Taylor & Francis
Taylor & Francis Group

Disability and Rehabilitation

ISSN: (Print) (Online) Journal homepage: https://www.tandfonline.com/loi/idre20

Community reintegration post-stroke in New Zealand: understanding the experiences of stroke survivors in the lower South Island

Ines Becker, Morake Douglas Maleka, Aimee Stewart, Matthew Jenkins & Leigh Hale

To cite this article: Ines Becker, Morake Douglas Maleka, Aimee Stewart, Matthew Jenkins & Leigh Hale (2022) Community reintegration post-stroke in New Zealand: understanding the experiences of stroke survivors in the lower South Island, Disability and Rehabilitation, 44:12, 2815-2822, DOI: 10.1080/09638288.2020.1839792

To link to this article: https://doi.org/10.1080/09638288.2020.1839792

DISABILITY AND REHABILITATION
2022, VOL. 44, NO. 12, 2815–2822
https://doi.org/10.1080/09638288.2020.1839792

Taylor & Francis
Taylor & Francis Group

RESEARCH PAPER

Community reintegration post-stroke in New Zealand: understanding the experiences of stroke survivors in the lower South Island

Ines Becker[a], Morake Douglas Maleka[b], Aimee Stewart[b], Matthew Jenkins[a] and Leigh Hale[a]

[a]Centre for Physiotherapy Research, School of Physiotherapy, University of Otago, Dunedin, New Zealand; [b]Physiotherapy Department, School of Therapeutic Sciences, Faculty of Health Sciences, University of Witwatersrand, Johannesburg, South Africa

ABSTRACT

Purpose: Optimal community reintegration is a key rehabilitation outcome post-stroke. This concept has been investigated in many countries but not qualitatively in New Zealand. We explored perceptions about community reintegration of stroke survivors living in southern New Zealand.

Method: Qualitative interviews were used to collect data. Recruitment was via local stroke clubs, inviting adult stroke survivors (stroke duration > six months, any severity or type) living in the lower South Island. Data were analysed using the General Inductive Approach.

Results: Eight stroke survivors (two female, six males; age range 50–80 years, mean 66 years (SD = 12); mean time since stroke 6.5 (SD = 4) years) participated. Participants' perceptions of what is integral to reintegration into their community were shaped by four themes, namely: (1) personal relationships, (2) re-establishing normality (old and new), (3) purpose in life, and (4) independence.

Conclusions: Stroke survivors in New Zealand hold many similar perceptions about optimal community reintegration with those living elsewhere. Key to successful community reintegration, irrespective of geography, culture and ethnicity, appears to be involvement in meaningful activities, and reduced reliance on others whilst maintaining or developing good social relationships. These fundamental components are then contextually nuanced by what is meaningful and important to the individual.

➤ IMPLICATIONS FOR REHABILITATION

- Optimal community reintegration post-stroke is arguably the key goal of rehabilitation, and thus should be enabled and measured.
- To optimise community reintegration post-stroke, rehabilitation should focus on enabling stroke survivors' social relationships, independent community mobility, and engagement in meaningful activities.
- Optimal community reintegration post-stroke is however contextual. Rehabilitation professionals must understand what each patient considers successful community reintegration to be for them and tailor their rehabilitation accordingly.

ARTICLE HISTORY
Received 13 February 2020
Revised 15 October 2020
Accepted 17 October 2020

KEYWORDS
Stroke; community reintegration; rehabilitation; qualitative; New Zealand

Introduction

Stroke is a major cause of death and disability around the world [1], including in New Zealand (NZ), which has a hospital admission rate of 185/100 000 [2] and about 32 000 people currently living with a stroke induced disability [3]. Experiencing a stroke is a life-changing event, leaving potentially long-lasting physical, functional, psychological and cognitive impairments in its wake. A review conducted by Walsh et al. showed that over 75% of stroke survivors report reduced mobility, fatigue, concentration and emotional difficulties post-stroke [4]. Rehabilitation from stroke is thus a complex process to enable holistic functional recovery. One important marker of successful stroke rehabilitation is optimal community reintegration [5].

Dijkers referred to community reintegration as being involved in the day-to-day life of the family and the community, taking on usual roles and responsibilities, and actively engaging with and contributing to society [6]. Community reintegration was similarly characterised by McColl et al. as aiming to include "relationships with others, independence in one's living situation, and activities to fill one's life" (p. 16) [7]. The importance of community reintegration post-stroke was highlighted by Bhogal et al., who stated that stroke impacts not only the patients in terms of issues around self-concept, identity, and reduced capacity, but also those immediately surrounding them (for example, caregiver burden and depression, family strain due to work, transportation, socialisation and role-change issues) [8].

