

# BMJ Open What are the core features of stroke care that support well-being? A qualitative study from the perspectives of people with stroke, whānau and stroke care providers in Aotearoa New Zealand

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## ABSTRACT

**Objectives** To identify the core attributes of quality care that supports well-being from the perspectives of those who access and provide stroke services.

**Design** Qualitative Interpretive Description study design involving in-depth semistructured individual and group interviews and analysis using journey mapping and conventional content analysis.

**Participants** 24 people with stroke, 13 family/whānau members and 34 healthcare professionals located throughout New Zealand.

**Setting** Participants were recruited through health services, stroke support organisations and professional networks. Interviews were completed in person at people's homes or workplaces or on an online videoconference.

**Results** Analysis generated a quality framework of domains. High-quality care that supports well-being after stroke in Aotearoa: supports people through uncertainty; fosters a sense of belonging; prioritises relationships and connecting 'as people'; attends to the emotional aspects of stroke; centres people's preferences and supports people to have choice and control; honours Māori knowledges and practices; responds to the strengths and needs of friends and whānau; and attends to people's holistic long-term well-being.

**Conclusions** This study offers a framework for considering holistic stroke care that supports areas of need not consistently addressed in stroke services. This framework can help structure practice and policy and can underpin future research in well-being.

## BACKGROUND

Stroke is a leading cause of disability and death internationally, with nearly 94 million people living with stroke in the world.<sup>1</sup> Within New Zealand, around 9000 people experience a stroke each year; this is projected to increase by 40% by 2028.<sup>2</sup> The impacts of stroke vary, but commonly include physical, cognitive and communication impairments, impacting on people's activities, participation and quality of life.<sup>3</sup> The impacts further extend to people's well-being.<sup>4–6</sup> Well-being is multidimensional

## STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ Use of a robust qualitative methodology by experienced qualitative researchers with expertise in stroke practice and research.
- ⇒ Engagement of people with lived experience of stroke and healthcare professionals in designing the research and commenting on study findings.
- ⇒ A diverse sample of people with stroke, with equal representation of Māori (Indigenous people of New Zealand) and non-Māori, but limited involvement of Pacific and Asian people with stroke.
- ⇒ Research conducted in Aotearoa New Zealand means some aspects may have limited transferability internationally.

and can include areas such as mood, self-identity, emotions, hope, social relationships, autonomy, cultural identity, connections with people and places, and spiritual well-being.<sup>5–8</sup> Notions of well-being are culturally grounded, with our recent work demonstrating aspects unique to Māori, the Indigenous people of New Zealand.<sup>5</sup> This work showed that some elements of well-being were common across people with stroke, such as the importance of social connections, sense of self, hope for the future and a sense of progress; however, there were unique elements for Māori, including connection to places of meaning and to the spiritual realm; connection to one's cultural identity as Māori; and the importance of rangatiratanga (autonomy and control) over one's recovery journey. Further, Māori highlighted how their experiences in stroke care could negatively impact their well-being due to there being 'no Māori-ness about them', not having cultural identity integrated into care, and in some instances, experiencing culturally unsafe care.<sup>9</sup> This highlights the need for care practices that are holistic and culturally grounded, designed for the local



clinical, social and cultural contexts in which care is provided.

In New Zealand, stroke care is predominantly oriented toward clinical management of the stroke, addressing physical functioning and moving patients toward discharge.<sup>10</sup> However, in New Zealand and internationally, stroke survivors and their families identify that well-being is a critical area impacted by stroke; they also identify that this is an area that is not well-supported within stroke services.<sup>5 11 12</sup> When well-being is impacted, this can contribute to disengagement from services,<sup>13</sup> high rates of depression and anxiety post-stroke<sup>14 15</sup>—rates that are nearly doubled when someone has aphasia,<sup>16 17</sup> social isolation<sup>18</sup>—again, higher when someone has aphasia,<sup>19</sup> increased suicide risk,<sup>20 21</sup> and can impact on family well-being.<sup>22</sup> These contribute to poorer post-stroke recovery. Healthcare professionals are aware of the need to support well-being and desire further guidance on how to support well-being.<sup>10 23</sup> National and international guidelines have a limited focus on well-being, attending more to how to address emotional and psychological issues that arise rather than preventing issues arising in the first place with mood disorders the most common dimension discussed internationally.<sup>3 24 25</sup> Within guidelines, some dimensions of well-being are addressed in the context of community integration,<sup>25</sup> and activities such as return to work and sexual activity.<sup>3 26</sup> Other dimensions of well-being, such as social relationships are sometimes recognised as important<sup>3</sup> but little guidance on how to address these in stroke services is provided. Within research, approaches to addressing well-being have predominantly focused on discrete interventions that can address specific dimensions of well-being such as psycho-education to support adjustment and emotional well-being<sup>27</sup> and psychotherapeutic-informed interventions to address anxiety and depression.<sup>28</sup> Other interventions have addressed more diverse aspects of well-being such as life story approaches to support identity (re)development post-stroke,<sup>29</sup> peer befriending to support adjustment, resilience and hope, and reduce distress<sup>30 31</sup> and improving social participation post-stroke.<sup>32</sup> Yet, models such as the Stepped Care model of psychological intervention<sup>33</sup> and recent psychosocial well-being guidelines in New Zealand<sup>34</sup> have emphasised the importance of embedding well-being into routine care practices. The literature does provide some guidance as to how this could be done. For instance, McClure and Leah<sup>35</sup> emphasise the importance of supporting autonomy,<sup>35</sup> Brewer and colleagues<sup>36</sup> provide recommendations for supporting Māori through culturally informed aphasia rehabilitation practice and Bennett<sup>37</sup> provides rich description of how nurses support people's emotional well-being in stroke services. However, there is limited literature that details a multicomponent approach to supporting well-being in routine care practices in stroke services. Given our previous work has shown a persistent challenge in providing support in everyday stroke care in Aotearoa New Zealand, and that healthcare practitioners

seek further guidance on how to support well-being,<sup>10</sup> it is clear that there is a need for empirically informed frameworks to support future practice development. Given the fact that well-being is not well-addressed within stroke services and that this contributes to ongoing distress and disability post-stroke,<sup>4 5 12 38</sup> we suggest that there is a real need to consider how healthcare professionals can be supported to better address well-being within everyday care practices and processes, with the aim of improving patient and family experience and reducing the distress that may arise from stroke.

