table 2) ranged from low to high for qualitative studies, medium quality for the quantitative study and low quality for the mixed methods study.

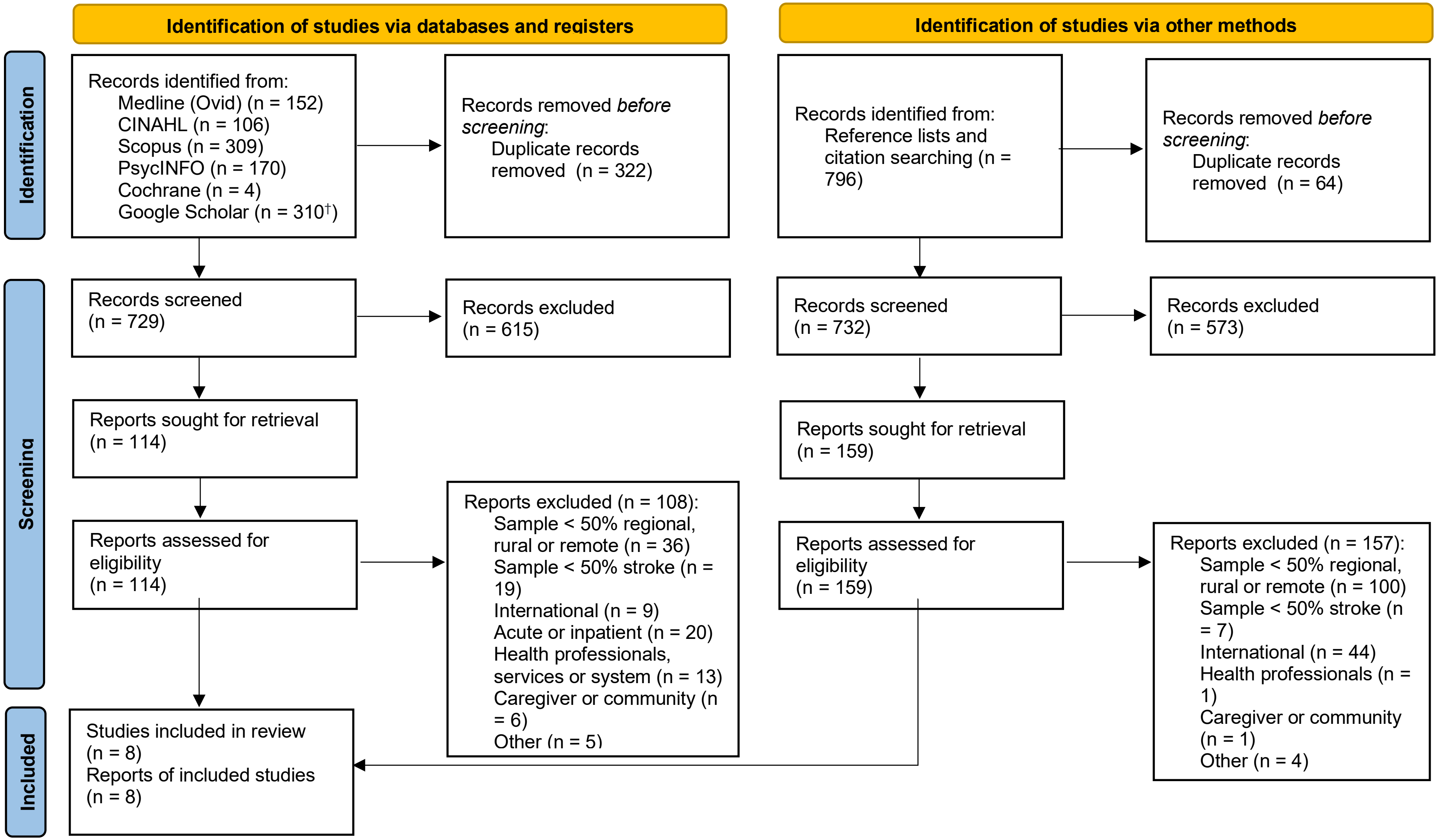

Figure 1. PRISMA Flow Diagram adapted from Page et al. (2021). †Extracted 310 of an estimated 256,000 records.

Table 1. Characteristics of included studies (n = 8).

