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The journey to recovery: experiences and perceptions of individuals following stroke

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ABSTRACT

Stroke is a common cause of long term disability in New Zealand and can have a large impact on an individual's life. This study aimed to identify and discuss the experiences, perceptions and challenges faced by those living with stroke, to provide health professionals with an insight into the journey to recovery following stroke. Participants were recruited via the New Zealand Stroke Foundation. We used semi-structured interviews to gather data from 11 participants (ten males, one female) aged 49 to 72 years and analysed the data with the General Inductive Approach. Three main themes emerged from our data: a) "Journey to the new me", b) "Moving forward; the highs and the lows", c) "A big learning curve; a whole new life". Data saturation was achieved after nine interviews. The journey to recovery following stroke is a long, personal, and a highly individualised process. Health professionals need to carefully interpret the experiences and perceptions of individuals with stroke in order to gain a better understanding of where they are in their post-stroke recovery. This will ensure individualised and enhanced level of care to promote recovery after stroke.

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INTRODUCTION

Stroke is the third most common cause of death and long term disability in New Zealand following cancer and heart disease (Dyall et al 2008, New Zealand Stroke Foundation 2012). The 2006/2007 New Zealand Health Survey estimated the prevalence of stroke to be over 57 000 (Ministry of Health 2008). One third of the approximate 6000 new patients with stroke each year are left with long term disability (New Zealand Stroke Foundation 2008). As a life changing event, stroke has an enormous impact on the physical, psychological, social, and financial wellbeing of stroke survivors and their families. The high prevalence and the impact of stroke have increased the burden on both the health system and on stroke survivors and their families (New Zealand Stroke Foundation 2012). Improvements in medical technology and a better understanding of stroke pathology, in conjunction with an ageing population, means that increasing survival rates post-stroke has led to an increase in the number of people living with stroke in the community. Often these stroke survivors are left with significant impairments and require assistance with activities of daily living (Kolominsky-Rabas et al 2006). To enable best possible management and rehabilitation, it is important that we, as health professionals, understand stroke from the perspective of the individuals with stroke themselves.

Dissatisfaction with rehabilitation is common following stroke (Langehorne and Pollock 2002, Mayo et al 2002, Pang et al 2007). A 2003 review of 23 qualitative studies identified deficiencies in health service provision as a frequently occurring

long term issue reported by stroke survivors and their informal caregivers living in the community. Stroke survivors indicated that rehabilitation was physically driven and lacked social and psychological inputs (Bendz 2003, McKeivitt et al 2004, Murray et al 2003, Peoples et al 2011). Problems have also been identified with the way in which goals are set with rehabilitation professionals, lack of awareness about local services for support, and inadequate long term contact with the rehabilitation teams (Murray et al 2003). Critical social support systems tend to diminish following discharge from hospital, and this is likely to contribute to the manifestation and persistence of psychosocial issues (Mayo et al 2002, Pang et al 2007).

Research has established that emotional and cognitive functioning, coping strategies, and social support are important contributors to well-being after stroke (Labi et al 1980, Robinson et al 1985, Viitanen et al 1988). Review of stroke management strategies to more adequately address the management of stroke survivors after discharge from hospital is thus required (Wood et al 2010).

The New Zealand Stroke Foundation has listed post-discharge follow-up services and community support for over 65's as a research priority, but post-discharge support is currently not listed as one of the Ministry of Health's targets, nor is it listed as one of their current priorities (New Zealand Stroke Foundation 2012). Thus we can expect to see little increase in the amount and/or quality of post-discharge stroke support in the near future. However, the New Zealand Stroke Foundation's 2010

clinical guidelines for stroke management do recommend that people with stroke be offered training in self-management skills, which includes training in active problem-solving and individual goal setting (Stroke Foundation of New Zealand and New Zealand Guidelines Group 2010).