Learning from people with stroke can give insights into what aspects of care are important for supporting their well-being. It is clear from the wider literature on quality of care that patients and healthcare professionals often prioritise different things when describing what is important for high-quality care<sup>39</sup> and gathering perspectives of patients, family and healthcare professionals is key in developing comprehensive understandings of quality of care.<sup>40</sup> In designing this research, a Māori woman with decades of lived experience of stroke challenged us to identify how stroke services could 'do things different' to better support people's well-being. In this, she urged us to not perpetuate the status quo, but to challenge what and how services were provided, and provide a framework for how stroke practices could be different. In response to this challenge, we have undertaken a research programme on well-being after stroke that seeks to understand how well-being is currently being addressed, to identify why care is provided in this way, and to propose how well-being might be better addressed in stroke services in New Zealand in the future. In this paper, we aim to identify and articulate core components of stroke care that support well-being, from the perspectives of those who access, experience and provide stroke services, generating a holistic practice framework that can be applied across stroke services to guide practice and quality improvement initiatives to improve people's well-being after stroke.

## METHODS

This research was underpinned by Interpretive Description,<sup>41</sup> a practice-centred qualitative approach that seeks to examine issues of practice (in this case, the perpetual failure to address well-being in stroke services) and identify solutions to enhance practice.

## Participants

People were eligible to participate if they:

1. Had experienced a stroke themselves, were over 18 years of age and were able to communicate with the researchers in English, with support provided for those with cognitive and communication impairments.
2. Were a family/whānau member of a person with stroke and were over 18 years of age (whānau referring to people within a person's wider kinship network).
3. Worked with people with stroke in a professional capacity, for instance, as a healthcare professional, in

management/leadership roles, or within a stroke support organisation. Within this paper, this participant group is referred to as ‘healthcare professionals’.

### Recruitment

We intentionally sought diversity in participants, seeking equal representation of Māori and non-Māori participants impacted by stroke, and diversity in geographic location, age and stroke effects. For healthcare professionals, we sought a range of professional discipline, organisation types and experience. Using purposive sampling,<sup>41</sup> we recruited through multiple means. For people with stroke and whānau, we recruited through two public stroke services covering urban and rural areas in the North Island with information about the research provided by treating healthcare professionals, emails and online notices through national stroke support organisations, and leaders in Māori stroke support groups who shared information about the research with group members. For healthcare professionals, we recruited through the same two public stroke services, across acute and rehabilitation services, with researchers sharing information in presentations and emails and by publicising the research through the personal and professional networks of the research team via conversations and emails. Data collection and initial data analysis occurred in parallel with early analysis informing ongoing recruitment and sampling approaches. The sample size was guided by the concept of information power<sup>42</sup> with our sample considered adequate given the study’s specific aim, dense sample of people with significant lived experience, rich, quality data gathered through interviews and focus groups with experienced researchers, and in-depth case and cross-case analysis.

### Ethical approval

All potential participants were provided with verbal and written information about the study. Informed consent was gained prior to data collection commencing. Ethical approval was obtained from the Auckland University of Technology Ethics Committee and organisational approvals were obtained from recruiting localities.

### Data collection

Data were collected through in-person and online semi-structured interviews with individuals (n=40) and small groups (n=31 participants across 14 groups). Small group interviews occurred with family groups (n=10, 21 people), groups of stroke survivors/whānau who were friends (n=1, 3 people) and with colleagues who preferred to be interviewed together (n=3, 7 people). These occurred in a variety of locations, including online, in people’s homes and at people’s workplaces. Interview guides were developed, informed by a review of the literature<sup>5</sup> and by feedback gathered during the consultation phase (see ‘patient and public involvement’ section below). The interview guides are provided in online supplemental files.

Interviews with Māori participants recruited through the Māori stroke organisation were led by a Māori researcher following tikanga (protocols) of engagement. These prioritised whakawhanaungatanga (building connections through conversation and mutual sharing about oneself) followed by interviews. Interviews with all other people with stroke were conducted by a Pākehā (non-Māori, of European descent) researcher (CIR). Interviews with people with stroke and whānau explored people’s understandings of well-being, their journeys of well-being post-stroke, influences on well-being, their reflections on how it was addressed within their care during their stroke journey, and how care practices and processes could be enhanced to support people with stroke. Interviews with Māori also explored the unique experiences and needs of Māori accessing services within a Western stroke system. Interviews with healthcare professionals were led by Pākehā researchers (FB and CIR). Interviews explored their understandings of well-being, how it was addressed within services, differences between actual and desired service provision, different influences on how care was provided, and reflections on how well-being could be better provided within stroke services. The research team all had experience in undertaking qualitative interviews; all were experienced healthcare professionals as well as researchers with experience relating to the topic, including patient experiences in stroke care, well-being and kaupapa Māori research.

Individual interviews lasted between 60 and 90 min, while small group interviews lasted between 60 and 120 min. All interviews were audio-recorded and transcribed.

### Data analysis

Analysis involved multiple iterative techniques, something encouraged within Interpretive Description.<sup>41</sup> Our research team commenced analysis with a process of deep familiarisation, writing detailed memos of each interview and summarising core messages. We created journey maps, a method for organising complex data from various sources to examine people’s experiences of care and well-being across different services over time.<sup>43</sup> Our maps captured care practices and processes, people’s well-being needs and experiences, areas of met and unmet needs, and layered in the perspectives and work of healthcare professionals, and the organisational and structural factors that shaped practice. These maps of care served as the base for the analysis that underpins the framework presented in this paper. Examining these maps using conventional content analysis,<sup>44</sup> we identified key areas that people with stroke and whānau identified as important for their well-being, both at the point of care and for their long-term well-being after stroke. Through regular analytic discussions, we refined these to eight key areas that form the basis of this framework. We then returned to the journey maps and to interview transcripts to examine how people suggested these eight areas were, or were not considered or addressed within services. We also identified people’s suggestions for service



improvement. Throughout this analysis, we prioritised the perspectives of people with stroke and their whānau; data from healthcare professionals were used to supplement and extend understandings and provide exemplars of care processes and practices that impacted well-being.