Author, State	**Purpose**	**Design, Methods**	**Participants n(%)**	**Rurality (SS only)** ***n*****(%)**
Qualitative				
Armstrong et al. (2019) WA	To explore the experiences of Aboriginal Australian adults with ACDs after brain injury to inform service delivery models.	Principles of an Aboriginal Research Framework for health contexts incorporating Indigenous Standpoint Theory Semi-structured interviews using yarning	Total n = 32 + 16 CG SS = 23 (72%) SS +TBI = 3 (9%) TBI (only) = 6 (19%) M 19 (56%)/F 13 (41%) R 35 – 79yr Aboriginal 32 (100%) Chronic	MM7: 4 (15%)[†] MM6: 8 (31%)[†] MM3: 4 (15%)[†] MM1: 10 (38%)[†]
Barker and Brauer (2005) Qld	To explore SS' perspective on factors that contribute to upper limb recovery	Principles of grounded theory Focus groups and in-depth interviews	19 SS + 9 CG M 12 (63%)/F 7 (37%) Mean 64yr (R 42 – 82) Late subacute to chronic	Rural: 7 (37%) Regional: 3 (16%) Metropolitan: 9 (47%) MM5: 7 (37%)[†] MM2: 3 (16%)[†] MM1: 9 (47%)[†]
Finch et al. (2000) SA	To describe the telerehabilitation experience with two country clients	Case study Satisfaction surveys, clinical outcomes Intervention: multi-disciplinary (1:1) rehabilitation provided via videoconference with local in-person support, in hospital facility, for several sessions/week over 3 months.	Total n = 2 SS (with CP) = 1 (50%) TBI = 1 (50%) M 1 (50%)/F 1 (50%)	Rural and remote: 1 (100%) MM3: 1 (100%)
O'Connell et al. (2001) Vic	To determine the impact of stroke on survivors and to identify their physical and psychosocial needs in rural and regional settings	Exploratory: content analysis (thematic) Focus group interviews: 3 groups of SS, 1 with CG and 1 with key informants.	40 SS, CG and key informants Mean 58.4yr (R 20 – 89) [‡] Early subacute to chronic[‡]	Rural and regional: 40[§] (100%) Unable to determine MMM classification
Quigley et al. (2019) Qld	To identify the needs of Aboriginal and Torres Strait Islander SS in FNQ to inform model of care	Exploratory: principles of thematic analysis Survey, administered through interviews	24 SS + 10 CG + 70 stakeholders Aboriginal or Torres Strait Islander 24 (100%)	Regional, rural and remote: 24 (100%) MM7: 13 (54%)[†] MM6: 4 (17%)[†] MM2: 7 (29%)[†]

White et al. (2015) NSW	To explore SS experience of acceptability of having access to and use of tablets, during the first 3 months of their stroke recovery.	Pragmatic paradigm, naturalistic approach: inductive thematic analysis In depth semi-structured interviews Intervention: iPads provided for ≤ 3 months with training prior to discharge home. Participants used apps, videoconferencing, email and internet, for therapy and leisure activities.	12 SS Median 73yr (IQR 53 – 83) M 8 (67%)/F 4 (33%) Early subacute to chronic (at time of interview)	Regional/Rural: 7 (58%) Metropolitan: 5 (42%) MM3: 7[†] (58%)[†] MM1: 5[†] (42%)[†]
Quantitative				
Marsden et al. (2010) NSW	To explore whether a group programme for community-dwelling chronic SS and their carers is feasible in rural settings; to measure the impact of the programme on health-related quality of life and functional performance; and to determine if any benefits gained are maintained.	Randomised, assessor blind, cross-over, controlled trial Intervention: CLASSiC Group programme combining physical activity, education, self-management principles and a 'healthy options' morning tea for 1 day/week x 7 weeks in three rural communities Outcome measures: SIS, 6MWT, TUG	25 SS + 17 CG M 19 (76%)/F 6 (24%) Mean: Int 70.0yr (SD 9.0); Ctrl 73.1yr (SD 9.3) Chronic	Rural: 25 (100%) MM3: 15[¶] (56%)[†] MM1: 11[¶] (44%)[†]
Mixed Methods				
O'Hara and Jackson (2017) Qld	To understand the experience of clients and providers using telehealth to improve continuity of care for people with neurological conditions living in remote NWQ	Sequential explanatory: purpose-built survey + debrief (with AHPs only) Intervention: single session inter-professional review conducted via videoconference with local AHP support, in a community rehabilitation facility.	Total n = 10 SS = 5 (50%) Cerebellar ataxia = 2 (20%), Spinocerebellar ataxia = 1 (10%) SCI = 1 (10%) ABI = 1 (10%) SS only (n = 5)[†]: Mean 60.9yr (R 45.9 – 71.5)[†] M 4 (80%)/F 1 (20%)[†] Aboriginal 2 (40%)[†] Chronic[†]	Remote: 5 (100%) MM6: 5 (100%)