There is a growing base of evidence to suggest that self-efficacy plays a substantial role in the improvement of management of long-term conditions, including stroke (Jones 2006, Korpershoek et al 2011, Marks and Allegrante 2005, Resnick 2002). Self-efficacy programmes help people with chronic disability manage their life roles and have been seen to improve psychosocial outcomes (Marks and Allegrante 2005). For people living with stroke, self-efficacy is positively associated with mobility, activities of daily living, and quality of life, and negatively associated with depression (Robinson-Smith et al 2000). To enable the development of resources to facilitate self-efficacy and self-management for stroke survivors in the community, a comprehensive understanding of the role of self-efficacy and self-management in improving health outcomes of patients living with stroke in the community is required.

We interviewed people living with stroke in the community to gain an insight into how they viewed their abilities to cope with new challenges arising from their stroke. We were interested to see if self-management would emerge as a theme. Our purpose was to gather stories of life after stroke and the challenges faced by those living with stroke in order to gain insight into what helps and hinders stroke survivors through each step of their journey. This paper reports the findings of these interviews

METHOD

Participants and Recruitment

Recruitment was via the Stroke Foundation in Canterbury and Otago who informed their members of the study, and invited members who were interested to contact the researchers. Potential participants were then provided with additional written information about the study and written consent was obtained from those who wished to be included in the study. Ethical approval for the study was gained from the University of Otago ethics committee. The inclusion criteria were that participants had to have had a stroke, be living in the community, and be able to participate in an interview using some form of communication, not necessarily verbal.

Data collection

Participants were interviewed by one or two researchers at their place of residence. When there were two researchers, one researcher took the lead in guiding the interview whilst the other researcher moderated, observed non-verbal behaviour and recorded field notes.

A semi-structured interview process was used to allow flexibility and opportunities for new questions to be brought up during the interview where appropriate. Interviews were audio-recorded. If participants had aphasia, interviews were conducted via notation and interpretation of body language, answer to interview questions written onto a whiteboard, and through questions being answered on the participant's behalf by his/her spouse. In every case where the spouse answered a question, the participant was then asked by the interviewer to indicate whether he/she agreed with the answer from his/her spouse.

The duration of each interview was typically 45 minutes.

Participants were initially asked about their life since stroke and what they have done to help themselves. Researchers encouraged participants to elaborate on this theme with prompting as necessary. We avoided using leading questions although "Yes/No questions" were necessary for participants with more severe aphasia. Five questions were developed by the research team based on the study objectives, as a rough guideline for the interview (Table 1).

Demographic information collected during the interview process

Table 1: Guideline questions

- "Tell us about your life since your stroke and what you have done to help yourself."
- "What are the challenges you have faced and how have you managed them?"
- "How have you helped yourself improve function and quality of life?"
- "How did you find the hospital experience and support after discharge?"
- "What advice would you give to someone else who has had a stroke?"

included the participant's age, sex, ethnicity, time since stroke, and main impairments as a result of stroke.

Data analysis

The audio recordings were transcribed verbatim by two researchers and checked against the audio-recordings. We used the General Inductive Approach as described by Thomas (2006) to analyse data. This process included condensing the raw data into codes and allowing common themes to emerge from the analysis that answered the study objectives. The coding was carried out using an independent parallel coding method in which two coders read through each transcript individually and developed independent sets of codes. These two sets of codes were then merged into a combined set via discussion between the two coders. If overlap of coding between researchers was low, further analysis and discussion took place to develop a more robust set of codes. Codes were assembled in a table as they emerged, and definitions of codes were discussed and agreed on by all researchers to ensure consistency of coding. Relevant raw text was assigned to each code in the form of direct quotes. As new codes emerged with analysis of further interviews, transcripts were reread to ensure that all raw data were included in any new codes.

Once all transcripts had been obtained and codes extracted, overarching themes were identified and defined through rereading of coded raw text and discussion between researchers. In order to check the unambiguity of the developed themes, an independent coder was given the final themes and their descriptions. A transcript was given to the independent coder who was asked to code the interview into the themes. A check was then made to assess the extent to which the raw text sections coded by the independent coder overlapped with the raw text sections coded by the researchers.

