

Barriers to optimal stroke service care and solutions: a qualitative study engaging people with stroke and their whānau

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ABSTRACT

AIM: The aim of this study was to explore the perspectives of people with stroke and their whānau on barriers to accessing best practice care across Aotearoa, and to brainstorm potential solutions.

METHOD: We conducted ten focus groups nationwide and completed a thematic analysis.

RESULTS: Analysis of the data collected from the focus groups identified five themes: (1) inconsistencies in stroke care; (2) importance of effective communication; (3) the role of whānau support; (4) the need for more person- rather than stroke-centred processes; and (5) experienced inequities. Participants also identified potential solutions.

CONCLUSION: Key recommendations include the need for improved access to stroke unit care for rural residents, improved post-discharge support and care coordination involving the whānau, improved communication across the patient journey, and a concerted effort to improve culturally safe care. Next step is to implement and monitor these recommendations.

Stroke is a leading cause of death and disability globally.¹ In Aotearoa New Zealand, hereafter referred to as Aotearoa, stroke incidence has been estimated at up to 9,000 strokes per year and is expected to increase by 40% in the next decade.² In Aotearoa, inequities in access to hospital-based stroke care occur by ethnicity and geography. Our recent research shows that patients presenting to non-urban hospitals and Māori experience major access barriers and worst patient outcomes.^{3,4} Although this research identified several of the issues in stroke care that need to be addressed, patient perspectives and self-determined solutions of people with lived stroke experience is required to inform next steps.

Several Aotearoa-based evaluations of patient healthcare experiences, including stroke care, report varying levels of satisfaction.⁵ Experiences also differ between ethnic groups, with unique issues such as structural racism and lack of cultural safety being described by Māori and Pacific peoples, and travel and distance from family support reported by people living rurally.⁶⁻⁸

To date there has, however, been no systematic

attempt to gather information on the patient's overall experience (from pre-hospital to post-rehabilitation) of stroke care across the country. Perceptions from patients and their whānau and caregivers (referred to collectively as whānau in this paper) about access to and the quality of healthcare through stroke services would provide meaningful information. Such information would be further enriched by including a diverse range of voices, including people of different ethnicities, ages, cultures and locations. There is also opportunity to explore potential solutions to improve service access for all New Zealanders.

We have previously reported on results from patient, whānau, and health provider surveys.⁹ Here we report additional data obtained from patient focus groups. These groups can add particular value, as ideas are communicated in an open, supportive environment with mutual encouragement from the participants who share a lived experience.

The aim of this study was to explore patient and whānau perspectives on accessing best practice care across Aotearoa, and to brainstorm potential person-centred solutions.

Method

This is a qualitative sub-study of the wider REGIONS Care project; a multi-part nationwide observational study that investigated geographic and ethnic inequities in stroke care access and post-stroke outcomes.¹⁰

This sub-study specifically explored access barriers using qualitative data obtained from focus groups involving persons with stroke and whānau. This approach has previously been shown to add value,¹¹ and builds on prior work consisting of small focus group interviews of Māori with stroke, their whānau, and health providers and managers.¹² It offers the additional opportunity to engage with stakeholders to determine what other decision criteria might be important when deciding on service priorities (e.g., acceptability to the community and feasibility).¹³ Focus groups were utilised in order to allow participants to encourage each other to comment. In addition, the focus group method of data collection is preferred when investigating cultural perspectives and diverse views.¹⁴

Patient recruitment

While obtaining consent for the REGIONS care project, participants were asked to indicate whether they were interested in taking part in a survey⁸ and/or a qualitative focus group interview. Those who agreed to participate in a focus group underwent purposeful sampling according to age (<65 and >65), residence (urban versus non-urban), gender and ethnicity (Asian, Māori, Pacific, and NZ European). In total, we aimed to conduct ten focus groups; five at urban and five at non-urban hospitals.