A growing body of qualitative research has developed around community reintegration post-stroke, highlighting the complexity and contextual nature of community reintegration post-stroke and what successful integration may mean. For example, Walsh et al. [9] synthesised the results from 18 qualitative interview studies in this domain undertaken across several high income countries (UK, Sweden, Ireland, Canada, USA). Walsh et al. developed four overarching themes that describe what supports optimal community reintegration: (i) the primary effects of stroke; (ii) personal (e.g., perseverance, emotional challenge, meaningful activities, adaptability of the individual); (iii) social (e.g., sense of

CONTACT Leigh Hale leigh.hale@otago.ac.nz Centre for Health, Activity, and Rehabilitation Research, School of Physiotherapy, University of Otago, Dunedin, New Zealand

belonging versus perceived stigmatisation, support and dependency; environmental); and (iv) relationships with professionals (e.g., being supported versus abandoned) [9]. A subsequent focus group study conducted in Scotland identified use and enjoyment of the environment (for example, theatres, cafes or just being out the home) enabled community reintegration, interaction with others, and participation in social and recreational activities [10]. In a distinctly different world region, a qualitative study of the barriers to satisfactory community reintegration post-stroke from the perspective of Black stroke survivors from a poor urban socioeconomic area in South Africa [11] were reported as: (i) Loss of, or restriction in, community mobility, (ii) Social isolation, (iii) Role reversal and loss of personal identity within the family and community, (iv) Loss of role within family and community, (v) Loss of meaningful activities of daily living, (vi) Threat to livelihood (sustainable/productive livelihood), and (vii) Loss of hope. An exploration of the lived experience of 30 Latino stroke survivors living in New York identified similar barriers to community reintegration including challenges in maintaining a positive self-concept, valued identities and roles; stigmatisation due to impairments; restricted travel and access to valued activities leading to becoming house bound and socially isolated [12]. A Malawian study of stroke survivors found key social barriers to community reintegration to be relationship changes with relatives, friends and employers, and the physical barriers to include poor terrain, long distances to places of interest, and inaccessible structures [13].

Whilst the above qualitative studies identified many commonalities deemed important to stroke survivors to facilitate community reintegration post-stroke, there appeared to be geographical nuances. Given the complexities of community reintegration post-stroke and the highly contextual nature of "successful" reintegration [11], a number of outcome measures that include assessment of community reintegration post-stroke have been developed. Specifically for stroke these include the Stroke Impact Scale [14], a measure of health-related quality of life, which includes 59 items assessing eight domains with one domain more specific to reintegration, and the Subjective Index of Physical and Social Outcome [15] which has 10 questions focusing on an individual's ability to function physically and socially to his/her own satisfaction. A far more detailed measure developed for community reintegration of Black South Africans stroke survivors living in low socioeconomic areas, the Maleka Stroke Community Reintegration Measure, has an urban version (40 questions over eight domains) and a rural version (34 questions over six domains). Many of these questions are of specific contextual relevance, for example, attending traditional events and fulfilling traditional roles, being able to collect water from a river, and being able to clean your house and yard (including sweeping and "mudding" the floors with cow dung) [16,17].

Such questionnaires led our group to deliberate on the measurement of community reintegration post-stroke and if complex questionnaires are required, or if there were core components of optimal community reintegration post-stroke that were universally common for all humans irrespective of culture, ethnicity and geography, and whether these core components could comprise a globally relevant measure. As a first step to address this consideration we decided to compare the perceptions of two disparate stroke populations with regards to their reintegration into their communities.

Qualitative studies have explored community reintegration post-stroke in many countries, such as England, Ireland, Scotland, Sweden, Canada, USA, and South Africa [8–13], no study has however considered the perceptions of New Zealander stroke survivors. The only study investigating community reintegration in New Zealand was a longitudinal study in the Auckland region of 255 adults post-stroke. This study found that age, employment status and education levels at baseline could significantly predict community integration levels (measured with the Community Integration Questionnaire) four years post stroke [18].

The context of stroke survivors living in the southern region of the South Island in New Zealand could be considered completely different to stroke survivors of our previous work with Black people with stroke living in low socioeconomic rural and urban areas of South Africa. The southern region of the South Island, an area sized 65 608km^2, is more sparsely populated and predominately Caucasian (329 890 people; 88% Pākehā (non-Māori), 10% Māori, 2% Pacifica). The Southern region urban areas are small and range in population from 1200 to 104 500, with an economy based mainly on agriculture, education, manufacturing, publishing and technology-based industries. This area has a high proportion of people in the least deprived section of the population and a low proportion in the most deprived section [19]. This contextual difference allows for an interesting contrast to our previous work in the exploration of stroke survivor perceptions of community reintegration.

The aim of our study was therefore to explore the perceptions of stroke survivors living in the southern region of the South Island of New Zealand with regards to their reintegration into their communities in order to build on our previous similar study based in South Africa.

Method

Design

The methodological framework that informed this study was based on the General Inductive Approach. This specific design is similar to Grounded Theory for the analysis of qualitative data [20]. This approach is considered more "straightforward" compared to other more commonly used qualitative methods, because data analysis is conducted with a specific objective in mind [20]. In this study, semi-structured interviews were analysed through a lens that focused on what stroke survivors perceived as being integral to being reintegrated into their community after stroke. The research team included four physiotherapists with experience in neurorehabilitation, qualitative and community reintegration research and one physical activity researcher with experience in qualitative and behaviour change research. Team members were from diverse nationalities (New Zealand, South African, British and German). One team member was of Tswana (Black South African ethnic group) descent and the other four were of Caucasian descent.