Note: Chronicity rating (Bernhardt et al., 2017) determined using mean, median or range of time since stroke as provided in study, where early subacute = 7 days to 3 months; late subacute = 3–6 months; chronic = >6 months post-stroke.

Abbreviation: 6MWT, 6-min walk test; ABI, acquired brain injury; ACD, acquired communication disorder; AHP, allied health professional(s); CG, caregiver(s); CP, cerebral palsy; Ctrl, control group; F, female; FNQ, Far North Queensland; Int, intervention group; IQR, interquartile range; M, male; MMM, Modified Monash Model (Commonwealth of Australia (Department of Health), 2019) where MM1 = metropolitan; MM2 = regional centres; MM3 = large rural towns; MM4 = medium rural towns; MM5 = small rural towns; MM6 = remote communities; MM7 = very remote communities; NSW, New South Wales; NWQ, northwest Queensland; Qld, Queensland; R, range; SCI, spinal cord injury; SD, standard deviation; SIS, Stroke Impact Scale; SS, stroke survivor(s); TBI, traumatic brain injury; TUG, Timed Up and Go; Vic, Victoria; WA, Western Australia; yr, year(s).

† Author correspondence.

¶ From larger study.

§ Estimated.

‡ Dropout (*n* = 1) prior to intervention commencing from unknown site.

Table 2. Quality appraisal of included studies using Mixed Methods Appraisal Tool (MMAT) (Hong et al., 2018)

Qualitative	**Is the qualitative approach appropriate to answer the research question?**	**Are the qualitative data collection methods adequate to address the research question?**	**Are the findings adequately derived from the data?**	**Is the interpretation of results sufficiently substantiated by data?**	**Is there coherence between qualitative data sources, collection, analysis and interpretation?**
Armstrong et al. (2019)	Y	Y	Y	Y	Y
Barker and Brauer (2005)	Y	Y	Y	Y	Y
Finch et al. (2000)	U	U	U	N	U
O'Connell et al. (2001)	U	U	U	Y	Y
O'Hara and Jackson (2017)	N	U	U	U	U
Quigley et al. (2019)	U	Y	Y	Y	U
White et al. (2015)	Y	Y	Y	Y	Y
Quantitative - RCT	**Is randomization appropriately performed?**	**Are the groups comparable at baseline?**	**Are there complete outcome data?**	**Are outcome assessors blinded to the intervention provided?**	**Did the participants adhere to the assigned intervention?**
Marsden et al. (2010)	N	Y	Y	N	Y
Quantitative – Descriptive	**Is the sampling strategy relevant to address the research question?**	**Is the sample representative of the target population?**	**Are the measurements appropriate?**	**Is the risk of nonresponse bias low?**	**Is the statistical analysis appropriate to answer the research question?**
O'Hara and Jackson (2017)	Y	U	U	Y	U

Mixed Methods	**Is there an adequate rationale for using a mixed methods design to address the research question?**	**Are the different components of the study effectively integrated to answer the research question?**	**Are the results adequately brought together into overall interpretations?**	**Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?**	**Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?**
O’Hara and Jackson (2017)	N	U	U	U	U
Abbreviation: N, no; RCT, randomised controlled trial; U, cannot tell; Y, yes.					

Characteristics of included studies

Characteristics of the eight included studies are provided in Table 1. No studies described rurality using a classification tool. An estimated 152 stroke survivors participated across the studies, with an estimated 84% from regional, rural, or remote locations across Australia.