Data collection

Consumer group sessions were facilitated by research staff, experienced in facilitating focus groups and impartial to the reported findings, and with little to no affiliation with the hospital services discussed. Research questions were open-ended but focused on the following themes: overall experience of care, description of difficulties in accessing services, perceived barriers to accessing services, and any suggestions to reduce access barriers. Interviews were digitally recorded and transcribed.

Analysis

Focus group interviews underwent data-driven thematic analysis. This was intended to provide flexibility and ensure data that were important to participants was captured and interpreted as intended. Key themes were named according to scope, and defined and described incorporating participant quotes for illustration purposes. Triangulation of results occurred with four researchers (MH, KB, AR and ST) to ensure robust

and valid conclusions. We present participant quotes by the hospital they attended grouped into “urban” versus “non-urban” as geographic differences in hospitals was a main focus of the overarching REGIONS Care project. Urban setting was defined as hospital <25km from a city of >100,000 population.¹⁰ We do not present quotes by individual hospital or individual patient characteristics such as ethnicity, in order to preserve participant anonymity in the setting of a small sample size.

Study consent, funding, and ethics

Focus group participants were sent information sheets prior to the meeting and given an opportunity to ask questions at the beginning of the session before providing written consent. The study was funded by the Health Research Council of New Zealand (HRC 2017/037) and received ethics approval from the Health and Disability Central Ethics Committee (17/CEN/164).

Results

We conducted ten focus groups at five urban and five non-urban hospitals. There were two to seven people in each focus group, with a diverse range of ages, ethnicities, genders and other factors, such as the inclusion of some caregivers. See Table 1 for group characteristics and Table 2 for participant characteristics.

Analysis of the data collected from the focus groups identified five themes: (1) inconsistencies in stroke care; (2) communication; (3) family/whānau support; (4) stroke-centred processes; and (5) inequities. Participants also identified potential solutions to issues.

Theme 1: inconsistencies in stroke care

Participants described the services they received and the people involved along their stroke journey, and grouped these across the timeline from diagnosis and acute care, to inpatient rehabilitation, and through to “life with stroke” in the community, as presented in Table 2.

Diagnosis and acute care

Overall, participants offered many positive reviews of the diagnostic process and acute care phase. However, some inconsistencies were highlighted, especially for young people for whom stroke was not considered in the initial differential diagnosis. This is described in detail in the Equity section below. Participants also raised some negative experiences e.g., that the stroke care workforce appeared to be “run off their feet” and not always experts in the stroke field, as these two people at opposite ends of the country pointed out:

Table 1: Characteristics of groups.

| FG | Date | No. of participants | DHB – Hospital | Setting |
|----|------------|---------------------|--------------------------------------|-----------|
| 1 | 28.11.2018 | 7 | Counties Manukau DHB – Middlemore | urban |
| 2 | 12.12.2018 | 5 | Capital & Coast DHB – Kenepuru | urban |
| 3 | 23.01.2019 | 5 | Canterbury DHB – Christchurch | urban |
| 4 | 25.03.2019 | 4 | Waitemata DHB – Waitakere | urban |
| 5 | 09.04.2019 | 4 | Northland DHB – Whangarei | non-urban |
| 6 | 15.04.2019 | 3 | Waikato DHB – Hamilton | urban |
| 7 | 20.05.2019 | 7 | Southern DHB – Invercargill | non-urban |
| 8 | 10.06.2019 | 6 | Hawke' Bay DHB – Napier | non-urban |
| 9 | 17.06.2019 | 2 | Lakes DHB – Rotorua | non-urban |
| 10 | 30.07.2019 | 3 | Bay of Plenty DHB – Whakatane | non-urban |

Table 2: Characteristics of patients.

| Demographic information of all participants | |
|---|------------|
| People with stroke | 34 (72.3%) |
| Whānau/family | 13 (27.7%) |
| Age range, years | 32–94 |
| Age >50 | 31 (91.2%) |
| Sex, female (%) | 23 (48.9%) |
| Ethnicity, n (%) | |
| NZ European | 19 (55.9%) |
| Māori | 9 (26.5%) |
| Pacific | 3 (8.8%) |
| Asian | 2 (5.9%) |

*Demographics data exclude whānau as data for these were not available.