Recruitment and ethical approval

Recruitment was initiated via social media platforms associated with the Stroke Foundation of New Zealand and via group presentations at "stroke clubs" in communities in the lower South Island of New Zealand. As we were interested in a wide range of perspectives, we had broad inclusion criteria, namely, adults who had experienced a stroke (of any severity, type) of six months or longer and who lived in urban areas (populations of 1000 or more) [21] or rural centres (populations of 300 to 999) [22] in the southern region of the South Island. Participants were excluded if they were unable to participate in semi-structured interviews (e.g., the presence of severe aphasia). Interested people contacted the first author by telephone. Participants gave written informed

consent before data collection began. Ethical approval for this study was granted by the University of Otago Ethics Committee (Reference number 12/027).

Data collection

Data were collected between April and September 2012. All interviews were conducted in participants' homes. Two members of the research team (LH, MDM) conducted the first four interviews. One author (LH) then conducted the remaining interviews until data saturation was reached, a point where no new findings or observations were forthcoming in the interviews [23]. With the stroke survivor's permission, partners of the stroke survivors' could be present during the interview. All interviews were audio-recorded with participants' consent. We used broad open ended exploratory questions, similar to those we have previously used, to enable participants to freely talk about their life after stroke, allowing them to focus on what they considered important. The key questions used were: (1) What has life been like for you after your stroke? (2) How do you occupy your days? (3) Before the stroke, what hobbies and activities did you enjoy? (4) Do you think you have settled back well into your community? (5) What would help you settle better?

In addition to the audio-recording, the interviewers noted any relevant non-verbal communication occurring during the interview, and for the first four interviews conducted together, immediately post-interview we discussed and made note of important thoughts or considerations.

Data analysis

The audio-recordings were transcribed verbatim by a professional transcription service. Participants were provided with pseudonyms to provide anonymity. Data were analysed using the General Inductive Approach [20]. This approach allows for the analysis to be deductively guided by the research objectives and inductively by multiple readings and interpretations of the raw data. The underlying assumptions of the General Inductive Theory enabled us then to caste a specific analytical lens on our data, teasing out what participants considered important to community reintegration. An author (IB), who was not involved in the interviewing process or in our previous study, initially analysed the data. In line with the General Inductive Approach, IB read each transcript and listened to each audio recording multiple times. Text that related to the study's aims of exploring perceptions of community reintegration were identified and coded. Using a process of independent parallel coding [20], a second author (LH) separately coded four interviews. IB and LH then discussed their individual coding to reach a consensus agreement of the common codes. The remaining interviews were then coded by IB using these common codes, allowing for the incorporation of any new identified codes. With further discussion by IB and LH, multiple codes were reduced into categories and then into potential themes. The resulting themes were then discussed amongst four study team members (IB, LH, MDM and AS) and the coding clarified until consensus was reached and themes finalised. Once themes were finalised, quotes that illustrated the essence of the themes were identified. In addition, and where appropriate, non-verbal communication and post-interview discussions recorded by the interviewers was incorporated into the analysis.

Findings

Participants

Twelve participants volunteered for the study. After interviewing the first eight participants data saturation was reached and interviewing ceased. Of the eight participants interviewed (two females, six males; age: mean 66 (SD = 12), range 50–80 years), seven lived in main urban areas (population ranging from 90 000 to 230 000) and one lived in a rural centre (population of 500). The mean time since first stroke was 6.5 years (SD = 4). From the ethnicity data, seven participants were Pākehā (New Zealand European) and one was Māori. One participant lived on her own in a residential care unit, all her family residing overseas. The other seven participants lived with their spouses, one participant's wife was in a motorised wheelchair. All but one participant had retired. Previous occupations included fisherman, business owner, artist and farmer. One participant had part-time employment running a competition from home and another participant had taken over the housework to enable his wife to return to work. Two participants were dependent on wheelchairs, the other six were able to walk independently with or without walking sticks. Five attended a local stroke club and none was currently receiving rehabilitation.

All interviews lasted between 30 and 60 min. In half the interviews, partners of the stroke survivors' were present during the interview but did not participate. On one occasion, a wife of a stroke survivor participated in an interview along with her husband.

Themes

Participants' perceptions of what is integral to reintegration into their community were shaped by four themes: (1) personal relationships, (2) re-establishing normality (old and new), (3) purpose in life, and (4) independence. These themes are presented below, illustrated with participant quotes. Names of participants for each quote are pseudonyms. Table 1 shows participant age and time since stroke relative to the group mean.

Personal relationships

Being in contact with other people within supportive and caring relationships was perceived as an essential aspect of post-stroke rehabilitation and community reintegration. Relationships were formed with a wide range of people, from partners, family members, and friends, to healthcare professionals and carers. Regardless of the relationship type, participants consistently expressed that they wanted to be respected for who they were, and what they experienced as their new identity, that of being a survivor of stroke. Although relationships were critical to community reintegration, they were described in different nuances:

Table 1. Participant age and time since stroke relative to group mean.