Factors influencing recovery in rural and remote locations were investigated in four studies; the remaining four studies investigated interventions trialled in rural and remote settings, three of which utilised technology. Qualitative studies focused on the stroke survivors' experiences of recovery (e.g., access to services, cultural implications, upper limb recovery and using technology). The quantitative study and quantitative component of the mixed methods study used self-report measures to determine participants' perspectives on recovering. However, there was nothing to indicate that factors measured were those of importance to study participants. Small sample sizes, typical of recruitment in a rural area, meant that statistical significance could not be determined in the pilot randomised controlled trial (Marsden et al., 2010).

Integration of findings of included studies

Living my life, as it evolves

Stroke survivors' views on the ways and the extent to which stroke and stroke recovery affected their lives were described across six of the eight studies (Table 3). Their experience of stroke, its consequences and their recovery, affected how they lived their lives, how they felt and how they saw themselves. Their lives were changing with the losses they suffered, additional challenges they experienced, and to a lesser extent, any gains they made. Recovery was generally viewed by stroke survivors as being able to do what matters, often physically or functionally. Adapting to, adjusting to and sometimes accepting the changes in their lives helped some survivors get on with living their life while maintaining hope for further recovery.

> *Don't give up trying because you will get back a certain level of normality.*
> *(O'Connell et al., 2001)*

The process of recovering was mediated by a range of different experiences happening within, and around them, for instance, with time, the choices they made, the support they received, how they experienced disability and where they were living.

Endeavouring to recover my way

Stroke survivors described trying to recover 'my way' in all eight included studies. Their personal beliefs and circumstances could motivate them, directing their recovery efforts according to what mattered to them.

> *It’s what comes from inside. What you bring out of yourself. (Barker & Brauer, 2005)*

Stroke survivors described driving their own recovery in ways that worked for them in accordance with or in the absence of professional advice. Some reported even forgoing strategies ‘known’ to help recovery, instead choosing strategies that mattered to them or making decisions they perceived necessary. Concerns about themselves, their recovery or their circumstances could make recovering more challenging. Staying positive about their potential for recovery was hard to maintain over time, especially when progress was slow, when the experience of disability was challenging and in the face of other people's disbelief about their recovery potential. Exercise and activity were considered key to physical recovery; however, getting started or progressing exercises could be challenging. In contrast, feeling supported emotionally and practically made it easier to keep going. Stroke survivors, particularly Aboriginal stroke survivors, found benefit in drawing on their connections with family, country, culture and language to manage challenges they encountered.

Stroke survivors reported using technology to foster their own recovery and in their daily lives.

> *It’s [the iPad] great. I’m more independent and go out more now – since I can google if I am lost. (White et al., 2015)*

Engaging with technology was considered easier by stroke survivors who were familiar with or willing to use technology, or when using it to achieve what mattered to them, and with the increasing availability of online resources. Conversely, feeling overwhelmed by their current situation or a preference for accessing care in person discouraged stroke survivors from using technology. Uncertainty about using technology or difficulties experienced due to limitations from the stroke were commonly overcome by stroke survivors, either on their own, with time, practice and space to explore in privacy, or with support, typically from spouses or health professionals.

Navigating my recovery in my world

Stroke survivors described various ways of ‘navigating my recovery in my world’ in all eight included studies. A view that was commonly reported was that their ability to recover was shaped by what their world looked like and what was happening in it at the time.

> *And, yes, a balancing act, you know, you get all this complicated stuff happening in a person’s life already and then along comes another*

> *complication. (Partner of 46 year old who had a stroke one year earlier). (Armstrong et al., 2019).*

Appreciation was generally expressed by stroke survivors for the support they received from partners, family, friends and community, including social, practical and cultural support provided in person or via technology. Yet others felt they could do more for themselves without the support of a spouse. Reportedly, interactions with the people around them were changed as a result of the stroke and its debilitating consequences, as did others' perceptions of their capabilities. These changes affected how some stroke survivors, and the people they interacted with, saw them and their role in life; others were left feeling isolated and aware of the burden borne by those closest to them, often with minimal support. Feeling connected with and supported by other people with stroke or any type of brain injury or similar culture (e.g., Aboriginal) was valued by stroke survivors.

Stroke survivors viewed being at home, or in their community, as beneficial for their freedom and the connections available to them. Yet, they also recognised that living in a rural location posed challenges to their recovery efforts, such as when accessing specialist rehabilitation services far from home, or trying to get support or items they needed locally. Some stroke survivors adapted by relying on the people around them or using technology to continue doing what mattered.