Once themes were finalised and placed in tables with quotes from the raw text assigned to each theme, a summary of the developed themes was sent to each participant as a stakeholder

check. Participants were invited to comment on whether the themes and outcomes described related to their personal experiences, and to share any additional information they wanted. No feedback was received.

Findings

The sample population comprised 11 participants who had survived mild to severe strokes and were now living in the community (Table 2). There was one woman and ten men with ages ranging from 49 to 72 (mean 58.9 years). Two participants were of Māori ethnicity and nine were New Zealand European. Data saturation was reached following the ninth interview and a further two interviews were completed to confirm this. Participants presented with a wide range of impairment; two participants had aphasia.

Table 2: Participant demographic data

Participant (pseudonym)	Age	Sex	Ethnicity
Benjamin	72	M	NZ European
Shaun	58	M	NZ European
Anita	42	F	NZ European
Andrew	55	M	NZ European
Richard	63	M	NZ European
Stan	54	M	NZ European
Tane	49	M	Māori
Stewart	66	M	NZ European
Jonathan	69	M	NZ European
Bruce	65	M	NZ European
Hemi	55	M	Māori

On analysis, three themes emerged from the data: (1) "The journey to the new me", (2) "Moving forward; the highs and the lows", and (3) "A big learning curve, a whole new life". Coded data which were found to be of importance to the majority of participants were placed into categories to further explain these themes as can be seen in Table 3. These themes are described in detail in the following section. Participants were provided with pseudonyms.

The journey to the 'new me'

This theme illustrated how our participants underwent a personal and on-going journey to discovering their new self after stroke. Although this theme was evident in each participant's interview, with many common aspects perceived by our participants, individual journeys also differed in some respects. All participants spent a long time describing their impairments resulting from their stroke and how they had to learn to manage and accept these impairments. Impairments varied largely between participants and included changes in muscle function, balance, vision, memory, speech, swallowing, breathing, neglect, and fatigue. All participants spoke of the initial changes which occurred in the early stages following stroke. For example, one participant's wife described, "...he wasn't really with us..."

Participants also reflected on the progress that had been made since their stroke and spoke of the impairments they were still

Table 3: Themes and categories

Themes	Categories
"Journey to the new me"	- Impairments
	- Progress
	- Goals
	- Support
	- Hospital experience
"Moving forward; the highs and the lows"	- Attitude
	- Motivation
	- Independence
	- Frustration
	- Financial burden
	- Response from the community
"A big learning curve, a whole new life"	- Limitations
	- Learning
	- Coping strategies
	- Adapting
	- Self efficacy
	- Acceptance

left with. It was quite clear that their current impairments still posed a major challenge to everyday life with phrases such as "ongoing battle", "major setbacks", "really hard", and "I've struggled a lot" used to express their thoughts. As Andrew explained:

"...life living after stroke is like getting up in the morning and every morning picking up the supermarket trolley with the crook wheel. You know the one you get, you always seem to get it but with stroke you get it every day, so that all day you're um...you're working around your disabilities."

Despite having to cope with the initial shock of the stroke, all participants spoke of the progress they have made since their stroke. Goal setting emerged as a strong component to this process, with eight participants mentioning the use of goals or stated a goal which they have achieved or were currently working on. Tane highlights:

"I wanted to go to the toilet, and I had one of those rooms where they had a toilet attached to the room, or of course I could use a bottle or something like that, and y'know how um humiliating that can be? To anyone really; I feel sorry for people like that...um so that sort of encouraged me to try and make my own way to the toilet and that was really...oh and I ended up on the floor, and ringing the bell, but at the time I didn't care because I just wanted to get that goal, reach that toilet."

Vital to assisting with the participant's journey to recovery was the support received from family members. In most cases a family member became the primary caregiver and it was clear that participants felt strongly that this journey would have been extremely difficult without this type of family support. Andrew explained the interaction between himself and his wife

as “she is the eyes at times, and I’m the brains” describing the partnership that this couple had built up. This was in contrast to Bruce whose perception of his spouse was that “y’know actually I think she’s made me quite lazy because she does so much y’know!”.