Table 3: Various services involved in stroke care, as named by participants.

| Acute care and diagnosis | Hospital inpatient care | Community care |
|-----------------------------------|------------------------------|--|
| Public | | Stroke Foundation |
| Ambulance including helicopter | | Accident Compensation Corporation |
| General Practice staff | | Work and Income Aotearoa staff |
| Emergency Department staff | Hospital doctors | Social workers |
| Radiology (called the “Scanners”) | Hospital nurses | Needs assessors |
| Hospital orderlies | Hospital therapists | Employers |
| Hospital doctors | Rongoā (traditional healers) | Inland Revenue Department |
| Hospital nurses | Family/whānau | New Zealand Transport agency (for drivers’ licences) |
| Therapists | | Sports and hobby groups |
| Family/whānau | | Therapists |
| | | General Practice staff |
| | | Whānau |

Five subthemes emerged: diagnosis, stroke rehabilitation, community, stroke units, and hidden costs.

“They were simply run off their feet. Good people trying to do a good job, but they just couldn’t manage everything” – urban hospital

“They can do their best, and that’s it, if they don’t specialise in one thing. At the hospital you get three or four doctors coming around, and different ones come and see you ... and you don’t know whether they’re on the button or not.” – non-urban hospital

Many also described not receiving enough information, particularly to understand why they had had a stroke. This question, “why did I have a stroke?” was asked at all focus groups. When participants attempted to request further investigations to understand “why”, they felt that their concerns were often dismissed or mis-labelled:

“Then something would change in you, actually, if you knew why [you had a stroke]. Because you can’t see anything happening you can’t understand it.” – non-urban hospital

“Or I wanted to know how How does it heal? How long does it take? How is it going basically? Then I got told I was paranoid and suffered from post-traumatic stress and

depression I said, ‘It’s not depression. It’s about being active about your health. It’s about wanting to know’.” – non-urban hospital

Stroke rehabilitation

Descriptions of stroke rehabilitation were mostly positive, often highlighting the comprehensive care received from several different therapists:

“Great, every hour I had someone different, like a physio for one hour, and then they’d tell me to go back to my bed and have a sleep. Then I’d have a speech therapist, have lunch and I’d have another sleep, and then I’d have a psychologist in the afternoon, and all these people getting you well again. It was amazing.” – non-urban hospital

Community care

Unsurprisingly, when considering the number and variety of agencies that engage with people after stroke (Table 2), there were major inconsistencies in community care, including waiting times and access to types of therapy, especially speech and language therapy. Most waited one to two weeks, but others waited two to five months for follow-up care. Consequently, people felt that their recovery had not reached full potential, or they had to improvise at their own cost:

“Seven and a half weeks before they came round home to see whether I needed a shower stool and raisers and that sort of thing. That was a bit; I was a bit peeved about that because I had to buy them. I’d had to adapt to do things myself anyway.” – non-urban hospital

Some described feeling they had been lost in the system, and once “found” they were then overwhelmed by stroke service visits:

“Heard from nobody for months, and then next minute you’re inundated with everybody. They all want to see you, all in that week, and ‘How’s this been, and how’s that been?’ Almost as if they’re trying to catch up on what they’ve done ... Yes, or what they haven’t done.” – non-urban hospital

Stroke units

When available, stroke units were generally praised for the multi-disciplinary approach, their stroke expertise, and coordination. Even those who could not access a stroke unit wished they had been able to, confirming a desire for stroke-focused, coordinated care:

“I think being in a stroke ward I think would be great for everybody, to talk about what’s happened to their bodies, and how they’re managing it and everything.” – non-urban hospital

“I thought the cardiologists had organised it. But, I now know it wasn’t; it was general medicine. So, there was a problem in the system. I found that people were operating in silos. There was no sharing of information.” – urban hospital

