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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ABSTACT

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 semi-structured 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 service. This framework can help structure practice and policy and can underpin future research in well-being.

Article summary:

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

Keywords: Stroke, quality of health care, quality of life, qualitative research, mental health

BACKGROUND

Stroke is a leading cause of disability and death internationally, with nearly 94 million people living with stroke in the world [1]. Within New Zealand, around 9,000 people experience a stroke each year; this is projected to increase by 40% by 2028 [2]. The impacts of stroke vary, but commonly include physical, cognitive and communication impairments, impacting on people's activities, participation and quality of life [3]. The impacts further extend to people's well-being [4-6]. Well-being is multi-dimensional 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 [5-8]. Notions of well-being are culturally grounded, with our recent work demonstrating aspects unique for Māori, the Indigenous people of New Zealand [5]. this work showed that some elements of well-being were universal, 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 [9]. This highlights the need for care practices that are holistic and culturally grounded, designed for the local clinical 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 [10]. However, in New Zealand and internationally, stroke survivors and their families identify that well-being is a critical area impacted by stroke *and* they identify that this is an area that it is not well-supported within stroke services [5, 11, 12]. When well-being is impacted, this can contribute to disengagement from services [13], high rates of depression and anxiety post-stroke [14, 15] – rates that are nearly doubled when someone has aphasia [16, 17], social isolation [18] – again, higher when someone has aphasia [19], increased suicide risk [20, 21], and can impact on family well-being [22]. 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 [10, 23]. 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 [3, 24, 25]. Within guidelines, some dimensions of well-being are addressed in the context of community integration [25], and activities such as return to work and sexual activity [3, 26]. Other dimensions of well-being such as social relationships are sometimes recognised as important [3] but little guidance of *how* to address this 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 psychoeducation to support adjustment and emotional well-being [27] and psychotherapeutic-informed interventions to address anxiety and depression [28]. Other interventions have addressed more diverse aspects of well-being such as life story approaches to support identity (re)development post-stroke [29], peer befriending to support adjustment, resilience and hope and reduce distress [30, 31] and improving social participation post-stroke [32]. Yet models such as the Stepped Care model of psychological intervention [33] and recent psychosocial well-being guidelines in New Zealand [34], 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 [35] emphasise the importance of supporting autonomy [35], Brewer and colleagues [36] provide recommendations for supporting Māori through culturally informed aphasia rehabilitation practice and Bennett [37] provides rich description of how nurses support people's emotional well-being in stroke services. However, there is limited literature that details a multi-component 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 [10], 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 [4, 5, 12, 38], 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 [39] and gathering perspectives of patients, family and healthcare professionals is key in developing comprehensive understandings of quality of care [40]. 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 [41], 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 [41], 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 [42] 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 (Approval number 21/223) 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 [5] and by feedback gathered during the consultation phase (see 'patient and public involvement' section below). The interview guides are provided in 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 minutes, while small group interviews lasted between 60 and 120 minutes. All interviews were audio-recorded and transcribed.

DATA ANALYSIS

Analysis involved multiple iterative techniques, something encouraged within Interpretive Description [41]. Our research team commenced analysis with a process of deep familiarisation, writing detailed memos of each interview, 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 [43]. 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 [44], 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 was 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 [45]. 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 [46]). The majority of people had experienced stroke within the last five 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 One. Whānau members were predominantly female, Māori, and comprised a range of relationships including spouse, sibling and child as shown in Table Two. 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 Three.

Table 1: Characteristics of people with stroke

Age at time of stroke	
- <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
Years post-stroke	
- <1 Year	10
- 1-4 years	5
- 5-9 years	5
- 10-14 years	1
- 15-19 years	-
- >20 years	3
Self-reported impacts of stroke	
- 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
Gender (self-identified)	
- Male	11
- Female	13
Ethnicity (noting people self-identified ethnicity and some selected >1)	
- European	11
- Māori	12
- Pacific peoples	1
- Asian	1
Residential location using GCH classification	
- Urban 1	17
- Urban 2	6
- Rural 1	1

Table 2: Characteristics of whānau members

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

Table 3: Characteristics of healthcare professionals

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

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 One. 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 Four, 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 Supplemental File (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 that supports well-being after stroke

Attends to people's holistic well-being, both in the present and for the long-term
People are connected into people, places, and areas of meaning and importance that sustain well-being beyond stroke services.

Responds to the strengths and needs of whānau and friends
People remain connected within their support networks. People in these networks are equipped to provide long-term support.

Honours Māori knowledges and practices
Māori knowledges and practices are recognised, valued, and supported within stroke services.

Centres people's preferences and enables them to have choice and control
People have control and autonomy throughout their recovery.