Access to rehabilitation services in rural and remote locations was often seen by stroke survivors as falling short of their needs. For instance, some had no service at all; others had only a few sessions and not necessarily when they needed it, and rarely with health professionals with specialist stroke skills. Furthermore, the service environment could be unwelcoming or uninspiring. Little or no communication between services or with the stroke survivor was common. Failing to find the help they needed from health services left some stroke survivors feeling isolated or unable to fulfil their potential for recovery, leading to some giving up on services or looking for help elsewhere (e.g., complementary medicines). In contrast, approaches that brought specialist skills into their home or community, both in person and when aided by technology, were seen to be beneficial. Similarly, ongoing, interactive relationships with health professionals who supported and encouraged them, provided therapy consistent with their goals, and who they felt understood and accommodated their world, were valued. Aboriginal stroke survivors looked for greater involvement of Aboriginal Health Workers along their journey. In contrast, negative or dismissive attitudes of health professionals, seeing multiple providers, transitioning between services, or feeling like they were being treated the same as other stroke survivors despite their differences, was perceived as challenging. Improvements suggested by stroke survivors related to the timing and type of information provided to them and their caregivers, family or community; improving cultural security and communication between services; and enabling access to ongoing, skilled care as it fitted with their goals and life.

Stroke survivors’ perspectives on telehealth services were reported in three studies. Videoconferencing with health professionals from their home or in their community was considered beneficial by stroke survivors, particularly when it meant ongoing access to therapy, staying connected with health professionals or working towards their goals. The perceived benefits of telehealth generally outweighed the lack of physical contact associated with usual care, without compromising confidentiality. A small number of stroke survivors expressed a preference for face-to-face services.

Table 3. Findings from included studies mapped to the Living My Life framework (Jackson et al., 2021)

	Qualitative						**Quantitative**	**Mixed methods**
***Living my life* framework**	**Armstrong et al. (2019)**	**Barker and Brauer (2005)**	**Finch et al. (2000)**	**O’Connell et al. (2001)**	**Quigley et al. (2019)**	**White et al. (2015)**	**Marsden et al. (2010)**	**O’Hara and Jackson (2017)**
Living my life, as it evolves								
Losses (Gains)	Felt not the same person, a lesser person than before the injury Changed family roles and personal/social identity Loss of income/work	Many reduced to tears by arm impairment, overwhelmed by severe paresis	-	Interconnected physiological, emotional and social losses Unable to return to work, travel or drive Loss of independence Loss of friends, workmates, leisure and social activities Dislocated from all aspects of their everyday life Gains e.g., more leisure time	Physical/ functional deficits	Role restrictions/loss	Loss of independence	-
Challenges	Anger, frustration, powerlessness Communication with family, hospital staff, friends, and work colleagues; due to stroke or cross-cultural issues, or both Culture shock	Arm recovery neglected Magnitude of loss poorly understood or appreciated Disappointment, frustration and anger Depression could	-	Frustrated, especially when lacked control Emotionally ‘flat’, unable to cope, degrees of depression People speaking over them or unable to participate in	Away from family and community Financial strain	Depression, feeling overwhelmed	-	-

	when away from country, language Financial strain	allow hope for recovery to fade Getting started, progressing and keeping going with exercise Scared of doing harm (e.g., pain) Not enough movement to practise		conversation Drivers licences not always cancelled Altered relationships No assistance in returning to work or ‘normal’				
Recovery is about doing what matters, often physical or functional recovery	Communication alongside physical recovery Return to work, regain income and identity	Intensely personal: hope, familiar identity, valued activities and lifestyle choices Keeping the door open: continuing along in life hoping for and working towards improvement Good recovery: movement and feeling return, use of the hand, doing what you want to do and getting on with your life, believing further improvement possible Bad recovery: lose hope, forget	-	Returning to ‘normal’	-	Improved stimulation, participation, socialisation and functional outcomes with access to iPad	-	-