Participant pseudonym	Age relative to group mean of 66 years	Time since stroke relative to group mean of 6.5 years
Joyce	Above	Below
Anthony	Below	Above
Irene	Above	Above
James	Below	Below
Thomas	Below	Above
Donald	Above	Below
Roger	Above	Above
Robert	Above	Above

supportive relationships, missing relationships, negative experienced relationships, and relationship with self.

Supportive relationships

Most participants accentuated that, above all, relationships needed to be supportive and caring. Joyce highlighted this in relation to her osteopath: "She is wonderful; she gives me a really loving treatment," while Anthony emphasised the caring support of one nurse in particular: "She was a really nice nurse to go on walks with." Irene referred to her granddaughter: "I have my granddaughter, [who] is very supportive" and James mentioned the role of his friends in helping him adhere to physical activity: "I've maintained a regular walking regime, and I've got tremendous enjoyment out of that; I have been helped significantly by my friends."

Some survivors insisted that existing relationships needed to be maintained, with Irene describing the importance of "nurturing [present] relationships." This was reinforced by Thomas, who stressed that the support from partners needed to be valued and not taken for granted: "I was very fortunate because if it weren't for my wife, I would need to be in a home permanently … I don't know whether I could stomach that."

Missing relationships

In contrast to the presence of supportive relationships, unsurprisingly the loss of relationships was offered as a barrier to community reintegration. Some unique (e.g., parent-child) relationships, were particularly missed when they were not available. For example, Irene's children had all moved away from her home town, leaving her living on her own in a residential rest home, which reduced her capacity to reintegrate into her community, as Irene described: "Most people have got some family … mine all being away doesn't help matters."

Negative experiences with relationships

Relationships were not always perceived as supportive and positive. Donald for example reported frustration at the number of carers and their time schedule that needed to be juggled. As he explained: "We've got caregivers coming in here. They drive you nuts … Because there's too many people coming in."

Some relationships between the stroke survivor and their partners shifted, with the spouse or key carer taking on a more negative and sometimes domineering role, such as being over-supportive or over-protective. This was not always expressed as such in words, but could be observed during the interviews in the way the survivor and his/her partner related to each other during the interview. For example, during one interview the wife of a survivor (James) continuously answered questions that were directed toward her husband and did not allow him to answer questions himself.

Some participants perceived that support from health professionals was difficult in small towns. For example, Joyce expressed their concerns about difficulties in getting support from health professionals in her hometown:

> You do struggle to get someone around here … … she got me doing those [exercises], I just do five a few times a day but then one day she said to me, I am going overseas now for six weeks, and I said is someone else going to take your place and she said no …

Irene reported that she felt health professionals needed to be more mindful about how they interacted with stroke survivors during treatment sessions. As Irene described:

> After you have had a stroke and you are concentrating on doing something, people want to talk to you while you are doing it [rehabilitation activity], not waiting until you have got to the end … You are wanting to go but they are still trying to talk to you … [they] don't realise that it takes so much effort from your side to concentrate on what you are doing and not be distracted by lots of messages.

Relationship to self

Participants varied in their relationship to themselves. Some participants conveyed a degree of self-respect and had a positive and life-affirming outlook. For example, Thomas expressed: "You have to laugh at everything. I've been depressed a couple of times, but generally I laugh at everything that comes my way." In contrast, Roger conveyed an indifference toward his post-stroke life during the interview, communicated by his low mood and monotonous voice during the interview, and also reflected in his opinion about celebrating his birthday ("Nothing to celebrate really") and his perception of reduced autonomy following his stroke: "When you have a stroke you don't get to say what to do."

Re-establishing normality (old and new)

The theme "back to normality" was shaped by stroke survivors' longing for a certain normality in their life, away from focusing on the functional effects that their stroke had on them. This could mean going back to old known life activities and picking up activities that they were doing before having had a stroke (*old normality*), or establishing new patterns of living and joining in new activities adapted to the new situation (*new normality*). In both cases stroke survivors aimed to create again a pattern and purpose in their life, and to accept changes that were inevitable due to the new situation after having had a stroke. For example, Joyce described a drive through the countryside as "normalising" after her stroke, something she had enjoyed before her stroke (*old normality*): "I felt it was so normalising to go out to [name of town] and look at the people and see the trees on the way and the flowers and everything like that, that always takes me out." Similarly, returning home from hospital or a rehabilitation unit and being back in a known environment was important for Joyce on her way to feeling reintegrated into her community, in spite of her still being unable to walk:

> When I came home, I looked at these walls and I thought "oh god they are so wonderful, the curtains are so wonderful" … Hospitals are so bland … I am not bland, we are not bland.

On the other hand, Donald acknowledged his new situation and accepted his new normality: "I just carried on with life … I haven't given up on not being able to carry on with life." However, accepting a *new normality* could also lead to frustration and disappointment. In this situation, participants were mainly confronted with the fact that certain things in their lives had to change after their stroke. Donald expressed this when asked about whether he was still able to drive:

> LTSA [Land Transport Safety Authority] took my licence off me and said you can never have it back because [the rehabilitation unit] in [name of town] let LTSA know that I couldn't drive again … It made me feel pretty mad when it happened but reality is reality.