Attends to the emotional impacts of stroke
People feel staff are attuned to what they are feeling; they feel heard and supported as they navigate the emotional impacts of stroke.

Prioritises relationships and connecting 'as people'
People feel known and understood as individuals. They feel they know their healthcare professionals and feel a sense of safety and trust with them.

Fosters a sense of belonging and connection
People feel known and understood as individuals. They feel they know their healthcare professionals and feel a sense of safety and trust with them.

Supports people through uncertainty
People's uncertainty is acknowledged. People have the information they want and need which supports a sense of control and hope about their future.

Figure 1. Quality framework for stroke care that supports well-being after stroke

Table 4: Core features of each quality domain

Quality domain	Elements of high-quality care
Care supports people through uncertainty	• Uncertainty is explicitly acknowledged • The stroke, its causes and care processes, are explained as many times as needed • All the key people are included in conversations • Informative is given at appropriate times, in a relational manner, with time to discuss, ask questions, and have these answered • Information is not generic but responds to the questions, priorities and context of the person with stroke • Before leaving hospital, people understand have details about post-discharge services
Care fosters a sense of belonging	• People can access stroke-specific services in a timely manner • Services provide a welcoming, age-appropriate environment for people with stroke • Transfers between wards are minimised wherever possible • People are offered facilitated connections with others impacted by stroke • Whānau Māori are offered a connection with other Māori • People with aphasia are connected with others with aphasia • People connect with supports from outside stroke services to support wider sense of belonging and connection
Care prioritises relationships and connecting 'as people'	• People feel that staff want to know them which helps build trust • Staff get to know people by asking about their lives, interests and what matters to them • Staff share of themselves so they are also known by people with stroke and whānau • 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 • People feel comfortable reaching out to staff anytime, and are given a point of contact to make this easier
Care attends to the emotional aspects of stroke	• Staff are aware of the emotional impacts of stroke and are attentive to people's emotional experiences • Staff initiate conversations about emotions and provide opportunities for people to discuss, if they wish • Staff show empathy and are unhurried in their interactions • People feel their experiences are normalised *and* validated, and not minimised • Staff are supported to provide psychologically-informed care • People and whānau have access to culturally safe, and culturally-informed counselling or psychological support if they choose

	• People are encouraged to access emotional supports from outside stroke services
Care centres people's preferences and supports people to have choice and control	• People are asked what is important to them and what they would like to see happen in their care • People see staff taking action on things they have discussed together • Staff acknowledge the effort and problem solving that people put into their recovery • People are supported to have greater autonomy when people seek this • There is shared decision-making about what will work best for the person and their whānau • Staff and services honour the right of Māori to have rangatiratanga (autonomy) over their healthcare • Services are flexible and available at times that suit the person and whānau • When a person's wishes cannot be upheld, alternative options are discussed together
Care honours Māori knowledges and practices	• Services embed a holistic understanding of well-being grounded in te ao Māori • Whanaungatanga is prioritised • Care upholds Māori worldview, knowledges and practices (tikanga) in care, information and resources • Māori have space and support to be together as Māori • Whānau Māori are supported to determine their own healthcare journey • Whānau Māori feel listened to and understood • Staff recognise key supports for Māori may come from outside services and work to make this possible • Staff and services recognise their own cultural perspectives and how these might influence care
Care responds to the strengths and needs of friends and whānau	• Staff introduce themselves and maintain regular contact with whānau • Staff learn who key whānau members or friends are and don't make assumptions • The knowledge and perspectives of whānau and friends are sought and respected • 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) • Family meetings that are designed around patient and whānau needs and concerns • Services consider the current *and* future needs of whānau • There are comfortable spaces for the person with stroke to spend time with whānau and friends
Care attends to people's holistic long-term well-being	• Staff find out what is important for people's well-being • Care is holistic, integrating elements that support people to be and stay well in themselves • Goal setting is individualised revisited often as people progress through care • Staff actively support people to engage in activities, roles, relationships and social contexts that support their well-being, including those outside stroke services

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

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, we 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 help 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 this was supported by a culture of care that was 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 thingee, 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 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 than 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 [4, 10, 38] 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 [39, 40]. 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 [47] and humanised care, concepts recently explored in stroke literature [48, 49]. For instance, humanised care highlights the significance of "subtle, empathetic aspects of care" (Pound & Jensen, 2018, p. 1225) — small, everyday interactions critical to maintaining personhood [47, 49, 50]. Our research highlights these elements are not merely 'nice to have'. They are essential for high-quality care [40, 51]. As such, they require attention, resourcing, and systemic support, as well-being practices reflect broader cultures of care [10]. 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 [10].

