AUT CENTRE FOR
PERSON CENTRED RESEARCH

Psychosocial well-being after stroke

A study of care practices and processes in Aotearoa New Zealand

Funder: Health Research Council

Principal Investigator: Dr Felicity Bright

AUT
TE WĀNANGA ARONUI
O TĀMAKI MAKAU RAU

Psychosocial well-being after stroke

A sense of well-being is important for everyone. However, it is often affected when someone has a stroke. Many people feel grief, sadness and a loss of 'who they are'. The effects of stroke can make it hard to do the things that normally bring people joy and connection and influence a person's well-being.

Stroke survivors, whānau, and clinicians all say it is important that well-being is supported in stroke services. However, they also say there is scope for services to "do things different"[1], and do things better, to consistently support well-being for everyone.

In this project, we are seeking to:

1. Understand what matters for well-being within the experience of stroke
2. Identify how well-being is currently supported in stroke services, and identify how different aspects of care impact well-being
3. Together with stroke survivors, whānau and clinicians, explore how things could be done differently to better support well-being after stroke
4. Produce tangible resources to support care that enhances well-being

Who is doing this research?

This research is led by Dr Felicity Bright. Felicity is a speech-language therapist and rehabilitation lecturer and researcher at Auckland University of Technology.

Felicity is joined by Bobbie-Jo Wilson (Ngāti Tūwharetoa) who is leading our engagement with Māori, and Claire Ibell-Roberts. BJ and Claire are both physiotherapists and health researchers.

We are supported by Rukingi Haupapa (Te Arawa, Ngāti Whakaue).

A number of students have also contributed to this work: Kelsey Beet, Chelsie Park, Nikita Ngarongo-Porena, Holly Hing, Kira Milne, Caitlin Thomas, Karina Delemont, Olivia Grigg, April Reid and Lisa Keeley McDonnell.

This study has ethical approval from the Auckland University of Technology Ethics Committee (21/223), the Counties Manukau Health Research Committee and the Bay of Plenty DHB Clinical School Research Office.

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[1] A quote from stroke whānau at a wānanga in Whakatane

Our research approach

He Awa Whiria

Our research approach is based on *He Awa Whiria–Braided Rivers Model.* In this, Māori and non-Māori knowledges are uniquely engaged with, and considered together at different points throughout the research process. This approach enhances understandings but ensures each stands in its own right.

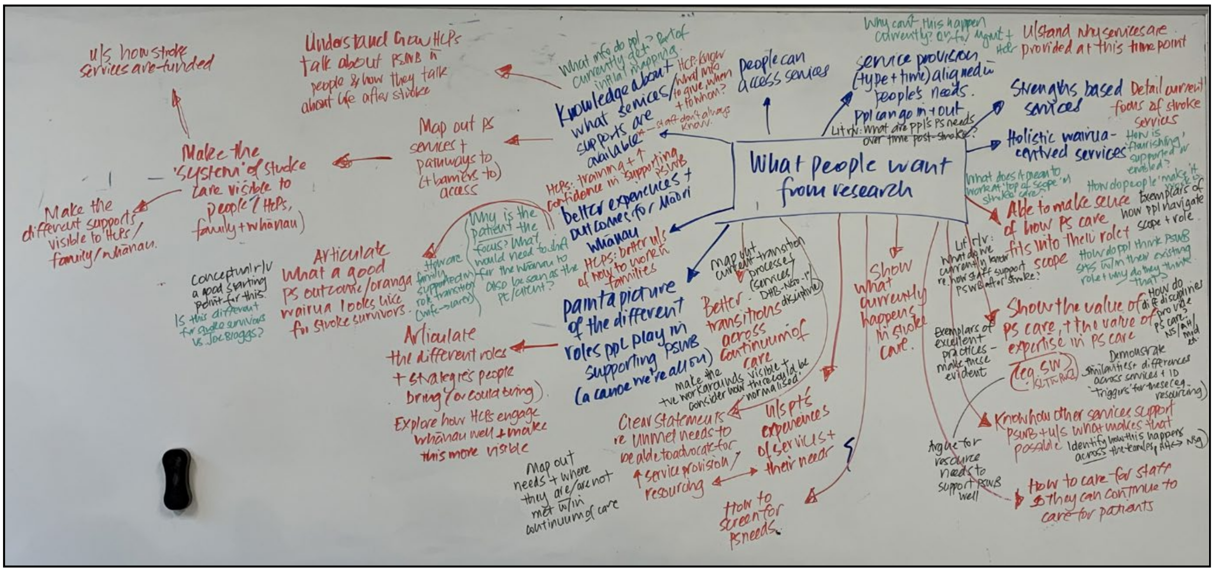
Utilising He Awa Whiria is one way we are honouring our responsibilities under Te Tiriti o Waitangi. Māori and non-Māori experiences, perspectives and knowledges hold equitable value and privilege. We acknowledge mātauranga Māori as its own interwoven form of knowledge that is critical for ensuring research and resulting practice recommendations are Māori centred, reflect Māori aspirations and contribute meaningfully toward achieving health equity for stroke whānau.