Thomas spoke of how he had given up on returning to university to complete a doctorate after his stroke, resigning himself to a new reality: "I was two years into a PhD when my stroke struck, and I was unable to complete it. I am getting on now. I'm nearly sixty, I probably won't be able to return to university."

Purpose in life

Participants spoke of how having a purpose in life brought meaning back into their lives, which lead to them being more positive and life-affirming. Having a purpose in life was perceived by stroke survivors as feeling valued and appreciated in what they could offer. Also, a feeling of self-worth and being able to contribute was felt as purposeful:

> I, enjoy that contact and being part of it, so ah, I have a past colleague who going to come around and ask me, he's taking up a new job in Dunedin and ask me about work and I always get a bit of pleasure out of that … can still use and ask for advice …. That's what it is, its feeling valued as if I've done something a bit positive … (James)

For some, this was achieved by connecting to their partners, offering their advice to other stroke survivors or being actively involved in a club or classes. For example, most participants regularly attended Stroke Club, where they would discuss their experiences with stroke or rehabilitation: as Joyce expressed "That is what made me tell it because I thought it may help."

Thomas described how, although stroke had changed the parameters of what he could do, this did not stop him from doing things he felt were important to him:

> I still have a part-time job … I run a … …. competition which brings in fifteen thousand dollars a year, and that competition I do most of the work by computer and my wife does the physical work like, stacking the envelopes et cetera. My life is drastically changed as a result of the stroke. But still I still manage to do things and lead a full-on life.

Other participants met their aim of getting better functionally with determination, enabling them to participate in old hobbies as a purpose in life after their stroke. For example, when Robert was asked what motivates him to keep trying, he stated: "To try and get the use of this hand or the arm as much as I can so I get back on the golf course."

Independence

Stroke survivors perceived being independent after their stroke as an aspect important to community reintegration. Independence allowed participants to socialise again, and to decide what and when to do things on their own. Independence also gave participants a sense of freedom, for example, James and his wife discussed the frustration experienced at not being able to drive a car, thus taking away a sense of his independence:

> Wife: When it came to driving a car, this was your biggest frustration wasn't it, because it took away the independence.
>
> James: Yeah

Thus, living a fully independent life could be hindered by physical and functional impairments, for example being able to walk or drive. Joyce reiterated this point: "I couldn't get into the car and I thought it was outrageous at the time because I want to do everything, and I want to be better yesterday." For other participants, external restrictions made independence difficult to attain. For example, rules in residential rest homes impeded participants' sense of independence: "I want to go out or something I can't just suddenly decide I am going to town" (Irene).

Some themes developed in the current data set were clearly interconnected or overlapping. For example, Roger discussed going back to playing bowls as a community reintegration experience. This represents both a return to *old normality* and a reconnection to a *purpose in his life* following his stroke. This also included the opportunity to socialise with friends when playing bowls (*personal relationships*). However, he felt that his inability to walk stopped him from returning to bowls independently. Robert stated:

> Interviewer: What sort of things would show you that you have reintegrated back to your community?
>
> Robert: When I get back playing bowls, that sort of thing.
>
> Interviewer: And why aren't you able to bowl now?
>
> Robert: My walking ability.

Discussion

In understanding what is integral to reintegration into their community for stroke survivors living in the southern region of the South Island of New Zealand, four important themes emerged: (1) personal relationships, (2) re-establishing normality (old and new), (3) purpose in life, and (4) independence. These themes are discussed below relative to findings of our previous study and to those from other parts of the world.

Personal relationships and community reintegration, a dominant theme in our study, has repeatedly been emphasised as important in the literature. Supportive social relationships have been shown to have a profound positive influence not only on reintegration, but also on functional recovery from stroke and overall quality of life [21,24]. Conversely, "missing relationships," as described by our participants, has a detrimental impact. Maleka et al. [11] alluded to missing relationships when they identified social isolation as a barrier to community reintegration post-stroke. Specifically, in the Maleka et al. study [11], isolation was described in terms of the deterioration of familial and social relationships, which occurred, for their participants, primarily as a result of restricted mobility. Participants in this rural South African study, where environmental constraints add to mobility limitations, expressed frustration regarding their inability to move around in their homes and in their communities, preventing them from participating in community events, core to the fabric of their society. These factors were likewise expressed in a Malawian study, where environmental constraints caused mobility restrictions, resulting in isolation [13]. Studies undertaken in high income countries in the UK, Sweden, Ireland, Canada, and USA also described how social isolation negatively impacts on community reintegration and individuals' psychological wellbeing and the importance of relationships with others [9,12,25]. It was noteworthy in our study that participants did not refer directly to loss of relationships or social isolation. Reasons for this may include that seven participants lived with their spouses and one participant, without nearby family, lived in residential care. It may also be a reflection of our recruitment strategy, which was predominantly via Stroke Clubs, entities that by their nature promote socialisation.

Our study identified that relationships can also have a negative impact on community reintegration, with relationships with others not always perceived as supportive and positive. Our participants spoke of how home-based formal carers and health professionals can cause them to feel stressed. This is an interesting finding as most studies, whilst reporting the adverse impacts of relationships, link this to the anxiety of stroke survivors about their over-reliance on support from others and perceptions of being a burden [8]. Or, as Erikson et al. (p. 831) [26] put it: "the burden of burden," encapsulating the burden experienced by people with stroke causing burden for other. Maleka et al. found this too, with

some stroke survivors reporting their distress at the thought of being an encumbrance to their children [11].