### Patient and public involvement

Prior to commencing the research, we engaged with people with stroke, whānau members and healthcare professionals to identify research priorities and gather advice on research conduct, recruitment, questions and outputs.<sup>45</sup> These priorities and recommendations underpinned the research process. We also returned to participants to share research findings and gather critical feedback on the aspects of care identified as being key in supporting well-being after stroke.

### RESULTS

Participants were 24 people with stroke and 13 whānau members. Across these two groups, 19 were Māori. 34 healthcare professionals in clinical, support and managerial roles also participated. People with stroke were from across the North Island of New Zealand, predominantly from urban areas (as classified using the Geographic Classification for Health (GCH), a system of defining people's health locations<sup>46</sup>). The majority of people had experienced stroke within the last 5 years. They were on average 54 years old at time of stroke, with a range of 34–80 years. They self-reported a variety of stroke impacts, predominantly describing physical, speech and language impacts. While we had strong Māori representation, we recruited only one Pacific person and one person of Asian ethnicity. The full description of stroke participants is provided in [table 1](#). Whānau members were predominantly female, Māori, and comprised a range of relationships including spouse, sibling and child as shown in [table 2](#). Healthcare professionals worked across stroke care settings in the North Island of New Zealand. Like stroke participants, most were located within urban centres. We had representation across healthcare disciplines and professional experience, with the median experience of 12.5 years (range 2–41 years). Most worked predominantly with people with stroke, but nearly all had a mixed caseload, working with people with a range of neurological or age-related health conditions. Characteristics of healthcare professional participants are shown in [table 3](#).

Within the interviews, participants provided clear information about what aspects of care they perceived to be important in supporting people's well-being, both in the moment (at the time of care) and in the long term (extending to the long-term future of months and years after stroke). As such, we propose an empirically derived quality framework of domains of care that appeared most important to people with stroke and their whānau, shown in [figure 1](#). High-quality care that supports well-being after stroke in Aotearoa: supports people through uncertainty; fosters a sense of belonging; prioritises relationships and

connecting 'as people'; attends to the emotional aspects of stroke; centres people's preferences and supports people to have choice and control; honours Māori knowledges and practices; responds to the strengths and needs of whānau and friends; and attends to people's holistic long-term well-being. These are detailed in [table 4](#), with indicators of each of these domains. We then provide a narrative description of each domain, sharing participants' descriptions of how these were addressed in care, considering these in the contexts of their experiences of stroke, accompanied by solutions identified by people with stroke, whānau and healthcare professionals. Further examples are shared in the online supplemental table S1, which incorporates many indicators of quality care, with supporting quotes, providing examples of when elements of high-quality care were achieved, and when they were not achieved.

### Care supports people through uncertainty

Patient and whānau participants described significant uncertainty after the stroke. This related to the cause of the stroke, subsequent care, available supports and what the future might look like. Participants across all groups highlighted the importance of acknowledging uncertainty with some healthcare professionals suggesting that this validated people's experiences and created space for people to discuss their uncertainty:

I would usually start by acknowledging the enormity of what's happened. I start from that point of, you know actually what a horrible, horrible shock, and a horrible thing to have to try and cope with, and so much has changed, and then just leave the whole thing open and just see what comes out (for the person with stroke). (Advisor, Pākehā)

People with stroke and whānau valued timely and repeated conversations about the stroke, care and future prognosis. They consistently described the importance of having key support people present for these conversations, especially when they related to potential negative outcomes. Personalised, repeated stroke-specific information appeared more likely to occur in services with a clinical nurse specialist for whom information provision was a key aspect of their role. Conversations were often also embedded in everyday conversations with nursing and allied health, often across multiple interactions in the context of consistent relationships:

They (OT and PT) were fantastic, they were really good. A lot of the time our sessions went longer than they were meant to because we were just yakking about what had happened and what I could look at achieving at those sorts of things, and how the progress was going and things to look out for. (Person with stroke, Pākehā)

Māori with stroke described the importance of understanding the wider impacts of stroke, not just on people's physical function, but their mental and spiritual

**Table 1** Characteristics of people with stroke

<b>Age at time of stroke</b>	
<20	1 (1 Māori)
20–29	–
30–39	2 (1 Māori)
40–49	7 (4 Māori)
50–59	4 (3 Māori)
60–69	7 (3 Māori)
70–79	2
>80	1
<b>Years post-stroke</b>	
<1 year	10
1–4 years	5
5–9 years	5
10–14 years	1
15–19 years	–
>20 years	3
<b>Self-reported impacts of stroke</b>	
Physical impairments including hemiplegia, reduced balance and co-ordination, sensory impacts	14
Speech and language impairments	12
Fatigue	8
Cognitive impairments including impacts on concentration, memory and processing	5
Stress and anxiety	2
Agnosia	1
Pain	1
<b>Gender (self-identified)</b>	
Male	11
Female	13
<b>Ethnicity (noting people self-identified ethnicity and some selected &gt;1)</b>	
European	11
Māori	12
Pacific peoples	1
Asian	1
<b>Residential location using GCH classification</b>	
Urban 1	17
Urban 2	6
Rural 1	1

GCH, Geographic Classification for Health.

well-being. While sometimes this information came from healthcare professionals, it was more likely to come from other Māori with experience of stroke.