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 [52], workplaces [53] and community settings [54]. 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 [55]. This approach contrasts with dominant approaches to well-being in stroke which orient toward a disease model, seeking to identify mood disorders as they arise and addressing these with targeted interventions [24, 56]. Instead, this framework proposes universal interventions reflective of a stepped care model of psychological support after stroke [33], 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 [34], an approach also seen in cancer care and palliative care [57]. This approach also recognises the critical roles of those in non-clinical roles such as healthcare assistants and domestic staff [e.g. 58].

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 [59]. The different domains of well-being highlight the multi-faceted 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 [24, 56] or screening when there is suspected altered mood [25], 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 [56]. Interestingly, while at a global level there is attention to the importance of well-being in health [60], 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 into guidelines that we are able to produce guidance that reflects the totality of people's experiences and needs after stroke [61, 62].

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 [63, 64]. 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 [65, 66]. As such, international readers will be able to take most elements of the framework and consider transferability and adaptation to their own context [67]. 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 [68], 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 [69].

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 ten 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 [2]. 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 [2, 70]. 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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REFERENCES

[1] V. L. Feigin *et al.*, "Global, regional, and national burden of stroke and its risk factors, 1990-2021: a systematic analysis for the Global Burden of Disease Study 2021," *The Lancet Neurology,* vol. 23, no. 10, pp. 973-1003, 2024, doi: 10.1016/S1474-4422(24)00369-7.

[2] A. Ranta, "Projected stroke volumes to provide a 10-year direction for New Zealand stroke services," *New Zealand Medical Journal,* vol. 131, no. 1477, pp. 15-28, 2018.

[3] Intercollegiate Stroke Working Party, "National clinical guideline for stroke for the UK and Ireland," London, 4 May 2023. [Online]. Available: www.strokeguideline.org

[4] Stroke Association, "Feeling overwhelmed," 2015. [Online]. Available: https://www.stroke.org.uk/sites/default/files/feeling_overwhelmed_final_web_0.pdf

[5] F. A. S. Bright, C. Ibell-Roberts, and B.-J. Wilson, "Psychosocial well-being after stroke in Aotearoa New Zealand: A qualitative metasynthesis," *Disability and Rehabilitation,* vol. 46, no. 10, pp. 2000-2013, 2023, doi: 10.1080/09638288.2023.2212178.

[6] M. Kirkevold, B. A. Bronken, R. Martinsen, and K. Kvigne, "Promoting psychosocial well-being following a stroke: developing a theoretically and empirically sound complex intervention," *International Journal of Nursing Studies,* vol. 49, no. 4, pp. 386-397, 2012, doi: 10.1016/j.ijnurstu.2011.10.006.

[7] B. Moss *et al.*, "'Emotion is of the essence. … Number one priority': A nested qualitative study exploring psychosocial adjustment to stroke and aphasia," *International Journal of Language & Communication Disorders,* vol. 56, no. 3, pp. 594-608, 2021, doi: https://doi.org/10.1111/1460-6984.12616.

[8] E. Fuller-Thomson and L. A. Jensen, "Flourishing after a stroke: A nationally representative portrait of resilience and mental health among older Canadians," *Journal of Aging & Health,* vol. 32, no. 5/6, pp. 308-316, 2020, doi: 10.1177/0898264318822228.

[9] K. M. McLellan, C. M. McCann, L. Worrall, and M. Harwood, "Māori experiences of aphasia therapy: "But I'm from Hauiti and we've got shags"," *International Journal of Speech-Language Pathology,* vol. 16, no. 5, pp. 5219-540, 2014, doi: 10.3109/17549501.2013.864334.

[10] F. A. S. Bright, C. Ibell-Roberts, K. Featherstone, N. E. J. Signal, B.-J. Wilson, A. Collier, and V. Fu, ""Physical well-being is our top priority": Healthcare professionals' challenges in supporting psychosocial well-being after stroke," *Health Expectations,* vol. 27, no. 2, p. e14016, 2024, doi: 10.1111/hex.14016.

[11] C. Bulsara, R. Saunders, L. Emery, and C. Etherton-Beer, "Reflecting on experiences of care: an exploratory qualitative descriptive study of the perspectives of stroke survivors, families and staff," *BMJ Open,* vol. 11, no. 12, p. e047559, 2021, doi: 10.1136/bmjopen-2020-047559.

[12] J. Shipley, J. Luker, V. Thijs, and J. Bernhardt, "How can stroke care be improved for younger service users? A qualitative study on the unmet needs of younger adults in inpatient and outpatient stroke care in Australia," (in eng), *Disabil Rehabil,* vol. 42, no. 12, pp. 1697-1704, Jun 2020, doi: 10.1080/09638288.2018.1534278.