Connecting with Awhi Mai Stroke Trust

We have been fortunate to have the support of whānau from the Awhi Mai Stroke Trust in the Bay of Plenty. They have offered advice and direction as we have developed the research proposal and supported us in connecting with whānau. We will continue to connect back with Awhi Mai whānau, sharing research findings and supporting their aspirations for improving experiences for Māori in the Bay of Plenty.

How we developed our research

In developing this proposal, we met with clinicians, health managers, and stroke survivors and their whānau, to explore their priorities for this research. Everyone agreed that psychosocial well-being and psychosocial care is often invisible and undervalued. They want this research to make psychosocial well-being and psychosocial care visible and valued.



A summary of our discussions with stakeholders

Stroke whānau want strengths-based services that are holistic and wairua-centred. Clinicians want to know how to provide this—tangible examples of what this looks like. They want to be more confident and supported in providing this care, and in advocating for this approach to managers and funders. Whānau want to be recognised as key in supporting well-being and want knowledge and resources to do this.

We will keep connecting back with these communities throughout the research to make sure we are on track in supporting their needs and ultimately, supporting better experiences and outcomes for those with stroke.

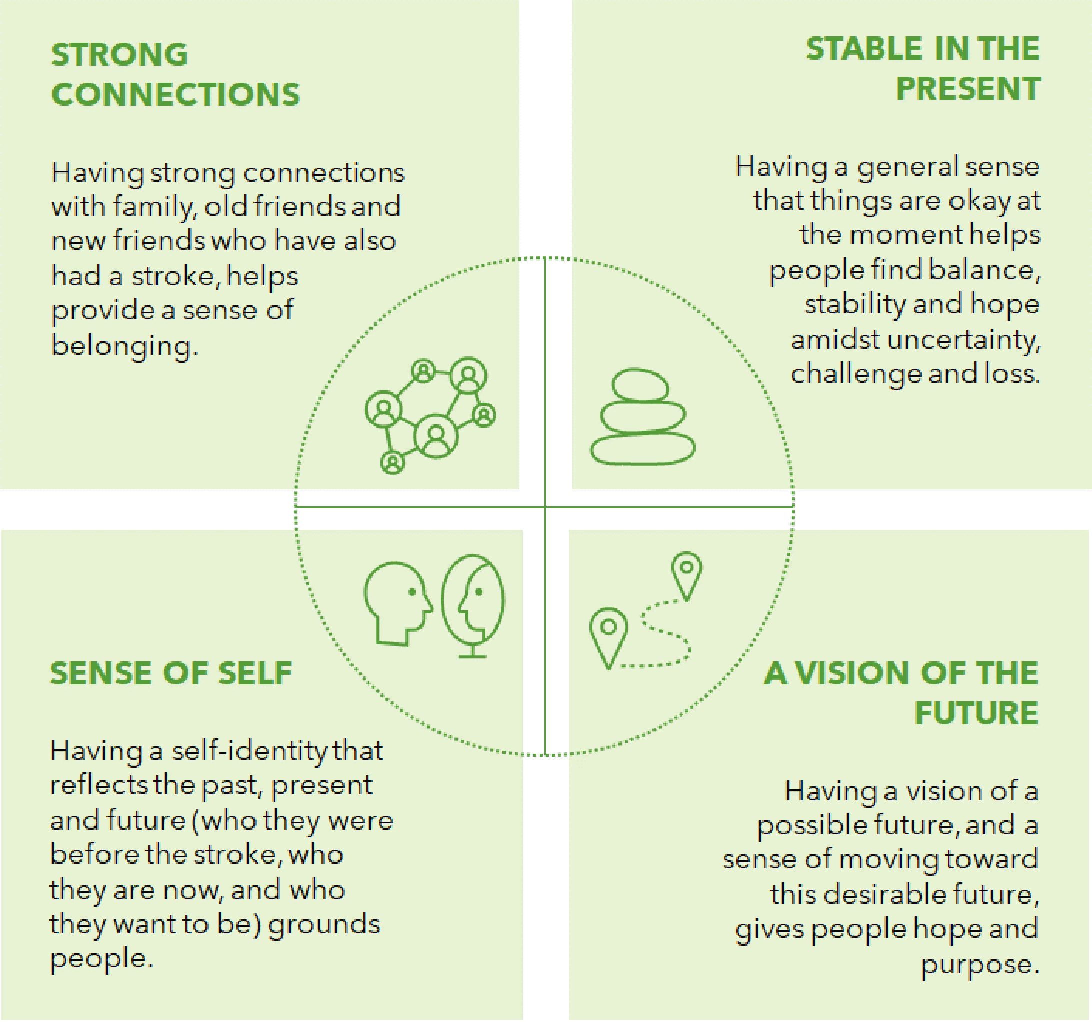
What is psychosocial well-being in Aotearoa?

A review of the literature

We wanted to find out what people have said about how they experience well-being after a stroke. Researchers have explored this overseas, but we weren't sure that their definitions would be 'fit for purpose' in Aotearoa New Zealand. We reviewed the literature on life after stroke in Aotearoa. We focused on qualitative literature in which stroke survivors shared their experiences with researchers, finding 19 papers which gave insight into how people experienced psychosocial well-being. Three of these papers specifically explored Māori experiences after stroke.

Well-being in Aotearoa New Zealand

Looking across all of the papers in the literature review, four things appeared to be key in well-being in Aotearoa.



STRONG CONNECTIONS

Having strong connections with family, old friends and new friends who have also had a stroke, helps provide a sense of belonging.

STABLE IN THE PRESENT

Having a general sense that things are okay at the moment helps people find balance, stability and hope amidst uncertainty, challenge and loss.

SENSE OF SELF

Having a self-identity that reflects the past, present and future (who they were before the stroke, who they are now, and who they want to be) grounds people.