However, it was common for people with stroke and whānau to describe receiving little information, or to identify that they received information but could not understand it:

I didn't really understand a word (the health professionals) were saying...(I could ask questions) but I didn't really want to cause I knew I wouldn't

understand what the heck they were about to say. (Family member, Māori)

People with stroke valued prognostic information but healthcare professionals reported caution about providing prognoses, concerned about providing incorrect information or false hope and often feel unequipped to handle these conversations. This exacerbated uncertainty for people with stroke.

People sought information about what core services and ward routines, with one suggesting a 'ward nana'—a

**Table 2** Characteristics of whānau members

<b>Gender (self-identified)</b>	
Male	3
Female	10
<b>Ethnicity</b>	
European	4
Māori	7
Asian	1
Not given	1
<b>Relationship</b>	
Spouse/partner	6
Child	2
Sibling	3
Carer	1
Parent	1

lay person familiar with the services—could help navigate uncertainty. Further, they sought knowledge of what to expect from post-discharge services, including contact

**Table 3** Characteristics of healthcare professionals

<b>Gender (self-identified)</b>	
Male	4
Female	30
<b>Professional role (noting some held more than one role)</b>	
Nurse	9
Allied health professional	17
Advisor (in stroke support organisation)	4
Manager	3
Doctor	3
Care co-ordinator	1
<b>Service working within</b>	
Primary care	1
Public stroke services (Acute, inpatient and community rehabilitation)	26
Non-government stroke rehabilitation services	2
Stroke support organisations	5
<b>Ethnicity (noting people self-identified ethnicity and some selected more than one ethnicity)</b>	
European	27
Māori	2
Asian	2
Other (not identified)	4
<b>Work location using GCH classification</b>	
Urban 1	27
Urban 2	7
Rural 2	1

GCH, Geographic Classification for Health.

timelines and details before leaving hospital. This information appeared more readily available in services with established community stroke teams and clear care pathways. When this was not available, friends and family sought information and support, but this was challenging without adequate knowledge of health and social systems, and even then, contributed to high levels of stress after discharge.

### Care fosters a sense of belonging

A sense of physical, cultural and relational belonging gave people with stroke and whānau a sense of stability and reassurance that they belong in the stroke services and were in the ‘right place’ for their recovery. People with stroke commonly felt reassured by being in stroke-specific services. They valued welcoming, age-appropriate and consistent care environments with one healthcare professional observing “being part of a community of others that understand your situation is a really important part of healing” (Advisor, Pākehā). However, this was not always easy to achieve. Many stroke services in Aotearoa are part of older person’s health services, or have predominantly older patients, making younger stroke patients feel out of place:

I was in the aged caring unit with people who were about 80 years old ...that was horrible, I hated it, I hated it, and I was just desperate to get out of there. I was depressed. (Person with stroke, Māori)

Young people who required residential care post-stroke felt particularly out-of-place as they were often transferred to aged care facilities. Healthcare professionals recognised these challenges, describing how they were exacerbated by funding models which were age-based. For Māori, who often experience strokes at a younger age, this sense of ‘not belonging’ was intensified by Pākehā-centric services that did not reflect Māori knowledges and practices.

People with stroke and whānau valued a sense of relational belonging, achieved through connection with whānau, with other stroke survivors, and for Māori, connection with other Māori with stroke. They valued staff who supported these connections; this often helped build a sense of identity as a stroke survivor:

The (community team) ended up getting another one of their clients, because he was a young guy like (husband), similar stories, and they had their gym sessions together. And that was good for (husband) because, well he needs to see people and it’s always good for him to chat to someone that kind of understands, they’ve lived similar things, frustrations and that. (Family member, Pākehā)

These connections helped patients navigate life after stroke, support them to recognise their strengths, and maintain hope. Relational belonging could also be supported through welcoming shared spaces on wards, engagement with stroke support



**Figure 1** Components of the quality framework replaced.

organisations across Aotearoa, and community organisations accessible to people with stroke. Relational belonging was further supported by services which incorporated aspects of meaning within their physical environment, resources and activities. This helped people with stroke feel they were seen as people; it also made care more meaningful and helped them see how they could integrate meaningful activities into their post-stroke life.

#### Care prioritises relationships and connecting 'as people'

The relationship between the person with stroke, whānau and healthcare professional contributed to people's

overall sense of well-being. A strong relational foundation was built when people with stroke and whānau perceived that staff wanted to get to know them as people, beyond the stroke. Participants described how this could be critical in deciding whether to engage, or how much to engage:

Know me before you fix me ... Don't rush ... When you know me, how will you know? There's no time with this ... Māori, when we engage with people at the beginning, we won't show you everything that we are, it's only as we start to trust people that we open up. (Person with stroke, Māori)

**Table 4** Core features of each quality domain

Quality domain	Elements of high-quality care
Care supports people through uncertainty	<ul style="list-style-type: none"> <li>▶ Uncertainty is explicitly acknowledged</li> <li>▶ The stroke, its causes and care processes are explained as many times as needed</li> <li>▶ All the key people are included in conversations</li> <li>▶ Information is given at appropriate times, in a relational manner, with time to discuss, ask questions and have these answered</li> <li>▶ Information is not generic but responds to the questions, priorities and context of the person with stroke</li> <li>▶ Before leaving hospital, people understand they have details about post-discharge services</li> </ul>
Care fosters a sense of belonging	<ul style="list-style-type: none"> <li>▶ People can access stroke-specific services in a timely manner</li> <li>▶ Services provide a welcoming, age-appropriate environment for people with stroke</li> <li>▶ Transfers between wards are minimised wherever possible</li> <li>▶ People are offered facilitated connections with others impacted by stroke</li> <li>▶ Whānau Māori are offered a connection with other Māori</li> <li>▶ People with aphasia are connected with others with aphasia</li> <li>▶ People connect with supports from outside stroke services to support wider sense of belonging and connection</li> </ul>
Care prioritises relationships and connecting ‘as people’	<ul style="list-style-type: none"> <li>▶ People feel that staff want to know them which helps build trust</li> <li>▶ Staff get to know people by asking about their lives, interests and what matters to them</li> <li>▶ Staff share of themselves so they are also known by people with stroke and whānau</li> <li>▶ Conversations with staff cover a range of topics, allowing them to gain a deeper understanding of the person and their whānau beyond the impacts of the stroke</li> <li>▶ People feel comfortable reaching out to staff anytime and are given a point of contact to make this easier</li> </ul>
Care attends to the emotional aspects of stroke	<ul style="list-style-type: none"> <li>▶ Staff are aware of the emotional impacts of stroke and are attentive to people’s emotional experiences</li> <li>▶ Staff initiate conversations about emotions and provide opportunities for people to discuss, if they wish</li> <li>▶ Staff show empathy and are unhurried in their interactions</li> <li>▶ People feel their experiences are normalised and validated, and not minimised</li> <li>▶ Staff are supported to provide psychologically informed care</li> <li>▶ People and whānau have access to culturally safe and culturally informed counselling or psychological support if they choose</li> <li>▶ People are encouraged to access emotional supports from outside stroke services</li> </ul>