The gratitude felt by all participants towards the family support received can be summed up with the words of Benjamin saying that his wife has been “...a tremendous help”. Jonathan spoke of how touched he has been by the support from his grandchildren. He shared:

“when I got grandchildren there that are coming over and are saying ‘Pops I’ll tie them up for you’ I mean that sort of grabbed at my heart y’know. Just realising how much these children were willing to help and things like that well I mean it’s only a little wee minor little thing but to me it was major”.

However many participants also felt a sense of burden towards their family members: “...I felt terrible about (spouse), coped marvellously there on her own...” and “...I just don’t like to rely on someone else all the time...”.

As well as the importance of family support towards helping participants go about their day to day functions, family members also provided motivation for participants to keep moving forward with life. As indicated by carer for one participant, “...I believe when people have strokes they need someone there with them, or someone that will call in and push them. Even if you argue um I couldn’t stand by and watch [participant] give up. I couldn’t let him do that and he hated me.”

A different type of support was evident from the stroke community itself. “It’s good to be with like people, a lot of the guys there are all on the same boat y’know and some of them are obviously ten or twelve years down the track and you see how they’re doing and it’s quite good to know that yeah and some of them are still in the same position as you and they’ve got a long way to go”.

All participants spoke of their various hospital experiences as they worked through the process to recovery. No consistent opinions were expressed amongst our participants; instead the experiences and thoughts on the rehabilitation services received were personal and varied between individuals. One participant had “no complaints” with the three hospitals (inpatient care, rehabilitation hospital and outpatient services), experienced on their journey towards recovery. One participant wished to have stayed longer in the rehabilitation hospital saying “you know, given me a couple more weeks because I want to work on this and work on that and work on something else”. In contrast some participants did not enjoy the journey. Those who did not enjoy the journey described it to be because of the situation they were in rather than the services provided by the health care team. “...I hate hospitals, no I really do...they’re (hospital staff) very good there, but um the fact you’re there, y’know? Imagine what it’s like being in prison.” As further elaborated by Benjamin:

“I must admit the hospital experience was terrible until I got to [rehabilitation hospital], there seemed to have a light at the end of the tunnel because pretty much the whole time I was in [local hospital] I was flat on my back I could not do anything, couldn’t sit up... I had to be showered and toileted

you know the whole lot, so I had no independence so and I hated it, cause I am quite an independent person I don’t like people doing stuff for me. I prefer to be self-reliant ummm but I found people were good in the hospital, the situation I was in, it was very uncomfortable for me personally”.

Moving forward: the highs and the lows

This theme emerged from the psychological aspects of living after stroke. It incorporates the different factors such as frustration, response from the community, attitude towards the stroke, and motivation to help themselves, which contributed to the personal highs and lows experienced by the survivor in the road to recovery.

The word “frustration” often came up to describe the negative feelings participants experienced in regards to certain aspects of life after stroke. Loss of employment, financial burden, and decreased function were key reasons for feeling frustrated. One participant expressed he was “very very frustrated with a lot of things because you know you sort of look at things there that you’ve been able to do for 50 odd years and then all at once you can’t do them”.

Communication was identified as a significant factor for those with aphasia which led to some of the ‘lows’ experienced by these participants. One participant with aphasia commented “Oh I’ve struggled a lot...about things about speech and that, I’d go to speak it and I couldn’t speak about it”.

Over half of participants commented on the response from the community; mostly they expressed dissatisfaction that the community did not understand their situation. The ‘community’ ranged from friends and family not allowing for changes in communication ability to having to take aids out in public so people would allow for disability. For instance:

“what I found my problem was that I look pretty normal, and you know people that know I’ve had a stroke, or three strokes, they seem quite surprised you know, I’m walking around and I can talk and everything, and it’s to get through the other people, that you’ve had a stroke and are handicapped in some way”

However, many participants expressed gratitude for their current situation, “I can’t complain...I’ve got lots to be thankful for and very little to moan about” and became aware of their own situation compared to others as one participant expressed “He’s (friend) in a wheelchair and um we both frown at people, we do, who don’t get up and help themselves y’know. I mean there’s worse people off than us”.

