Unspoken, unseen and at time silenced:
The emotional work of people in stroke services in Aotearoa

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TE WĀNANGA ARONUI O TĀMAKI MAKAU RAU

Background

Well-being is critical to living well and flourishing after stroke. While physical aspects of recovery are commonly well-addressed within services, broader aspects of well-being, including emotional aspects, can remain unrecognised and unsupported in care.

Study aim: To identify how people's experiences in stroke services impact on well-being.

Methods

Methodology: Interpretive Description, exploring the experiences of people, family and whānau[1] in stroke services

Data gathering: Semi-structured interviews

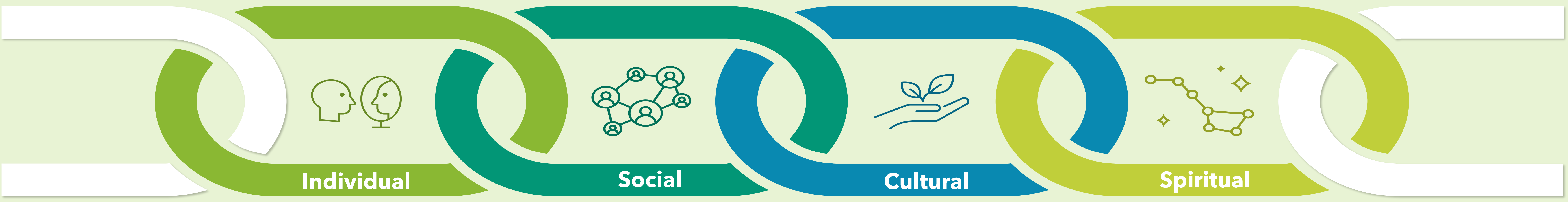
24 people with stroke and 13 family and whānau members

Data analysis: Reflexive thematic analysis

Findings

People undertake significant emotional work to navigate the impacts of stroke. People are involved in sense-making about the past and why the stroke occurred, (re)negotiating what is meaningful, navigating deep uncertainty and feelings of disconnection from self, from important others, and from elements of meaning in life. However, the depth of this work was reportedly unseen by others, sometimes hidden from staff, and at times, made visible but then actively or passively silenced through care practices. This could compound the emotional burden carried by people with stroke and whānau, and overall, contributed to people feeling alone and unheard. This burden could be mediated through the inherent resources that people held, through family, whānau and social networks, through cultural and spiritual identity, and through the practices of stroke clinicians.

Resources people draw on to support emotional well-being



Individual
Intrinsic drive for self-reliance
Setting small achievable goals
Seeing progress

Social
Emotional support from family, whānau and friends
Contributing in meaningful ways within whānau

Cultural
Wairua[2]
Connection to cultural identity as Māori

Spiritual
Anchoring to spiritual beliefs
Feeling connected to something larger than oneself

How services can hinder, or support emotional well-being

HOW SERVICES CAN HINDER EMOTIONAL WELL-BEING

> "You are not allowed to be pissed off that you had a stroke. The unending positivity that you have to display, so what you've had a stroke, just get on with it..it is one thing that we totally get pissed off hearing. It's going to be alright so you've had a stroke. And it's not."

> "You can't look after the hinengaro[3] without looking after the wairua and the tinana[4]. They all go together and it's when it's all broken up and things are done separately that people become unwell and the being is not well."

Busyness of staff
The perceived busyness of staff could inhibit people from reaching out for fear of burdening staff or being dismissed.

Focus on the physical
Staff did not always attune to or ask about people's emotions; instead conversations often focused on physical needs.

Minimise challenges
When told their emotions were "normal" or that they should "be positive", people could feel like their emotional needs were minimised.

Exclude family & whānau
Despite the importance of family and whānau as a source of, and support for, well-being, their involvement was not often actively sought.

Diminish worldview
Service environments, processes and care practices could actively diminish worldview and cultural identity, particularly for whānau Māori.

HOW SERVICES CAN ATTEND TO EMOTIONAL WELL-BEING

Value therapeutic relationships
When people felt they had a good relationship with staff, they were more likely to share their emotions.

Intentional check ins
Regular, intentional but informal 'check ins' and allowing time for "sitting and talking" supported people to discuss the past, present and future.

Share information
Consistent information about the stroke, what will happen next in care, and what might happen in the future helped to manage uncertainty.

Psychological support
Access to regular, specialised psychological support that included family was pivotal for some.

The small moments
Staff who "worked from the heart" had a significant impact. Even brief but genuine interactions could lift a person's day; the little things matter.

> "There was just something about their relationship that I think helped him a lot. Like she would acknowledge his capabilities and how it's a bit harder now, talked about his studies, yeah.. she talked to him often quite personably, like personal conversation."

> "She just spent a lot of the night with me. I really was disturbed, couldn't sleep and I was restless…She wasn't in a hurry. It was as if 'well no one else needs me um I'm here to help you' sort of thing, you know?"

IMPLICATIONS FOR SERVICE DEVELOPMENT AND DELIVERY

Care processes did not appear to prompt or support staff to attend to people's emotions; instead, this was reliant on individual staff recognising and providing support. A rethinking of what is considered valued and legitimate, and what is prioritised in care, is required to foster the well-being of people, family and whānau after stroke.

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[1] Whānau: An integral cultural construct for Māori which both includes, yet extends beyond commonly understood parameters of 'family', to those within a person's wider network who they identify as important to them
[2] Wairua: This has many dimensions relating to the spirit and spirituality. See Valentine,Tassell-Mataamua & Flett (2017) Whakairia ki runga: The many dimensions of wairua. *New Zealand Journal of Psychology. 46*(3), 64-71
[3] Hinengaro: Relates to mental and emotional well-being. [4] Tinana: Relates to physical well-being.

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