A VISION OF THE FUTURE

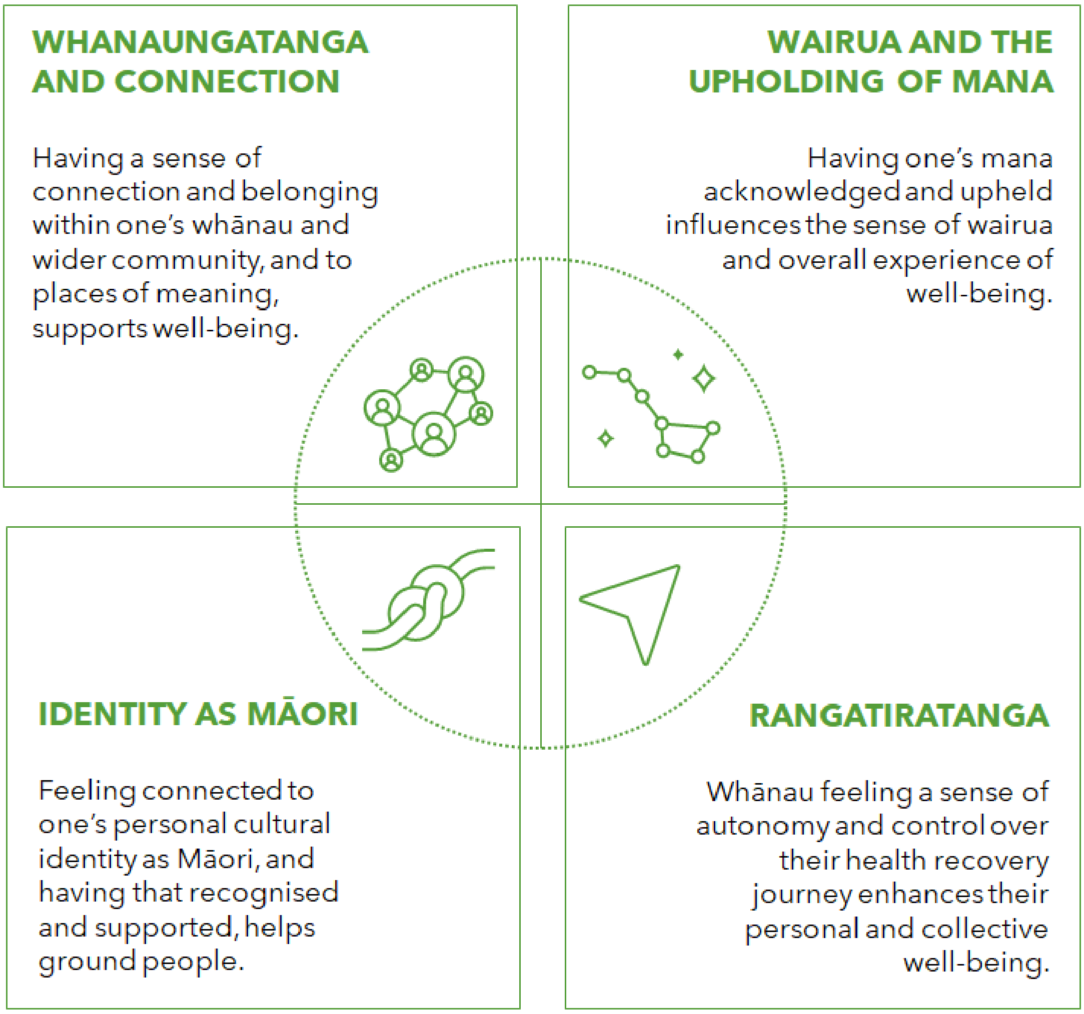
Having a vision of a possible future, and a sense of moving toward this desirable future, gives people hope and purpose.

This review will be submitted for publication shortly.

Oranga wairua: Māori experiences of well-being

A review of the literature

We are currently completing a literature review of Māori experiences of life after stroke, drawing on published research (six journal articles) and five theses. This deepens our understandings of what is important in well-being after stroke for Māori.



WHANAUNGATANGA AND CONNECTION

Having a sense of connection and belonging within one's whānau and wider community, and to places of meaning, supports well-being.

WAIRUA AND THE UPHOLDING OF MANA

Having one's mana acknowledged and upheld influences the sense of wairua and overall experience of well-being.

IDENTITY AS MĀORI

Feeling connected to one's personal cultural identity as Māori, and having that recognised and supported, helps ground people.

RANGATIRATANGA

Whānau feeling a sense of autonomy and control over their health recovery journey enhances their personal and collective well-being.