Continued

Table 4 Continued

Quality domain	Elements of high-quality care
Care centres people's preferences and supports people to have choice and control	<ul style="list-style-type: none"> <li>▶ People are asked what is important to them and what they would like to see happen in their care</li> <li>▶ People see staff taking action on things they have discussed together</li> <li>▶ Staff acknowledge the effort and problem solving that people put into their recovery</li> <li>▶ People are supported to have greater autonomy when people seek this</li> <li>▶ There is shared decision-making about what will work best for the person and their whānau</li> <li>▶ Staff and services honour the right of Māori to have rangatiratanga (autonomy) over their healthcare</li> <li>▶ Services are flexible and available at times that suit the person and whānau</li> <li>▶ When a person's wishes cannot be upheld, alternative options are discussed together</li> </ul>
Care honours Māori knowledges and practices	<ul style="list-style-type: none"> <li>▶ Services embed a holistic understanding of well-being grounded in te ao Māori</li> <li>▶ Whanaungatanga is prioritised</li> <li>▶ Care upholds Māori worldview, knowledges and practices (tikanga) in care, information and resources</li> <li>▶ Māori have space and support to be together as Māori</li> <li>▶ Whānau Māori are supported to determine their own healthcare journey</li> <li>▶ Whānau Māori feel listened to and understood</li> <li>▶ Staff recognise key supports for Māori may come from outside services and work to make this possible</li> <li>▶ Staff and services recognise their own cultural perspectives and how these might influence care</li> </ul>
Care responds to the strengths and needs of friends and whānau	<ul style="list-style-type: none"> <li>▶ Staff introduce themselves and maintain regular contact with whānau</li> <li>▶ Staff learn who key whānau members or friends are and don't make assumptions</li> <li>▶ The knowledge and perspectives of whānau and friends are sought and respected</li> <li>▶ Whānau or key friends are asked what is important to them, what they need and how they want to be involved in care (to the extent agreed by the person with stroke)</li> <li>▶ Family meetings that are designed around patient and whānau needs and concerns</li> <li>▶ Services consider the current and future needs of whānau</li> <li>▶ There are comfortable spaces for the person with stroke to spend time with whānau and friends</li> </ul>
Care attends to people's holistic long-term well-being	<ul style="list-style-type: none"> <li>▶ Staff find out what is important for people's well-being</li> <li>▶ Care is holistic, integrating elements that support people to be and stay well in themselves</li> <li>▶ Goal setting is individualised and revisited often as people progress through care</li> <li>▶ Staff actively support people to engage in activities, roles, relationships and social contexts that support their well-being, including those outside stroke services</li> </ul>

People with stroke valued having a connection with staff as people, often helped by finding points of commonality, sometimes as simple as shared geographic familiarity or shared interest. This could create a relational connection and make it more likely that both parties would engage:

We had a wee conversation for a while, 'Where are you from?' Blah blah blah and I says, 'Oh yeah, I know where that is.' So, we connected on a different level. So every time, either she was in charge at that time or she'd be on another shift, and every time she came



passed me, it was, 'How are you today, Mr (name)? Are you well?' (Person with stroke, Māori)

People with stroke felt reassured and uplifted by empathetic, engaged staff who used various communication techniques, such as empathetic touch, tone, body language and humour. Positive relationships created an environment where people felt comfortable asking for support and had an uplifting effect, building people's self-belief. Participants across all groups suggested relationships appeared particularly crucial during unsettling times, such as the early days after a stroke and at times of transition. However, many people with stroke and healthcare professionals, especially Māori, suggested there was insufficient time for building strong relationships. This often depended on individual healthcare professionals prioritising relational work, something made more challenging if they did not feel skilled to do so, or if feeling pressured to focus on other aspects of care. Yet, the time and the relationship could be foundational for supporting conversations about well-being:

I find people when they want help around psychosocial issues, will not be direct with you, because through embarrassment and the stigma that still exists. I find they will send out little clues to you. And you can only pick up on those clues by actually having the time to sit and talk to them and making them feel relaxed. (Nurse, Pākehā)

Prioritising relational connection, especially during times of transition, and recognising whanaungatanga as core to stroke care appeared to lay the foundations for relationships that supported well-being.