Clearly, social relationships are key to optimal reintegration into the community, which perhaps seems obvious considering the inherent social aspects in this endeavour. In their systematic review, Kruithof et al. [27] highlight the need to understand the role of social support in post-stroke rehabilitation, specifically in terms of quality of life. Across 11 studies undertaken in a range of countries (Australia, Belgium, Canada, China, Nigeria, Poland, Taiwan, Turkey, UK, and USA), the authors demonstrated strong associations between stroke survivors' health-related quality of life and perceived social support. However, the authors also noted that the studies under review often failed to distinguish clearly amongst the different types of social support. Considering the range of relationships experienced by participants and the relatively small number of studies reviewed, Kruithof et al. [27] advised that further research was required to understand the true influence of social relationships on post-stroke rehabilitation.

Re-establishing normality is again not a new finding, it has been shown to be important in previous research undertaken in Canada, which reported the theme of "Getting back to real living" [28]. For many stroke survivors, a return to work may help re-establish "old" normality. Working contributes to life satisfaction, wellbeing, self-worth and social identity, giving an opportunity to maintain independence as far as physically possible with the income generated through employment; important findings reported in both South African and Australian studies [11,29]. For many individuals, employment represents a key source of purpose in life [30]. Further loss of work, a theme named "threat to livelihood" within the Maleka et al. study [11], illustrated the great impact of a low socioeconomic status on a survivors' life, particularly addressing the importance of having basic needs met and being able to provide for oneself. In our study, as most participants were retired, re-establishing normality was mostly focused on returning to old interests or activities, although for some it was about new normality, finding new activities or acceptance of reality. The latter a prominent theme, in the aforementioned Canadian study, the authors called "Adjusting my expectations" [28].

A purpose in life and having activities directed towards this purpose was identified by our participants as an important factor in community reintegration. Within the Maleka et al. study [11], a prominent theme related to finding purpose in life was "the loss of meaningful activities of daily living." Under this theme, participants report the loss of meaningful purpose, particularly in relation to their interactions with others in the community (e.g., attending churches and social clubs), as being a barrier to reintegration. Meaningful activities were also discussed by participants in the Wood et al. qualitative study of community reintegration post-stroke in Canada [28], who specifically described how meaningful roles, activities and relationships are fundamental to finding fulfilment and enjoyment in daily living. Finding a purpose in life aligns with finding meaningful ways to occupy one's time, which includes contributing socially and economically to their communities [30].

To our participants, being independent after their stroke enabled socialisation and a sense of freedom. Similar to the Maleka et al. [11] participants who linked mobility limitations with social isolation, our participants associated independence with mobility enablement. The increasing dependence on others means living in line with other peoples' schedules, rather than one's own, an unsatisfactory state of being for many [31–33].

The importance of community reintegration is recognised by current New Zealand clinical guidelines for stroke rehabilitation: "Rehabilitation is concerned not only with an individual's improvements at an impairment level, but also with facilitating the resumption or development of meaningful life roles and reintegration into their community. These issues are considered by people with stroke to be vital to their recovery." (p. 44) [34]. It could be argued that the participants in our study focused on three areas to enable their community reintegration. Firstly, the development and maintenance of supportive, yet non-dependent, social relationships; secondly, the act of finding some means of mobility, whether in the form of walking or driving, which facilitates independence and, in some cases, a return to some sense of normality. Finally, the role of employment or other meaningful activities provide stroke survivors with a purpose in life. In addition, employment enabled financial independence by providing a source of income. This reiterates what other studies have included in their definition of community reintegration, namely, involvement in meaningful activities, independence and relationships with others [35].

It could be argued that community reintegration is highly contextualised, what one person deems to be successful community reintegration will differ from another's perspective of what is important [16,17]. For people living in a culture based on communal and family importance, contribution to the wider family and community life is essential; whereas for those living in a culture based on individual independence and reduced reliance on others, not being dependent on anyone is also highly valued [36], and a lack of independence may lead to isolation [37]. Yet, in discussing our findings relative to those reported elsewhere in the world, it would seem that fundamental to community reintegration is involvement in meaningful activities, reduced reliance on others whilst maintaining or developing good social relationships. These fundamental aspects are then nuanced by what is meaningful and important to the individual based on their context.

These fundamental similarities in community reintegration across countries beg the question of whether we need detailed contextualised questionnaires such as the Maleka Stroke Community Reintegration Measure [16,17] or the Subjective Index of Physical and Social Outcome [15], to enable universal comparisons, or do we just need to focus on a simple rating of these three key aspects. Underpinning such a simple generic measure could then be the more detailed assessment to guide appropriate rehabilitation specific to contextual community reintegration.