Whānau is particularly important in supporting well-being, for enhancing people's wairua after stroke, and upholding mana. It is clear that stroke has a ripple effect on the well-being of others within the wider whānau that is often not recognised or acknowledged.

This literature review will be completed in 2022.

Exploring ‘psychosocial well-being’ in Aotearoa

Talking with those living with stroke and clinicians

We are **talking with stroke whānau**–people who have had strokes themselves, and the whānau who support them and are themselves affected by the stroke.

We are also **talking to a wide range of people working across stroke services**–from people working in acute stroke wards through to GPs and community support professionals who support people after they leave services.

In this, we are seeking to understand:

Those living with stroke

What matters for well-being

How people’s well-being was supported within stroke services

What services could do better to support well-being

Clinicians and service leaders

What matters for well-being

How clinicians currently support well-being

What impacts on how clinicians support well-being

To date, we have spoken with 17 Māori stroke whānau and 21 clinicians and stroke service leaders.

We are seeking to talk with ~35 people living with stroke and ~45 clinicians and service leaders.

How psychosocial well-being is supported in stroke services: An early analysis

We have started analysing the kōrero that people have shared with us.

We are **mapping out what happens in services**–*all* the work that goes on–and looking at where, within all of this activity, psychosocial well-being is addressed.

Picture of our whiteboard, mid-analysis!

We are seeing that **the 'small things' are important in psychosocial care**. This includes the way staff watch out for how patients and whānau are coping with the stroke, the way they create a space that is inviting and supports people to express what they're feeling, and the small conversations they have where they talk about what's happening now and where they talk about the future.

We are hearing about the importance of **engaging with whānau** and recognising the strengths they have. Whānau have deep knowledge of the person with stroke and can support clinicians. They are crucial in supporting the well-being of the person with stroke. They also have their own well-being needs. However, we are also hearing that whānau are not involved as much as they could be.

We are seeing **there are gaps in care**. These gaps become obvious when we compare what patients tell us they need with what clinicians tell us they do. But we are also starting to see *why* some of these gaps are there. By looking at why these gaps come about, we can better understand why clinicians work as they do, and we can start to think about what things might be able to change–and what things might be challenging to change.

Our next steps in the research

2022

Understanding people’s well-being needs and current service provision

In 2022, we will build a deeper understanding of what is currently happening in care, what stroke survivors and whānau experience in stroke services, and what they need to support their long-term well-being.

We need to learn more about how services are structured and funded, and how this impacts on what happens for patients.

We will keep connecting with our participants so they remain up to date with what is happening in the research.

2023

Identifying priorities for change

We are already hearing what people think is working well in supporting well-being. We are also getting clear messages about what could be done differently to support the well-being of stroke survivors and whānau. We will take our research back to the communities involved–clinicians, stroke whānau and stroke managers–to explore their priorities for change.

2024

Developing resources to support practice change

In the final year of the project, we will develop resources to support psychosocial well-being. The exact nature of these, including who these will be for, will be determined (with stakeholder engagement) during the research process. Whilst there may be many resources that might be helpful, we will likely focus on one or two particular areas, given the resources *we* have to work with.

We would love to talk with you

Are you interested in sharing your perspectives and experiences about psychosocial well-being in stroke?

We are particularly keen to talk with:

- Clinicians in acute care and rehabilitation,
- People working in support roles who often play an important (but unseen) role in supporting well-being such as ward clerks or assistants
- GPs
- Health service managers
- People who have been affected by stroke in the last two years and their whānau
- People who are living in residential care, or who have whānau in residential care

Would you like to be involved in priority setting for service change?

Please feel free to contact us if you are interested in taking part in this in 2023.

Would you like to hear more about the research as it progresses?

Just let us know! We are really happy to share information on a regular basis via email.

If you would like us to share any of the work we're doing with your team (e.g. at an inservice), we're really happy to explore this with you.

We can be contacted at wellbeing.study@aut.ac.nz or

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