### Care attends to the emotional aspects of stroke

The emotional impacts of stroke were profound, with many people with stroke describing deep distress, grappling with loss of control, helplessness and fear during their time in stroke services. They described trying to 'get through', to make sense of the stroke and to navigate feelings of disconnection. Patients valued feeling safe to share their emotions, which is more likely when there is a sense of connection with staff. Implicit and explicit actions of staff were key in creating a relational environment and sense of psychological safety. This included unhurried interactions, asking about feelings, listening and responding to people's verbal and non-verbal communication, and validating experiences:

(The nurse) just spent a lot of the night with me. I really was disturbed, couldn't sleep and I was restless, and she just was there, and then she'd say, 'look you're not comfortable, how about you sit on the side of the bed for a while?'...And she wasn't in a hurry. It was as if 'well no one else needs me, I'm here to help you', you know? (Person with stroke, Pākehā)

Some people with stroke encountered 'toxic positivity', being told to 'be positive' which inhibited them

from discussing their true feelings and resulted in people masking their emotions. Some felt staff did not seem to have the skills, knowledge or willingness to address emotional need, a sense shared by many healthcare professionals who described themselves as uncomfortable and unskilled in providing emotional support, who raised concern about working outside their scope of practice, or perceived this work could take away from their disciplinary-based work:

People feel pressured to get their session done and move on or do something that day in relation to your role and so ... no-one takes hold of that emotional well-being side of things and that just pulls away because the patient's doing physio, SLT and OT, but not other things. (Allied health, Pākehā)

When healthcare professionals viewed emotional support as part of their role and skillset, it appeared easier to attend to patients' emotional well-being and their physical well-being, meaning people with stroke felt more supported and seen as whole people. Further, Māori participants highlighted the importance of attending to wairua (spiritual well-being) and hinengaro (mental well-being) alongside tinana (physical well-being):

It's about the wairua stuff, it's about the emotional stuff, it's about learning to reconnect to the body that's still trying to recover, it's about all that stuff and I think that's really, really important. So, that's what I like to do with them to help them through their journey. (Allied health, Māori)

Māori participants suggested that emotional support for Māori may be better provided outside of stroke services and reiterated that emotional care must be culturally safe and reflect te ao Māori understandings of well-being.

### Care centres people's preferences and supports people to have choice and control

People with stroke and whānau often valued healthcare professionals managing their care and treatment decision-making immediately post-stroke; however, as their health stabilised and abilities changed, people wanted to be actively involved, able to voice their preferences and priorities and have these integrated into care:

What I really liked about the community team ... it's like, 'okay what is it that we can help you figure out how to do?' (Person with stroke, Pākehā)

For Māori, rangatiratanga (self-determination) is a central concept guaranteed by Te Tiriti o Waitangi, the founding agreement between Māori and the Crown. This includes rangatiratanga in health decisions. Whānau appreciated when staff upheld rangatiratanga, working collaboratively to enact their decisions.

Once (dad) was out of the immediate danger zone, he felt he needed to be back in his own environment... he didn't know where he was, it was really foreign.

So, for us to get him home, so long as it was safe, we thought was best for him...He had a wonderful specialist...he was amazing, and he agreed with that plan and we took him home. (Family member, Māori)

When this aspect of care worked well, it appeared to function as a process of shared decision-making, where staff shared different options based on their expertise and helped patients express their preferences, where patients were supported to build their independence and control, and were supported by a culture of care that valued patient expertise:

At the end of the day, (clinicians) don't tell people (what they need), they should be telling you and then you discuss it with them...So, why don't we try listening to them first, and most of the time, for me, 98% of the time (clients) have the answers. So get it out from them. (Nurse, Asian)

However, participants across all groups perceived that the systemic norms and physical safety which could limit patients' autonomy and independence and be in conflict with the rhetoric of valuing self-management and taking charge of their recovery.

Healthcare professionals identified how supporting people's choice and control needed to be supported by a culture of care, and reinforced within service practices and processes. However, service structures, such as pre-determined length of care episodes and strict entry criteria based on time post-stroke, could be a barrier to care that is centred on the needs and preferences of people with stroke. Attention to service structures and processes is needed to ensure that care genuinely reflects what matters to patients and whānau.

### Care honours Māori knowledges and practices

Māori perspectives on well-being were holistic, with Māori participants describing well-being as coming from weaving together tinana (body), wairua (spirit) and hinengaro (mind), that it was both individual and collective, rooted in relational connections with whānau and community and supported by interconnected elements such as cultural identity, mātauranga Māori (Māori knowledge systems), whakapapa (genealogy) and engagement with te ao Māori (the Māori world) and te taiao (natural world).

Well-being for me is holistic. It's not a piecemeal thing, it covers everything and luckily for us and our Māori culture and our Māori whakaaro (thinking), everything is like that. You can't look after the hinengaro (mind) without looking after the wairua (spirit) and the tinana (body), 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. (Person with stroke, Māori)

When this holistic understanding of well-being was recognised, valued and supported, it enabled a sense

of belonging and well-being. In contrast, when services failed to recognise or value the factors that support well-being, sometimes even discouraging or minimising them, this could further disconnect whānau Māori from the things that supported well-being.

Whanaungatanga (relational connections) is central to care that supports well-being, with time spent building relationships highly valued. People appreciated having Māori staff and connections with other Māori impacted by stroke. They described feeling seen and welcomed in services designed with and by Māori. This could be evident in physical spaces, therapy resources and practices that support cultural identity:

She was a kapa haka (Māori performing arts) teacher. So, I said 'Why can't we use the kapa haka part of her activity?' So, (therapists) started using that and she started to respond. That was more productive for this nanny than trying to do a board game or look at different words. (Allied health, Māori)

Care that honours Māori knowledges and practices was also evident in welcoming and valuing whānau, where they had spaces to be together, being able to connect with the things that support their holistic well-being and were supported in roles key to their identity as Māori. Māori with stroke emphasised that Māori cultural practices should be implemented thoughtfully and in agreement with them, avoiding tokenism. Enabling rangatiratanga (autonomy) also supported patient and whānau well-being, requiring flexible, whānau-centred ways of working:

'How can we as a service support your whānau managing you?' It's about giving them the control on how that looks. Services need to be flexible in that...Services need to respond to the need of their whānau, the patient and whānau, what's going to work for them, however that looks. (Allied health, Māori)

Whānau Māori were clear that well-being does not sit within services however, what happens in services can significantly influence people's well-being and impact as they navigate life after stroke. When services recognised this and created space for people to connect with that which supports well-being, it helped people thrive.