Hidden costs

Stroke care is publicly funded in Aotearoa yet there were multiple hidden costs affecting timely and efficient access to stroke services such as:

Transport and carparks

“And especially if you’ve got to go to places, like they say, catch a taxi or catch a bus and everything. Sometimes with the bloody buses I go at different times, and I catch another one that misses it altogether. So, my appointments have been missed because of different times. And taxis ... 30 bucks to come from there to here.” – Non-urban hospital

Primary care visits, laboratory tests and prescriptions

“Coming from an earning \$1,200 bucks a week right down to ... \$300 a week now. It’s really hard. You often think ‘it’s not pay week this week, I can’t go to the doctor this week. I’ll go to the doctor next week when I’ve got some money.’” – non-urban hospital

“Now he has to have a blood thinner – a tablet he takes now every day. His medications basically doubled since the stroke.” – non-urban hospital

The impact on wider whānau, requiring time off work or spent organising assessments and care

“So we really pushed for it, emailing back and forth to [DHB] staff and the Social Worker that we really need a needs assessor before mum goes home. Me and my sister we had to take turns looking after our mum. So we, you know, one of us have to stay home with while not working and one of us will be working.” – urban hospital

Theme 2: communication

Many participants acknowledged that the “FAST” message was very effectively communicated enabling the early identification of stroke, resulting in timely access to acute care:

“I was looking at his face because I automatically thought stroke, face. So at his face and nose, [and] I thought ‘oh my god they all add up’. So just keep on advertising all that information to everybody.” – non-urban hospital

“I was sitting down on the seat, I was falling over. And there was a girl right beside me and she’s going, ‘He’s having a stroke.’ Somebody said, ‘How do you know?’ She goes, ‘Well, I watch bloody TV.’... And she called the ambulance” – non-urban hospital

Regarding pre-hospital general practice encounters, face-to-face was preferred as many described misdiagnoses over the phone, leading to delays in stroke diagnosis and care:

“I rang the doctor, and they said, ‘Oh look, we don’t have any space today.’ This was a Friday, ‘We have space available on Tuesday, so come in then.’ I went, ‘Okay.’ Then Saturday

morning ... I was driving, and then I veered right to the side and hit the curb, and it wasn't until then that I stopped and thought, 'hey, something really is wrong', but they said I don't need to go until Tuesday. So on that I didn't ring an ambulance, or anyone, I waited until Tuesday" – urban hospital

Communication in hospital was variable. Many commented that with satisfactory communication they felt assured and empowered:

"Everything that happened there was comforting. I felt I was being given information I needed, about what was gonna happen, what they were doing, the scan, things like that. And that was really good. It was the atmosphere that I had never experienced before ... caring and support ... made me feel much, much more secure." – urban hospital

However, unsatisfactory communication occurred when participants were spoken "at" or about, or when there were delays. Consequently, participants felt abandoned:

"I feel that some of the people kind of think they are so far above you ... some people came into the room and they would have their own conversations with other people about you, in front of you, using terminology that I didn't understand and stuff like that, and then they'd go 'you alright?' and then they'd leave." – urban hospital

"He said, 'No you should be fine because you've got your wife to look after you. No driving for three months'. He went away and he left us to go. He said, 'We'll be in touch to put you under your own GP. Then we'll be in touch'. I still haven't heard from anybody." – non-urban hospital

As a result, people felt that they, or whānau, had to fight to be heard, and acknowledged that the required effort may be impossible for some:

"It was just little niggly fights that I had to do for myself ... nobody ... looking after you ... I had my kids to back me up ... they could go fight for me. But there's other people who come in that can't do that and wouldn't know where to start." – non-urban hospital

Some noted differences in communication styles

between acute and community services. One man reported good communication from the hospital team following discharge, but a negative comment made by an acute assessment unit (AAU) nurse when he initially presented to hospital had stuck with him one year later:

"I found it was quite personal and felt like they were talking to you and not just a group of people as such and concerned about your health rather than anything else. I found that very helpful actually and quite good. It was quite nice, a nice fuzzy feeling if that's a word to use ... when I got into AAU, the nurse said, 'Well, don't take your shoes off, you're not gonna stay here long'. And I thought I wasn't. That's alright ... it was just one of those funny things that sticks in your mind which is weird." – non-urban hospital

Participants made a specific request for stroke services to acknowledge that good communication works best when both parties are participants. Instead, they felt an expectation to just "sit and listen" and be available when it suited the service:

"I had people come to my house. They ... say to my daughter, 'Your father's never here'. She goes, 'Well, if you want to catch him, you come here at seven o'clock in the morning and catch him because he wants to up and he wants to be gone because he goes for walks. He doesn't sit at home like people do'. And they go, 'Oh well, we need to talk to him'. [She said], 'Well, that's what I mean. Here's his phone number, ring him up.'" – Non-urban hospital

Theme 3: whānau wellbeing

Families were involved across the entire stroke care journey. People relied on whānau for acute assessment, medical and nursing type care, therapy, child-care, income, information and aroha (love). Aroha was expressed in different ways, with one man saying it was wonderful to have family "beside me" at every step, with benefits on his wellbeing:

"The attitude at home was good. My health at home was good. I've got some step grandchildren and man-alive they were fantastic. They were right by my side the whole time. They would eat with me even though I wasn't eating. I was doing this pump thing. They were right beside me." – non-urban hospital

People described how whānau members gave up their lives/work to support them. This first quote from a young woman talking about her mother; the second from a man about his wife:

“Yeah, she even quit her job, because I couldn’t drive for two months either... she flew down and came to the hospital with me, and went to [rehabilitation in another city] with me, in rehab, and then lived with me, to drive me and the kids around.” – non-urban hospital

“I’ve got my wife, and I have asked her to stop working ... So, my case is different. If my wife can look after me, it’s better than if the government gives somebody else; because she knows in and out and she will be every time with me.” – urban hospital

Family meetings with stroke services were described as important to clarify information and ensure that everyone was on one page, as was the case for this woman talking about her husband with stroke and their daughters:

“We had a family meeting, and that’s when it was decided about [his] licence, and because they’re family, the girls came as well. They had questions to ask, and it was just about what he would be doing, was that in place, and they were very good weren’t they, very helpful? That was a good meeting and it sort of set us right on what he should do, and the girls too, because they knew him and so forth, and they could sort of hear all of this too.” – non-urban hospital

Theme 4: stroke-centred versus person-centred care

Participants felt that stroke services were stroke- and not person-centred. People described having multiple tests and assessments, and felt that these were a process or box-ticking exercise rather than being focused on improving one’s outcomes:

“I’d never had to sit and eat a meal with someone watching me eating and hearing me crunching or watching me walk, they wouldn’t let me leave until they got their boxes ticked” – Non-urban hospital

Person-centred stroke care was preferred because it was driven by the person and their whānau. For example, having rehabilitation in their own home enabled whānau involvement, allowed the therapist

to understand the person better and was considered more effective and efficient:

“I said, ‘But, he’s not familiar with these [hospital] surroundings. We need to get him back home in his own environment’. I said, ‘Give me a week at home, you come and visit him, and I bet you he can make a cup of tea straight away’. We did that.” – non-urban hospital

Person-centred care was considered to be strengths-based, building on current personal assets to achieve personal goals, yet recognising both the good in, and burden of, having a stroke:

“This stroke was a bit of a blessing in disguise. I found out about my health issues and I managed to get where I wanted to be in work. But, it came at a bit of a price at the time with all the emotional stress for myself and the family.” – urban hospital

Members of every focus group said that the little things counted. For example, people wanting to go to the toilet were often directed to wait for assistance. It upset many and people described going despite, or in spite of, these orders, to maintain dignity and independence:

“Sometimes they don’t come for ages. Sometimes they do. Mum she couldn’t press the button herself, so we had to press the button for her. Eventually my mum she just started going to the toilet by herself, even though she wasn’t supposed to because she was waiting there for a long time.” – urban hospital

Person-centred stroke services would also support people’s “return to my life but now with stroke”. A key issue for many, which reflects the “car culture” of Aotearoa, was a return to driving:

“Thank goodness it’s only for a short period. I feel so sorry for people in the predicament that lose their licence and lose their mean of getting round. That’s probably one of the worst parts, lack of transportation, independent transportation. Yeah, that’s a big thing. That’s it, eh? When you lose your licence, you lose your whole way where you’re gonna go. That’s right, you lose your independence don’t you?” – non-urban hospital

Getting back to work was also critical for maintaining a sense of the old self, and adjusting to the new. Stroke services did not feature in these narratives. Rather it seemed that this was largely left to the employers, with one describing his relief when his employer found new work:

“When I had a stroke my truck licence is gone. So, that was again another bit of uncertainty about whether I would return back to what was my current role. But, work were quite accommodating and they said, ‘No, we can fit you into other avenues in the business.’” – urban hospital

Many worried about returning to work, based on others’ or personal experiences, and would have appreciated timely advice from stroke services:

“I thought, ‘I’ll be alright, I’ll be alright to go back to work.’ Well, I tell you, it wasn’t long. I just wore myself out. I was not ready for it. My brain was not ready for the input ... I wish I had have had that information.” – non-urban hospital

All enjoyed the focus group as an opportunity to hear others’ personal experiences and share their own. As one person said, it helped put their stroke in perspective and they wished the local stroke service would provide similar programmes for them:

“I think the reason I came here today is to hear what’s happened to other people mainly to put it in perspective with what’s happening to me” – Non-urban hospital

Theme 5: equity

Participants expressed concerns about what were perceived as often unfair differences in the provision of stroke care due to rurality, age, body habitus and ethnicity. There were issues with travel to hospital on rural roads. Two people said the ambulance got lost in transit and the roads were in a bad state:

“I kept saying to her, ‘You’re going the wrong way, you’re going the wrong way’. I could tell by the way she was going. So, it took an hour and a half to get from our place to Hospital.” – non-urban hospital

“We had a terrible drive in the ambulance I remember now, boneshaking drive.” – non-urban hospital

Some were transferred to urban centres because

rehabilitation could not be adequately provided at the local, rural centre:

“Yeah, I was in hospital here for a week because I had to wait for a bed to come available in [the city]. I lay here for a week until I got rehab in [city] because there was just not enough beds.” – non-urban hospital

Transfers were especially hard for people whose whānau would also be isolated, or could not travel due to other commitments:

“I couldn’t just suddenly drop everything and head up to [other centre] ... the last thing I think you need to be is isolated. We’ve got no family in [city] of any description.” – non-urban hospital

There were also extra costs for people who lived rurally, and these weren’t considered by stroke services:

“Yeah, mum drove my kids up to visit me, and then we had to pay for accommodation for both the kids ... The kids stayed with us, with me [in hospital]. Yeah, and that’s more money in accommodation, and then your petrol. It was crazy but you can’t not see your children for [weeks].” – non-urban hospital

Though not many made comments on body habitus, one man did express his feeling of discrimination about his weight while in the hospital:

“I felt a little bit of discrimination, while I was in the hospital to do with my stroke, about my weight ... at one space there was a comment made in front of me along the lines of ‘what do you expect? Based on your weight’. Also there was a conversation right outside my door, about my weight that I overheard – I was a little taken aback about that.” – urban hospital

Age specific issues included problems getting a timely diagnosis when young, as stroke is considered a condition for older peoples. One man had his stroke in his 30s and described how the first responders initially thought his symptoms were due to alcohol intoxication:

“I remember them asking my wife, ‘Did he get on the piss last night? Is he drunk? Is he taking anything?’ No. I don’t do that. We’re fit people.” – urban hospital

He eventually had a CT of his head and stated that:

“12 hours after it had started. They said, ‘We’ve got some bad news. You’ve actually had a stroke.’” – urban hospital

There were also issues for some younger people to access rehabilitation:

“The hospital was fantastic and everything like that, but they said to him, ‘You have to go to [another centre] for rehab because you’re under 65.’” – non-urban hospital

At the other end of the age spectrum were descriptions of ageism:

“Yes, particularly me because I think most doctors immediately think that’s his age. Yeah. That’s what I heard. That’s the first thing they say. That’s what they say, because I remember they stand at the bed and they have the whole gang of doctors and. I heard him ... talking to his cohort saying, ‘What do you expect at his age?’, those things I think, oh, yeah.” – non-urban hospital

Māori participants described the lack of Māori staff and services within current stroke services, and accessed cultural support elsewhere:

“I went to Māori healing, Māori rongoā, and karakia. I believed they were all those things that helped me, because there was nothing else.” – non-urban hospital

“Because Māori are very high up in the people that get strokes – Māori and Pacific Island – I wondered why there was not one brown face at all that I saw anywhere. So, then if they were the top end of the clientele, so to speak, where is their role model? Where is their person that would make them feel comfortable culturally perhaps.” – Non-urban hospital

Solutions

As well as sharing their experiences, participants also put forward their suggestions of solutions for these issues:

Navigators to help communication and break down silos

“In the end somebody said, ‘You need an advocate’, then once the advocate

became involved, she did have trouble too, but it wasn’t as bad and it got sorted out eventually. Advocates are really important.” – urban hospital

Coordinated care

“A stroke is not something that you bring on yourself; it is an accident. So, hearing these stories, why isn’t it covered by ACC? [Stroke care could be] a bit more structured as far as your payments go, as far as your rehabilitation goes, and the constant check ups and things like that. That’s what I would like to see going forward. I didn’t actually realise at the time that it wasn’t normally covered by the ACC. When I heard that, I just didn’t understand it.” – urban hospital

More Māori and Pacific staff and services

“The needs assessor. Um having that more available and especially Māori and Pacific staff.” – urban hospital

“For me, Māori rongoā, karakia, mirimiri. Those are all things that I really believe in. I had my first lot up at the hospital actually.” – non-urban hospital

Shared experiences

“The very month that I had a stroke there was an article, and it was written by a chappie who’s surviving a stroke. It was an American one, and it was just an extract from the book, and I got more information from that than what I did from anything else really.” – urban hospital

“We’d been to a stroke meeting once ... and we’re definitely going to go back. You got so much out of that day didn’t you? It was only for about an hour, or an hour or two, just talking to other stroke patients.” – non-urban hospital

Discussion

In this study we gathered information about the views of people with lived experience of stroke about stroke care, what barriers need to be overcome and some proposed solutions.

Inconsistency in stroke care across different regions in Aotearoa was highlighted as an important issue. Participants felt that staff managing their

stroke at smaller non-urban hospitals were not always qualified to make accurate decisions and questions appeared to be not always effectively answered. People wanted to be in a stroke unit to feel more confident in their diagnosis and treatment, regardless of where they live. Communication was challenging in both urban and non-urban settings, and some people felt talked down to by health providers; something that should be addressed through raising awareness and training.

Some participants felt abandoned. They wanted their specialist doctors to continue working with them after discharge instead of giving them a list of instructions and sending them on their way. They reminded us that when someone has a stroke, it can change their entire life. Awareness about this aspect of life with stroke and ways to cope psychologically in daily life seem to be important gaps within stroke care, which should be addressed. Consumers very much valued their whānau and the support they provided. The help provided by whānau members throughout the stroke journey made people with stroke feel more supported and less alone. It is important that these voluntary services provided by whānau are acknowledged and valued as a vital part of coordinated stroke care.