Tane stated “I think the most important thing to somebody that has stroke is to stay motivated.” Motivation was identified as an important factor in encouraging participants to make the most of their situation. The desire to regain and maintain function for independence was crucial to successful rehabilitation. For instance, “they offered me an electric wheelchair and that was it, I wasn’t gonna have an electric wheelchair, I swore then I would walk out of that hospital no matter what”.

Participants expressed a range of attitudes in response to their stroke throughout the course to recovery. Many reflected on times where they had negative thoughts towards the stroke. “After I had my stroke, for a long time sort of I was always

thinking about what I couldn't do..." and "...you know I felt sorry for myself at the start". However since time had now passed, there was a sense of understanding by participants that a positive attitude was necessary to enhance their well-being and overcome the challenges presented by the stroke. One participant stated, " Yeah, to be able to you know, move forwards, you sort of get locked into this thing of, well I'll never be able to do that again and, and so, um, I have to focus on what parts of my life my physical incapacitation hasn't affected to have some sort of way to move forward".

A big learning curve, a whole new life.

This theme, a big learning curve, involved self-discovery after stroke. It encompassed the person learning about their limitations, discovering coping strategies, finding ways to adapt and help themselves, and working through the process of acceptance towards their new life. Our participants commented on learning as an ongoing process, as stated by one participant, "Yeah and ah I'm learning, I'm learning, I'm looking forward to every challenge that comes my way". Learning about one's limitations was identified as an important step in managing their new selves. Participants with aphasia were presented with an especially difficult change to their ability to communicate, which they had to learn to adapt to. Richard's wife explains "Now he can gesture to people to y'know to repeat or slow down. So that's new and really good." Participants without aphasia tended to dwell on the loss of their ability to carry out functional activities, especially the ability to drive. As a result of the stroke, the majority of our participants were deemed unfit to drive and this impacted heavily on them by limiting their independence and their ability to participate in work and social activities.

A range of coping strategies were used by all of our participants to help them come to terms with their stroke. To cope psychologically participants explained, "well I've sort of just tried to carry on as normal", "...find a purpose beyond the stroke, that's what I've tried to do", and "you actually block out the life before. If you keep thinking about it, you get too upset you know". One participant emphasised that "...the worst thing you can do is sit around and feel sorry for yourself. And um as I say, don't lose your sense of humour. I've been lucky, I mean I can see the funny side to everything virtually." Whilst another participant explained the importance of hobbies to keep busy "...I've got a model railway I'm building, so that's another interest you know to sort of take my mind off things..."

Participants learnt to adapt their new ability level to the environment through the use of assistive aids to increase mobility, improve communication, and gain the ability to perform everyday activities such as cooking. To manage fatigue levels, participants used planning to take into account their fatigue levels and abilities when participating in activities. Being flexible seemed to be an important factor in successful adaptation with participants saying things such as "probably improvising is the main thing" and "I'm always looking for new ways you know to do things". Participants also emphasised the need to work around impairments and be aware of their ability level "I've stopped over working myself with my regular rehabilitation exercise programme, I um don't just do moderation, I tend to push my body hard, but ah and ah I've learnt not to"

Acceptance played an important role in participants being able to move on and live their lives. Acceptance seemed to be necessary for regaining enjoyment with participants making statements such as "I've learnt to live with that there are things that I can't do anymore.....once you accept that I think it's a lot better" and "Yes indeed, indeed and that's where I am now... in that medium and accepting it and um enjoying it because I'm blessed to still be able to do a lot of those things".