		about trying to use the arm, find no way around or substitute Recovery ends with giving up						
Adapting to, adjusting to and/or accepting changes	Making necessary adjustments; accessing/needing services Acceptance, ‘getting on with life’, ‘living life to the full’ Learning to live with permanent disability (e.g., physical, cognitive, or communication)	Adjusting to the stroke and consequences, navigating rehabilitation services while getting back on with their life again	-	Changes devastating for some, less problematic for others Adapted by relying on others	-	Role restrictions/loss and lack of access to therapists mediated by access to iPad Adjusting to using iPad	Adopting strategies to manage mood, increase activity and adjust diet	-
Recovery mediated by what’s happening within and around them	Attitudes, beliefs, and motivators internal to the individual Facilitators and barriers external to the individual Depends on disability experienced, ultimate location, living arrangements, and family context	‘Hanging in there’, ‘drawing on support from others’, ‘getting going and keeping going with exercise’, and ‘finding out how to keep moving ahead’	-	Isolated by lack of services or expertise Personal attitude (e.g., “don’t give up trying”)	Returning home to family/community as soon as possible, sometimes sacrificing rehabilitation	Personal advantages to using iPad (e.g., increasing confidence and socialisation)	Adopting strategies to manage mood, increase activity and adjust diet Establishing local stroke support group	-

Endeavouring to recover my way								
Driving recovery in ways that worked for them	Participating in rehabilitation or self-initiated activities (e.g., reading, painting, singing) Acting out of necessity (e.g., family responsibility) or within means (e.g., financial burden/support) Drawing on connections with family, country, culture, language	Exercise and activity: starting soon; practicing regularly, intensively, appropriately and continually; using arm in everyday tasks. Helping self, being proactive Seeking complementary health medicines once traditional options exhausted Maintaining a strong reason to recover	Prefer face to face contact; compromised acceptance of telerehabilitation and its benefits	-	Returning home to family/ community, sometimes sacrificing rehabilitation	Exploring on their own Cognitive or language impairments made setting up or following instructions hard Practising on iPad improved functional outcomes	Adopting strategies for mood, activity and diet	-
Staying positive, feeling supported	Using own resources and determination, up to the individual Motivations related to family, work, identity, health, spiritual beliefs	Hanging in there: commitment required to persist, not give up Keeping hope alive; remaining open to future possibilities Harder with time, slow progress, other people's disbelief about their recovery potential, not	-	Attitude (e.g., “don’t give up trying”, “more free time”) Enthusiasm diminished with slow process or lack of progress Emotionally ‘flat’, unable to cope, degrees of depression	Managing concerns (e.g., finances, feeling guilty)	Desire to try anything suggested by health professionals that might assist/prevent decline Persevering despite apprehension; reframing problems as opportunities	Enjoyment, looking forward to attending, benefits daily life	-

		knowing what to do or how to get help, scared of doing harm Easier when supported emotionally and practically, attending therapy, proving others wrong, humour, goal-setting, celebrating successes				Depression, feeling overwhelmed prevented participant from trying Using iPad promoted self-management, and feelings of hope and freedom		
Using technology their way	-	Limited availability of online resources	E.g., voice activated computer Compromised acceptance of telerehabilitation and its benefits	-	-	Easier to use iPad if: familiar with computers, willing to have a go, doing something that mattered Harder when feeling overwhelmed, challenged or confused Adjusting to using iPad varied: most adjusted quickly; none had previous experience with iPad Difficulties could be overcome with time, practice,	-	Saves time/money, convenient, connect to therapists, enjoyment, access rehabilitation services, get better Challenged when unfamiliar with telehealth Small number prefer in-person

						help or space to explore Frequency of use varied: time per day; days used over the loan period		
Navigating my recovery in my world								
Being supported by those around them	Being with family; not always available Changed interactions and others' perceptions of them or their abilities Support from Aboriginal people, and people with brain injury (e.g., support group, newsletters)	Other stroke survivors/groups, health professionals, spouse, family, friends, community Physical, emotional and social support Positive, encouraging, celebrating successes Spouse support essential for some, not for others	-	'Community spirit'; stroke support groups; relying on others (e.g., driving) Changed relationships (e.g., marriage breakdown), interactions (e.g., social isolation) and others' perceptions of them and their abilities	Being with family, including escort Lack of support for those supporting the stroke survivor	Socialisation and participation from family and friends Spouse assisting technology use Using iPad reduced reliance on others	Stroke support group	-
Being at home in a rural location	Importance of being on country, with community Challenges: large distances to services, costs	Wanting more information (e.g., pamphlets, videos, websites)	Re-establishing family/community roles and relationships	Inadequate public transport, waiting for lifts Cold weather	Challenges: large distances to services, costs; harsh weather; poor telecommunications and network connectivity; home	Space to explore Adapting by using technology (e.g., navigating using maps)	-	-