Other inequities were highlighted. Driving from rural areas to hospitals made people feel unsafe and some had to drive themselves to other hospitals, which was very expensive. People experiencing strokes at younger ages often felt dismissed. Māori felt they had to seek desired Māori services outside of the public health sector. These barriers to optimal stroke care can be mitigated by providing consumers in rural areas with funding for travel and/or relocation, ensuring that stroke care is accessible for younger people, and improving availability of health services aligned with Māori values, including traditional healing.

In terms of cultural safety, several Māori and Pacific participants mentioned that they were perplexed by the limited number of Māori and Pacific hospital staff working in stroke services. When Māori doctors and other clinicians are available, Māori patients reported feeling safer and at ease; that there is already a connection between patient and clinician because of their shared culture. Especially te reo Māori speaking clinicians, as they would help address cultural and also language barriers.

Four key recommendations emerge from the outcome of this study. Firstly, there is a need for improved access to early specialist decision-making, management, and prognostication in non-urban areas. To adequately address this, centralisation will probably be required for some services, but much could be achieved through the implementation of

adequately funded telemedicine coverage in rural areas. This would also reduce barriers imposed by long travel distances offering care closer to home. “Telestroke” in the hyperacute setting is already available in some parts of the country and should expand. There is, however, little, if any, remote expert support offered to generalist teams at smaller hospitals beyond the first few hours of hospital presentation, and this should be explored in earnest. Secondly, there is a clear need for shared goal setting. Some study participants did not perceive that the therapy that was delivered was of practical value to them as individuals. We know that it is important to include patients and whānau when designing and, ideally collaboratively, delivering a tailored rehabilitation programme, but we need to ensure this happens consistently and effectively throughout stroke services in Aotearoa. Thirdly, there is a need for early targeted support on discharge with ongoing specialist care provided after discharge from hospital, and a smooth coordinated transition to available non-specialist community services. The Ministry of Health has set targets around optimising the first transition (i.e., community team contact within seven days of discharge), but services struggle to meet this target largely due to resource constraints. Follow-up with specialist doctors is almost non-existent again largely due to resource limitations. Both require increased sector investment. The transition from specialist community rehabilitation support to living with stroke long-term relies largely on non-government organisations such as stroke foundations and volunteer services. Implementing “Take Charge”; a community-based self-directed rehabilitation programme to allow the person with stroke to take charge of their own recovery, is another option.^{15,16} More information about available services, expanding on what is currently available, and finding effective ways to connect people with stroke with the services they want and need should be priorities moving forward. Stroke is a major life changing event, and post-stroke psychological support services are lacking entirely representing another area that requires investment. Finally, clinicians need to reflect on their communication styles, own personal biases and cultural competence. More training opportunities should be made available, and services should actively consider including course completion/demonstration of communication skills and cultural safety as part of their appraisal and certification models. The need for more Māori and Pacific doctors, nurses, and allied health professionals in Aotearoa is pressing, and needs to be a national priority.

A strength of this study is that the focus groups were diverse, including a wide range of people from different locations across Aotearoa, and of different ethnicities, ages and genders. Another strength is that these focus groups allowed people to bounce ideas off each other and to feel supported by one another when speaking about their experience with stroke. Participants expressed a feeling of consolidation when hearing about people's different experiences with stroke and the focus groups allowed for open discussions that were free of judgement, encouraging people to really speak their mind.

A limitation was that some of the focus groups were very small and lacked the diversity of perspectives that can spur more interesting discussions. It raises the question of whether we missed important perspectives. There is a possibility that if there was only one

person of a certain ethnicity, age or gender in a focus group, they may have felt hesitant to speak up.

Conclusion

Much work has gone into improving stroke care processes and outcomes, but efforts have mainly focused on what clinicians, funders, and planners think people need. In this study, we have identified what is important to people with stroke and their whānau in Aotearoa. Key recommendations include improved access to stroke unit care for rural residents, improved post-discharge support and care coordination involving whānau, improved communication across the patient journey, and a concerted effort to improve culturally safe care. The next step is to implement and monitor these recommendations.

COMPETING INTERESTS

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