Through the journey of learning and discovering their new life, all of our participants demonstrated self-efficacy in their individual ways, as outlined by Tane:

"At the end the reason I wanted to go for a walk was I saw a few of my mates had gone out of hospital, because I had sort of made associations with other patients...a couple of guys were in the wheelchairs with one leg sticking out, so we're all the same. And they started leaving, and I thought well what the heck am I going to do...I don't want to be left there by myself. At that time I didn't realise the amount of different patients that were coming down to the place...I thought bugger this! I ain't going to sit and be like some other person and just die, so got up and really put my what do you call it, got aggressive...not aggressive...determined, yeah."

It was common for participants to talk about how they had taken initiative in implementing their rehabilitation. Eight participants talked about physical and/or mental activities they took part in either in their own homes or in the community which were aiding their recovery. These included sports-type activities such as swimming and walking as well as mentally challenging tasks such as reading and puzzles. Having a positive attitude, motivation, and good support, were seen as leading to self-efficacy, whilst negative thoughts and poor community reactions hindered the participants' ability to take control of their life after stroke.

DISCUSSION

The purpose of this study was to gather stories of life after stroke and the challenges faced by those living with stroke to gain insight into what helps and hinders individuals through each step of their journey to recovery. The findings of this study demonstrate that this journey is an individualised experience; however these experiences resonate strongly between individuals at a thematic level. Our findings suggest that stroke has a significant impact on an individual's way of life, facilitating an alteration of lifestyle, and resulting in the individual undertaking a learning process which ultimately enables them to deal with these changes, challenges, and restrictions. Most studies define post-stroke recovery using a linear incremental model. The path to recovery is portrayed by these studies as an impersonal journey which can be broken into defined phases (Appelros et al 2009, Cox et al 1998). However, our study found that our participants' journey to recovery was personal and individualised, where experiences and personal developments vary in nature and timing, having different effects on individuals. While the journey is individual there were common themes that existed between journeys and overarching themes that are common to all.

We found many factors that help an individual with stroke on their journey to recovery. Support from the family and the stroke community helped our participants to gain motivation and take

initiative towards their recovery, a finding consistent with prior research, that having good support systems enhances quality of life (Clark and Black 2005, Glass et al 1993, Lynch et al 2008). By sharing experiences with other individuals with stroke and their families, our participants were able to help others faced with similar difficulties. They were able to enhance their psychological well-being by being able to talk about their lives as well as gain benefit by learning of other's stories and advice. After meeting other individuals with stroke who have more debilitating impairments, many of our participants felt gratitude for what they had and took a more positive outlook of their situation following this experience.

Goal setting emerged as a crucial factor in achieving progress post-stroke for our participants. Additionally, they reported that for goal setting to be effective it needs to be individualised and under their personal control. Goals played a large part in our participants' rehabilitation progress. Furthermore, they often had personal goals and goal setting measures that they used during their journey of finding "the new me". Our findings revealed that participants often used tasks and abilities from their pre-stroke life to set goals for recovery. These goals were often very personal and based on regaining independence. Similarly Gubrium et al (2003) reported that individuals with stroke use personal benchmarks and goals in relation to life before and after stroke. Using personal goals that an individual can relate to gives ownership of the goals which increases the want to achieve them. This resonates with Jones et al (2008) who found that having control over their goals can be beneficial in a stroke survivor's continued recovery in relation to physical milestones.

We identified that learning about one's limitations helped our participants to manage their challenges resulting from stroke. Stroke is a life changing event. Individuals face learning a large range of new skills, which includes learning about their new limitations, adapting themselves and things around them, and finding ways to help themselves. It was evident that our participants tried to adapt around their impairments by trying to normalize their current situation in order to find a purpose beyond stroke. This finding is similar to that of Clarke and Black (2005) who discussed that individuals with stroke often learn to adapt and adjust to their impairments in order return to meaningful roles.