Limitations and future research suggestions

We recognise that this study cannot stand as a representation of community reintegration post-stroke in New Zealand as a whole, due to the fact that seven of eight participants were of Pākehā/NZ European descent and lived in the southern regions of the South Island. For example, considering the familial cultural practices inherent in Māori and Pacific Island cultures in New Zealand, we would expect differences in the progression of community reintegration amongst these populations. Thus, given our study had a very specific geographic cohort, its findings cannot be transferred to the whole New Zealand population.

To this end future research should explore what different cultural groups across New Zealand perceive as successful community reintegration. For example, how do the familial/whānau and general community support structures differ across ethnicities? Are there any issues pertaining to social stigma and social isolation that are particularly prevalent within different ethnic

communities? Importantly, what effect do any such differences have on community reintegration?

The findings from our study come exclusively from the perspectives of stroke survivors. Understanding how successful community reintegration can be attained also requires consultation with service providers. For example, there is likely a conflict of priorities in many instances, and so understanding the perspectives of service providers is vital in obtaining a clear and broader picture of how community reintegration can occur in real world settings. Further limitations to this study were that most participants attended a Stroke Club, and may be different from other individuals who do not receive similar formal support from others. In addition, caregivers were permitted to attend the interview, and as mentioned, in some cases intervened in the interview with the stroke survivors potentially impacting on what the stroke survivor participants might say.

A final gap in the current research is regarding the carers' perspective, in particular family carers. Stroke events can bring about sudden and drastic changes in roles and relationship dynamics, in addition to potentially increased burden of care. We know that in other conditions such as dementia, the burden of care placed on family members can be difficult to shoulder and can have consequences for physical and psychological wellbeing, as well as the capacity of familial carers to provide adequate care [38]. In the context of stroke, what are the consequences of suddenly becoming a carer for a family member? How can we support these carers in the work that they do? Xu et al. [39] identified in a Singaporean based study that carers of stroke survivors considered reducing falls risk in community-dwelling stroke survivors more important than promoting their community participation. These findings lead to intriguing philosophical dilemmas between stroke survivor autonomy and carer anxiety and protectionism, matters worthy of further enquiry [39]. To extend this notion, how does the wider community (friends, social networks) experience the process of community reintegration by stroke survivors, and how can they be supported? Again, bearing in mind the inherent differences across ethnicities in New Zealand, drawing comparison amongst different familial structures is essential.

Conclusion

We aimed to understand the perceptions of stroke survivors living in the southern regions of New Zealand with regards to their reintegration into their community. Our findings demonstrate that stroke survivors in New Zealand share many similarities in their efforts to reintegrate into the community with those in other nations, including the UK, Canada, Sweden, Ireland, and South Africa. This lead us to contemplate whether key to successful community reintegration, irrespective of geography, culture and ethnicity may be involvement in meaningful activities, and reduced reliance on others whilst maintaining or developing good social relationships. These fundamental elements may then be nuanced by what is meaningful and important to individuals based on their context. Whilst these ideas require further extensive validation, they are, for now, worthy of critical consideration.

Acknowledgements

We acknowledge and thank participants.

Disclosure statement

No potential conflict of interest was reported by the author(s).

References

[1] Norrving B, Kissela B. The global burden of stroke and need for a continuum of care. Neurology. 2013;80(3 Suppl 2):S5–S12.

[2] Ranta A. Projected stroke volumes to provide a 10-year direction for New Zealand stroke services. NZMJ. 2018; 131(1477):15–28.

[3] Stroke Foundation NZ [Internet]. Stroke Foundation NZ – Facts and FAQs. Wellington, NZ. 2019 [cited 2019 Dec 17]. Available from: https://www.stroke.org.nz/facts-and-faqs.

[4] Walsh ME, Galvin R, Loughnane C, et al. Community reintegration and long-term need in the first five years after stroke: results from a national survey. Disabil Rehabil. 2015; 37(20):1834–1838.

[5] Langhorne P, Bernhardt J, Kwakkel G. Stroke rehabilitation. Lancet. 2011;377(9778):1693–1170.

[6] Dijkers M. Community Integration: conceptual issues and measurement approaches in rehabilitation research. Top Spinal Cord Inj Rehabil. 1998;4(1):1–15.

[7] McColl MA, Carlson P, Johnston J, et al. The definition of community integration: perspectives of people with brain injuries. Brain Inj. 1998;12(1):15–30.

[8] Bhogal SK, Teasell RW, Foley NC, et al. Community reintegration after stroke. Top Stroke Rehabil. 2003;10(2): 107–129.

[9] Walsh ME, Galvin R, Loughnane C, et al. Factors associated with community reintegration in the first year after stroke: a qualitative meta-synthesis. Disabil Rehabil. 2015;37(18): 1599–1608.

[10] Brookfield K, Mead G. Physical environments and community reintegration post stroke: qualitative insights from stroke club. Disabil Society. 2016;31(8):1013–1029.

[11] Maleka MD, Steward AS, Hale L. The experiences of living with stroke in low socioeconomic areas of South Africa: the results of a qualitative study. SAJP. 2012;68(3):a21.

[12] Aguirre AN. Community reintegration among Latino stroke survivors: an ecological framework. Dissertation Abstracts International: Section B: The Sciences and Engineering. 2018; 79(9-B(E).