### Care responds to the strengths and needs of whānau and friends

Whānau played a crucial role in a person's recovery bringing expert knowledge of the person and providing ongoing support beyond discharge. Participants across all groups described the importance of including whānau in care, supporting them as well as the person with stroke. One nurse described how this started from the point of admission:

We (stroke unit staff) normally would be in ED, identify the whānau, bring them all with us, welcome them, look after them all. (Nurse, Pākehā)



This approach recognises that stroke has ripple effects across the whānau and can impact their well-being, not just the well-being of the person with stroke.

Whānau wanted to be included and sought genuine collaboration with staff. However, they commonly described being only peripherally involved and highlighted there was a lot of potential for services to improve:

The fact that no one had actually been with (husband), family wise when he was told that if he had surgery, he could become a ‘cabbage’. And to this day nobody spoke to me, not a doctor, nobody. I got little snippets from the nurses, but I saw no doctor, nothing, and we were visiting him every day and there was no mention, I was just going on what (he) had been told. (Family member, Pākehā)

Whānau valued being welcomed and known by the healthcare team. This was helped by staff introducing themselves, visiting when whānau were present, finding out who key whānau members and decision-makers were, sharing information, asking about how they wanted to be involved (as opposed to assuming), and asking about their needs and how the stroke impacted on them. It also included acknowledging changes in family dynamics, such as shifts from partner or child to carer roles, and recognising impacts across generations. Open communication, enabled by having key contacts on each side, ensured whānau did not feel they have to ‘battle’ with staff. Family meetings, often the primary formal communication mode, appeared most effective and useful for whānau when these centred the needs of the person with stroke and whānau. However, these meetings could sometimes feel like they served the staff’s agenda rather than done with the person and family. This reinforced power imbalances and could override the voices of people and whānau:

(Before a family meeting) I always work with whānau – okay, what is it that you want to look at, what are the main things you want to bring across, what are your thoughts about where you want to be and what your goals are? What do you think would need to happen for you to feel comfortable that your whānau’s being looked after for you to feel comfortable to remain here as a patient and continue getting rehab? (Allied health, Māori)

Given their knowledge of the person and support role post-discharge, actively including whānau in care appears important. However, people with stroke and whānau members were clear that this needs to occur in conversation with the person with stroke and their whānau, so as to not make assumptions about whānau roles, capacities and dynamics. Understanding the needs of the wider whānau could significantly support their well-being, which in turn supports the well-being of the person with stroke.

### Care attends to people’s holistic well-being, in the present and for the future

What was important for well-being after stroke was closely entwined with what mattered for well-being in life before the stroke. It was inherently holistic and extended beyond stroke recovery to include connection with whānau, with community, to te taiao (natural world), and spirituality. People with stroke valued staff who found out what mattered for holistic well-being and supported them to (re)connect with what makes them ‘come alive’:

It’s about wairua (spirit), and wairua is about the ability for your battery to be fully charged.... so it takes conversation, it takes recognition of who you are, where you’re from and all those things are incorporated into the way you think and do things. (Man with stroke, Māori)

This involved knowing the person and integrating their identity into stroke care; it also involved consideration of the person’s social and financial resources—things which could support or detract from well-being.

While healthcare practitioners commonly suggested goal setting was key to finding out what was important, people with stroke suggested this process often felt reductionistic, focused on stroke recovery and service priorities with one describing this as ‘superficial’, appearing as a paperwork exercise. Further people with stroke and whānau felt services were not set up to provide holistic supports, instead focusing on physical functioning and task completion:

There was no awareness from any of the services that put any weighting on his ability to reconnect on the marae (meeting place) or in any other space apart from getting your physical capability back, get your hand working, get yourself back into employment... but there was just no taking into account that he was the kaikōrero (speaker) for an Iwi (tribe). How’s he going to be supported to get that back?...And looking at things from a Māori lens but things that were important to him were not factored into any of their rehabilitation programmes. It’s very very linear, just get your body working again, your heart’s an issue so we’re gonna do this to fix your heart...none of the other stuff, the wider picture. (Family member, Māori)

As this quote shows, supporting long-term well-being also required looking beyond traditional Western models of well-being. For many Māori in this study, well-being was deeply connected to their identity as Māori, which there was often little consideration of in Western healthcare systems which prioritise patient flow and progress toward discharge. Many healthcare practitioners were unsure of how to provide holistic support, reporting a lack of knowledge of wider support services and being unsure of whether that was in their role. It appeared that healthcare professionals were better able to support long-term well-being when they had autonomy in their roles, were based

in the community, saw facilitating well-being as a core component of their role and had community connections to link people with external supports:

For us in the community ... we have to be really holistic about how we view the patient because we're looking at how they're living their day to day lives. We can't just kind of isolate what we want to focus on. So I feel like we have to look at their well-being as a whole. (Allied health, Pākehā)

When long-term well-being was addressed in stroke services, this saw practitioners incorporate meaningful aspects for the person or creating opportunities for them to connect with people, places and cultural practices outside of healthcare services.

## DISCUSSION

This research proposes a framework for high-quality post-stroke care that supports well-being for both individuals and their whānau. Increasing recognition of the importance of well-being after stroke<sup>4 10 38</sup> reinforces the need for practice guidance grounded in the experience of those living with stroke. Our findings suggest that well-being is fostered through cumulative interactions with healthcare professionals, reinforcing existing research on quality care which highlights the importance of interactions and relationships in provision of high-quality care.<sup>39 40</sup> However, beyond individual interactions, well-being is shaped through a combination of positive healthcare encounters, social and cultural networks, and the physical and social environments within stroke services. This aligns with core healthcare principles, including person-centred care<sup>47</sup> and humanised care, concepts recently explored in stroke literature.<sup>48 49</sup> For instance, humanised care highlights the significance of 'subtle, empathetic aspects of care',<sup>49</sup> p. 1225)—small, everyday interactions critical to maintaining personhood.<sup>47 49 50</sup> Our research highlights these elements are not merely 'nice to have'. They are essential for high-quality care.<sup>40 51</sup> As such, they require attention, resourcing and systemic support, as well-being practices reflect broader cultures of care.<sup>10</sup> Yet, prior research suggests that well-being-supporting practices often occur as a result of the efforts of individual professionals rather than being supported by the system, which commonly prioritises metrics such as timely assessment, physical recovery and patient flow.<sup>10</sup>