					modifications; equipment; medications; transport; respite; domestic assistance	Problems with internet connectivity		
Interacting with health services	Little or no communication; issues compounded by language and communication disorders Not involving family or Aboriginal health workers Valued ongoing relationship with single therapist, social/emotional support, clear explanations, yarning, humour Seeing multiple providers was confusing; poor communication between services Being treated the same as everyone else despite differences Medical jargon and information overload; wanted	Limited by time or quota; prefer staggered services Lacking expertise; suggested annual review by visiting expert team Feeling isolated, disadvantaged, abandoned; unable to fulfil recovery potential; arm recovery neglected Looking for help elsewhere Valued ongoing relationship with therapist: therapy, training, guidance, encouragement; working hard to maintain therapist support Discouraged or motivated by professional's negative attitude,	Access rehabilitation service otherwise unavailable	Rehabilitation appreciated by those who attended Inconsistent follow up post-discharge Lack of expertise in community Feeling isolated Being treated the same as everyone else despite differences Drivers licences not always cancelled despite impairments	Little or no communication: timeliness, accessible language, translators, including family/ community, between services Lack of services Siloed government and non-government agencies Difficulties accessing home modifications, equipment, medications	Reduced staff limiting access to therapy, mediated by iPad Try anything suggested by health professionals that might assist/prevent decline Videoconferencing with health professionals using iPad	88% of participants attended ≥6 of 7 sessions Enjoyment, looking forward to attending, benefits daily life	Telehealth service in local community

	more practical information and education for family/young children Discouraged by confusing environment, unhelpful staff, therapist negative attitude, stereotyping, costs Rehabilitation in the home beneficial Service not long enough, lack of follow up; feeling isolated; not knowing who to call, not being contacted Needing assistance dealing with multiple issues (e.g., comorbidities, financial, social)	however, they are not always right Need access to ongoing skilled care: information, guidance, encouragement, demonstration, feedback, ‘open door’ Information: difficulty understanding and remembering from early stages; little relevance later on; failed attempts to get help						
Using technology in their world	-	Lack of information online	Satisfied with videoconference in community No barriers for speech and counselling	-	-	Able to solve technical issues independently, with help from family or therapist	-	Videoconference in community Saves time/money, convenient, connect to therapists,

	Satisfactory compromise for physical therapies		Many keen to purchase iPad Using iPad promoted confidence, access to health information and therapy, independence and socialisation Problems with internet connectivity	enjoyment, access rehabilitation services, get better Confidentiality not compromised Challenged by audio delay, unfamiliar with telehealth Some prefer in-person service locally

Discussion

This review appears to be the first to explore the literature on stroke survivors' perspectives on recovering in rural and remote Australia. By viewing the findings through a remote stroke survivors' lens, we gained insight into what it is really like for stroke survivors to recover in rural Australia and what they believe is key to enabling them to continue to recover. Overall, review findings highlighted that, from the stroke survivors' perspectives, recovering is about finding ways to continue doing what matters, even when it is challenging in rural and remote locations. It was clear that recovering could be made easier if support was available in ways that worked for them, in their own environment, when they needed it. These findings provide outsiders, perhaps health professionals or supportive community members, with a more comprehensive picture of what is important to the stroke survivor themselves in achieving a meaningful recovery.

Review findings indicate that rural and remote stroke survivors perceive recovering to be about doing what matters to them, similar to stroke survivors all over the world (Hafsteinsdottir & Grypdonck, 1997). Yet, stroke survivors' goals for recovery are often influenced by health professionals (Lloyd et al., 2018). Similarly, their progress is generally measured according to pre-determined criteria (e.g., modified Lawton's Instrumental Activities of Daily Living Scale (Capell et al., 2019)), rather than by what matters to the individual stroke survivor (e.g., looking after a baby (Armstrong et al., 2019)). Greater emphasis needs to be placed on self-report measures that enable the stroke survivor to measure what matters to them (Duncan Millar et al., 2019). Furthermore, self-report measures that can be easily adapted and interpreted by the stroke survivor need to be prioritised. The Patient Specific Functional Scale (PSFS) is one such measure, which is currently being investigated for use in this population (Evensen et al., 2020). Use of the PSFS allows stroke survivors to set their own goals and to revise their goals as and when their goals or circumstances change. Hence, an important step in supporting recovery for stroke survivors from any location, but particularly in rural and remote locations, is to consider how best to measure what matters to them and how best the stroke survivor can use and interpret the information without a health professional to support them.