A common trend of acceptance of limitations also emerged, with participants reporting that accepting that they were not able to do certain tasks helped them to move on and enjoy their lives. This also helped them to maintain their motivation towards achieving and taking control over their personal targets or goals. Previous authors Lin and McLaren (2002) have discussed this acceptance of limitation as discovering a new normality in the face of changes that stroke brings upon individuals and have proposed that this acceptance helps individuals following stroke to find self-worth and an identity.

Utilising coping strategies was also reported to be helpful in the journey to recovery. For example, some participants planned their days according to their fatigue levels. The majority of our participants utilised various coping strategies to keep themselves motivated and to achieve their goals, a positive attitude being one such coping strategy. Effective coping strategies play a crucial role in assisting individuals with stroke in their journey of living life after stroke (Clarke 2003, Cox et al 1998, McKeivitt et al 2002).

Robinson Smith et al (2000) reported that self-efficacy greatly impacts the recovery process of stroke and if individuals do not have good self-efficacy, they become reliant on external factors for motivation. Many of our participants appeared to have good self-efficacy. It is therefore important to build and improve a person's self-efficacy to allow that person to take control of their lives and increase their ability to self-manage.

A number of factors were found that hindered our participants' recovery; these included negative thoughts about stroke and negative responses from the community, both of which can adversely affect an individual's attitude and hamper progress. All our participants tended to focus in the early stages of recovery on what they could not do and mourned lost ability, but then they moved onto accepting their limitations and began to reflect more positively on their situation. It appears that the longer the time to reach this more positive outlook can have negative influences on an individual's recovery.

Our participants particularly experienced frustration, especially due to their decrease in function and loss of employment, leading to a perceived burden on family, and this had an adverse effect on their recovery and progress. It was also evident that participants with aphasia felt that communication was the major hindrance in their recovery, in contrast to other participants who reported loss of ability to carry out functional activities, such as driving as a major hindrance in achieving their goals. Aphasia and other communication problems led to major frustration with friends and family, and this impacted negatively on relationships and recovery; a finding previously highlighted by other studies (Dalemans 2010, Pound 1998).

Prior research has found that participants identified problems with primary inpatient stroke care, and lack of longer term contact and social support (Murray et al 2003). This was not the case in our study, where participants were negative only about the situation they were in and the fact that they did not like hospitals, not with the support and care they received.

A strength of our study was that no participants were excluded with regards to type or severity of impairment, type or severity of stroke, or time of stroke. Although the inclusion of individuals with aphasia or cognitive impairment presented communicative challenges to data collection, the resulting sample diversity means findings from this study are more readily extrapolated to the general stroke population. This study thus had a broader representation than is usually included in qualitative stroke studies (Townsend et al 2007).

Our study was restricted to the South Island of New Zealand, which is reflected in our sample's ethnic diversity. Due to the differences in ethnic make-up between the North and South Islands, our study's findings cannot necessarily be extrapolated to the North Island, thus there remains a gap for further research involving a sample which is representative of the ethnic composition of the North Island (Statistics New Zealand 2013).

CONCLUSION

Our study established that an individual living with stroke has to commence a new journey to discover their new self, and this journey involves a steep and challenging learning curve which can have an impact on the individual's progress and recovery. Another key finding was the individualised psychological

impact experienced through this journey of finding 'the new me'. Although life living after stroke was challenging; a positive attitude, control over goal setting, learning to adjust and adapt with the new limitations, and support from family and community, played a critical role in our participants' recovery. These processes also promoted self-efficacy and self-management, both of which can impact positively on the physical and mental recovery of an individual with stroke. These findings can be further explored to aid the health professionals' understanding during the management of individuals living with stroke through all the stages of their recovery.

KEY POINTS

- The journey to recovery following stroke is a long, non-linear, personal and highly individualised process.
- It is important to listen to what individuals with stroke say and work with them to set goals that are truly patient centred.
- Personalising treatment and listening to individuals with stroke will allow health professionals to gain a better understanding of where the individual is in their post stroke recovery.
- Assist the person to build self-efficacy.

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DECLARATION OF INTEREST

The authors report no conflicts of interest.

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