This framework proposes a proactive approach to fostering well-being through routine care interactions and practices. This reflects a health-promoting approach to care, in which healthcare professionals work deliberately to create an environment that promotes well-being, an approach used across areas including education,<sup>52</sup> workplaces<sup>53</sup> and community settings.<sup>54</sup> Reflecting principles from positive psychology, it underscores the importance of cultivating positive psychosocial and cultural resources to enhance well-being and support long-term outcomes.<sup>55</sup> This approach contrasts with dominant approaches to

well-being in stroke which orient towards a disease model, seeking to identify mood disorders as they arise and addressing these with targeted interventions.<sup>24 56</sup> Instead, this framework proposes universal interventions reflective of a stepped care model of psychological support after stroke,<sup>33</sup> providing clear examples of actions that can support well-being. These practical examples are intended for all staff in stroke services, positioning well-being as being part of everyone's role,<sup>34</sup> an approach also seen in cancer care and palliative care.<sup>57</sup> This approach also recognises the critical roles of those in non-clinical roles such as healthcare assistants and domestic staff.<sup>58</sup>

This framework explicates care practices and processes that people impacted by stroke describe as important for well-being and provides tangible examples of how these have been enacted in practice. It may serve to guide not only practice, but future outcome measurement, quality measures and service evaluation.<sup>59</sup> The different domains of well-being highlight the multifaceted nature of well-being beyond mood. This prompts us to consider what measures might be most appropriate. While many international stroke guidelines recommend screening for depressive symptoms<sup>24 56</sup> or screening when there is suspected altered mood,<sup>25</sup> this work points us toward a more comprehensive approach to considering well-being. We suggest gathering information about dimensions such as emotional well-being, community integration and social networks may provide a more holistic picture of well-being, may help identify resources that the person has access to, and may help identify areas where further supports could be provided. Further, this framework prompts services to attend to the relational and physical contexts of care, considering aspects such as therapeutic relationships and auditing different aspects of the physical, relational and social environment of care. This work also highlights the limitations of existing policy and guidelines in providing guidance for care that supports well-being, given their predominant focus on mood.<sup>56</sup> Interestingly, while at a global level there is attention to the importance of well-being in health,<sup>60</sup> there is still a way to go until this impacts routine health practice. However, it may be that through integrating patient voice, consensus-based recommendations and qualitative evidence, we are able to produce guidance for practice that reflects the totality of people's experiences and needs after stroke.<sup>61 62</sup>

Our approach to considering well-being is strongly influenced by the Aotearoa New Zealand context in which this research occurred. We had more Māori (Indigenous) participants with stroke than non-Māori. Because of their involvement, and the way in which engagement with Māori and an initial kaupapa Māori analysis was led by our Māori researcher, we have been able to surface areas specific to Māori. While some might ask if this framework is only relevant in New Zealand, we suggest that most areas can also be found in other literature that discusses areas of importance in living well after stroke.<sup>63 64</sup> Further, these areas also lay the foundation for building therapeutic collaboration and building people's trust, confidence and



resilience, factors known to be important to living well after stroke.<sup>65 66</sup> As such, international readers will be able to take most elements of the framework and consider transferability and adaptation to their own context.<sup>67</sup> However, by attending specifically to Māori voices, people who are disproportionately impacted by stroke which occurs on average 15 years younger than Pākehā (people of European descent) and for whom stroke is commonly more severe,<sup>68</sup> we may make some inroads to achieving equity in experience and outcome. This is critical for enabling health equity and upholding the Crown's obligations under Te Tiriti o Waitangi, the founding document between the Crown and Māori, signed in 1840.<sup>69</sup>

This research offers a comprehensive, empirically derived framework for care that supports well-being in Aotearoa, with international relevance. It provides guidance for healthcare professionals on how they can 'do things different', as our Māori advisor challenged us. However, there are limitations that are important to be mindful of. This work is based on interviews and predominantly on retrospective recall of experiences; approximately 10 of the participants with stroke were receiving stroke services at the time of interview. Additionally, gathering data through a range of methods, including observations, may have offered additional insights into practices that support well-being. 14 of the 24 participants with stroke were aged under 65, yet 76% of strokes in Aotearoa affect people over 65.<sup>2</sup> We had only one participant aged over 80, yet the older old are the people most impacted by stroke. Further, we had few Pacific peoples or people of Asian ethnicity, two groups who are significantly impacted by stroke.<sup>2 70</sup> As such, we cannot state that the framework can be universally applied across all people with stroke. Further refinement would be beneficial in the future. We cannot claim that this framework will sustain or improve well-being—operationalising this framework in practice and evaluating the impacts on patient well-being is an important next step. Despite these methodological limitations, this paper offers a comprehensive and practical framework that can support clinicians to provide more holistic, person-centred care after stroke.

## CONCLUSION

This research has produced a robust, detailed description of what constitutes quality care that supports well-being after stroke. Based on the lived experiences of people with stroke and their whānau, and supported by the perspectives of healthcare professionals, it provides a valuable guide for healthcare professionals seeking to better provide holistic, person-centred care after stroke. This work offers more nuanced approaches to conceptualising well-being, clearly demonstrating that this is more than mood, and the absence of mood disorders. The framework opens up opportunities for healthcare professionals to work intentionally to support well-being. It requires recognition of the importance of whānau, cultural, community and social supports, reflecting that

well-being occurs in community and in context. To return to the words of our Māori advisor, well-being is not the sole responsibility of stroke services, but they do have a critical role in creating an environment that influences well-being, and by 'doing things different', there is scope to positively impact well-being and to better support people as they navigate the challenges after stroke. Supporting well-being requires action from healthcare professionals, but critically, it requires services and stroke systems to recognise and value well-being as an area deserving of explicit focus.

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