With recovery viewed through the lens of stroke survivors, some of the strengths (e.g., family support) and challenges (e.g., keeping going with practice) described in the included studies appear to be universal, whereas others are specific to rural locations (e.g., distance to specialist stroke services) or individuals (e.g., spouses helpful for some and not others) and may change with time (e.g., growing confidence with using technology). The differing ways and life circumstances of different stroke survivors, as described in the literature, adds further breadth to the sentiments expressed by the *Living My Life* framework (e.g., for

Aboriginal stroke survivors, connecting with country and culture is entwined with recovery). The variation in circumstances described highlights the adaptability required by services to match the needs and lifestyle of the individual stroke survivor. Importantly, health professionals need to understand the individual stroke survivor's view of their circumstances, including getting to know the ever-changing strengths and challenges each stroke survivor experiences, and working with them to help them find their own way through. Perseverance, for example, is key to stroke survivors driving their recovery, possibly more so in the absence of services; so, tapping into their resilience, borne through living rurally; connecting with country, particularly for Aboriginal stroke survivors (Armstrong et al., 2019); or, using technology to make daily activities doable (White et al., 2015); may help stroke survivors to continue living their life, their way in rural and remote locations.

Technology was seen by many stroke survivors as helpful to their recovery, particularly when used in a way that worked for them. Evidence of translation of telehealth into rural rehabilitation practice, has been limited to date (Bradford et al., 2016), despite policy support and advances in technology applications. The rapid upscaling of telehealth associated with the recent COVID-19 pandemic, however, will likely lead to a growth in research in this area. For stroke survivors to gain the most from a technology approach, health professionals need to first understand what matters to the stroke survivor and what their needs are in relation to technology and connectivity. For instance, understanding the type of technology that works for the stroke survivor and what support they require to persevere with technology (Neibling et al., 2021).

Strengths and limitations

The strengths of the SMSR approach taken in this review lie in the value of integrating qualitative, quantitative and mixed methods studies giving a broad picture of research in this area. Limitations of this approach relate to the small number of studies that included small and diverse samples and that varied in quality and design.

Choosing to focus on the stroke survivor's perspective, by excluding the literature from the perspective of others, honours the insider's view and right to determine what they see as meaningful recovery (Brown, 2010). It is important to recognise however the potential for volunteer bias in included studies. Stroke survivors who chose to participate may have been those who believed that recovery was ongoing and that recovery could be enhanced with effort, whereas those who chose not to participate may have been those who felt recovery was over.

To use a stroke survivor lens and resist using a biomedical lens through which to review the literature was a strength of this review. Yet, the lens that was provided by the *Living My Life* framework emerged from the views of stroke survivors from one remote region of Australia and was co-constructed with two of the authors of this review (SJ, RB), bringing both authenticity and potential bias to the analytical lens. Hence, it is important to recognise that the lens used may be one of many possible stroke survivor lenses. Even so, the insights gained may be relevant to health professionals working with stroke survivors in other remote parts of Australia and other countries with similar geographical and cultural diversity (e.g., Canada).

Conclusion

The findings of this literature review highlight the stroke survivors' view that recovering from stroke is about being able to live their life, in their rural or remote location, despite the challenges they face such as distance to specialist services, limited network connectivity, harsh weather and more. To do so, they want to be supported in ways that work for them in their rural and remote location, which requires understanding the ever-changing strengths and challenges each stroke survivor experiences within their world and working with them to help them find their own way through. Further research is required to tailor services to support stroke survivors to exploit their recovery potential in their unique rural and remote world.

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Conflict of interest

The authors have no conflict of interest to declare.

Author contributions

The review was conceived by SJ and RB. Screening, and quality appraisal were conducted by SJ and BN. SJ analysed data with support from RB and BN. SJ prepared the manuscript, with revisions and final approval by RB and BN.

Data availability statement

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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