[13] Chimatiro G, Rhoda A. Environmental barriers to reintegration experienced by stroke clients post discharge from a rehabilitation centre in Malawi. SAJP. 2014;70(1):18–23.

[14] Duncan PW, Wallace D, Studenski S, et al. Conceptualization of a new stroke-specific outcome measure: the stroke impact scale. Top Stroke Rehabil. 2001;8(2):19–33.

[15] Trigg R, Wood VA. The Subjective Index of Physical and Social Outcome (SIPSO): a new measure for use with stroke patients. Clin Rehabil. 2000;14(3):288–299.

[16] Morake MD, Stewart AV, Hale LA. The development of a community reintegration outcome measure to assess people with stroke living in low socioeconomic areas. Edorium J Disabil Rehabil. 2017;3:3–24.

[17] Maleka MED. The development of an outcome measure to assess community reintegration after stroke for patients living in poor socioeconomic urban and rural areas of South Africa [thesis]. University of the Witwatersrand, Johannesburg, South Africa; 2010 [cited 2020 Oct 19]. Available from: http://wiredspace.wits.ac.za/xmlui/bitstream/handle/10539/10661/Douglas%20Thesis%20291010.pdf

[18] Dyke I. Community integration in long term stroke survivors [dissertation]. Auckland: Auckland University of Technology; 2018.

[19] Ministry of Health. Population of Southern DHB [Internet]; [cited 2020 Oct 19]. Available from: https://www.health.govt.nz/new-zealand-health-system/my-dhb/southern-dhb/population-southern-dhb
[20] Thomas DR. A General Inductive Approach for analyzing qualitative evaluation data. Amer J Eval. 2006;27(2):237–246.
[21] Glass TA, Matchar DB, Belyea M, et al. Impact of social support on outcome in first stroke. Stroke. 1993;24(1):64–70.
[22] Stats NZ. Urban and rural migration [Internet]; [cited 2020 Oct 19]. Available from: http://archive.stats.govt.nz/browse_for_stats/population/Migration/internal-migration/urban-rural-migration.aspx
[23] Guest G, Bunce A, Johnson L. How many interviews are enough?: An experiment with data saturation and variability. Field Methods. 2006;18(1):59–82.
[24] Lynch EB, Butt Z, Heinemann A, et al. A qualitative study of quality of life after stroke: the importance of social relationships. J Rehabil Med. 2008;40(7):518–523.
[25] Cott CA, Wiles R, Devitt R. Continuity, transition and participation: preparing clients for life in the community post-stroke. Disabil Rehabil. 2007;29(20–21):1566–1574.
[26] Erikson A, Park M, Tham K. Belonging: a qualitative, longitudinal study of what matters for persons after stroke during the one year of rehabilitation. J Rehabil Med. 2010;42(9):831–838.
[27] Kruithof WJ, van Mierlo ML, Visser-Meily JMA, et al. Associations between social support and stroke survivors' health-related quality of life-A systematic review. Patient Educ Couns. 2013;93(2):169–176.
[28] Wood JP, Connelly DM, Maly MR. 'Getting back to real living': a qualitative study of the process of community reintegration after stroke. Clin Rehabil. 2010;24(11):1045–1056.
[29] Wolfenden B, Grace M. Returning to work after stroke: a review. Int J Rehabil Res. 2009;32(2):93–97.
[30] Townsend EA, Polatakjko HJ. Enabling occupation II: advancing an occupational therapy vision for health, well-being, and justice through occupation. Ottawa (ON): CAOT Publications ACE; 2007.
[31] Burton CR. Living with stroke: a phenomenological study. J Adv Nurs. 2000;32(2):301–309.
[32] Gustafsson L, Bootle K. Client and carer experience of transition home from inpatient stroke rehabilitation. Disabil Rehabil. 2013;35(16):1380–1386.
[33] O'Sullivan C, Chard G. An exploration of participation in leisure activities post-stroke. Aust Occup Ther J. 2010;57(3):159–166.
[34] Stroke Foundation of New Zealand and New Zealand Guidelines Group. Clinical Guidelines for Stroke Management 2010. Wellington: Stroke Foundation of New Zealand; 2010.
[35] McColl M. Measuring community integration and social support. In: Law M, Baum C, Dunn W, editors. Measuring occupational performance: supporting best practice in occupational therapy. Thorofare (NJ): SLACK; 2001.
[36] Earley CP. Self or group? Cultural effects of training on self-efficacy and performance. Admin Sci Quart. 1994;39(1):89–117.
[37] Heu LC, van Zomeren M, Hansen N. Lonely alone or lonely together? A cultural-psychological examination of individualism-collectivism and loneliness in five European countries. Pers Soc Psychol Bull. 2019;45(5):780–793.
[38] Hale L, Mayland E, Jenkins M, et al. Constructing normalcy in dementia care: carers' perceptions of their roles and the supports they need. Gerontologist. 2020;60(5):905–915.
[39] Xu T, O'Loughlin K, Clemson L, et al. Developing a falls prevention program for community-dwelling stroke survivors in Singapore: client and caregiver perspectives. Disabil Rehabil. 2019;41(9):1044–1054.