[13] F. A. S. Bright, N. M. Kayes, K. M. McPherson, and L. E. Worrall, "Engaging people experiencing communication disability in stroke rehabilitation: A qualitative study," *International Journal of Language and Communication Disorders,* vol. 53, no. 5, pp. 981-994, 2018, doi: 10.1111/1460-6984.12409.

[14] M. L. Hackett and K. Pickles, "Part I: Frequency of Depression after Stroke: An Updated Systematic Review and Meta-Analysis of Observational Studies," *International Journal of Stroke,* vol. 9, no. 8, pp. 1017-1025, 2014, doi: 10.1111/ijs.12357.

[15] P. Knapp, A. Dunn-Roberts, N. Sahib, L. Cook, F. Astin, E. Kontou, and S. A. Thomas, "Frequency of anxiety after stroke: An updated systematic review and meta-analysis of

observational studies," *International Journal of Stroke,* vol. 15, no. 3, pp. 244-255, 2020, doi: 10.1177/1747493019896958.

[16] M. Kauhanen *et al.*, "Aphasia, depression, and non-verbal cognitive impairment in ischaemic stroke," *Cerebrovascular Diseases,* vol. 10, no. 6, pp. 455-461, 2000.

[17] R. Morris, A. Eccles, B. Ryan, and I. I. Kneebone, "Prevalence of anxiety in people with aphasia after stroke," *Aphasiology,* vol. 31, no. 12, pp. 1410-1415, 2017/12/02 2017, doi: 10.1080/02687038.2017.1304633.

[18] C. Byrne, C. W. N. Saville, R. Coetzer, and R. Ramsey, "Stroke Survivors Experience Elevated Levels of Loneliness: A Multi-Year Analysis of the National Survey for Wales," (in eng), *Arch Clin Neuropsychol,* vol. 37, no. 2, pp. 390-407, Feb 23 2022, doi: 10.1093/arclin/acab046.

[19] B. Davidson, T. Howe, L. Worrall, L. Hickson, and L. Togher, "Social participation for older people with aphasia: the impact of communication disability on friendships," *Topics in Stroke Rehabilitation,* vol. 15, no. 4, pp. 325-40, 2008, doi: 10.1310/tsr1504-325.

[20] M. V. Vyas, J. Z. Wang, M. M. Gao, and D. G. Hackam, "Association between stroke and subsequent risk of suicide," *Stroke,* vol. 52, no. 4, pp. 1460-1464, 2021, doi: doi:10.1161/STROKEAHA.120.032692.

[21] H.-Y. Y. Chun, A. Ford, M. A. Kutlubaev, O. P. Almeida, and G. E. Mead, "Depression, anxiety, and suicide after stroke: A narrative review of the best available evidence," *Stroke,* vol. 53, no. 4, pp. 1402-1410, 2022, doi: doi:10.1161/STROKEAHA.121.035499.

[22] P. Y. Choo, M. A. Shaik, G. Tan-Ho, J. Lee, and A. H. Y. Ho, "Living losses in stroke caregiving: A qualitative systematic review of systematic reviews on psycho-socio-emotional challenges and coping mechanisms," *International Journal of Stroke,* Review vol. 18, no. 3, pp. 268-277, 2023, doi: 10.1177/17474930221104908.

[23] S. Northcott, A. Simpson, B. Moss, N. Ahmed, and K. Hilari, "How do speech and language therapists address the psychosocial well-being of people with aphasia? Results of a UK online survey," *International Journal of Language and Communication Disorders,* vol. 52, no. 3, pp. 356-373, 2017, doi: 10.111/1460-6984.12278.

[24] P. Lindsay, K. L. Furie, S. M. Davis, G. A. Donnan, and B. Norrving, "World Stroke Organization global stroke services guidelines and action plan," *International Journal of Stroke,* vol. 9, no. SA100, pp. 4-13, 2014, doi: 10.1111/ijs.12371.

[25] Stroke Foundation, "Clinical Guidelines for Stroke Management ", Melbourne, Australia, 2017. [Online]. Available: https://informme.org.au/en/Guidelines/Clinical-Guidelines-for-Stroke-Management-2017

[26] B. Norrving *et al.*, "Action Plan for Stroke in Europe 2018–2030," *European Stroke Journal,* vol. 3, no. 4, pp. 309-336, 2018, doi: 10.1177/2396987318808719.

[27] H. Mou, S. K. K. Lam, and W. T. Chien, "Effects of a family-focused dyadic psychoeducational intervention for stroke survivors and their family caregivers: a pilot study," *BMC Nursing,* vol. 21, no. 1, p. 364, 2022/12/21 2022, doi: 10.1186/s12912-022-01145-0.

[28] C. Baker, M. L. Rose, D. Wong, B. Ryan, S. Thomas, D. Cadilhac, and I. Kneebone, "PRevention Intervention and Support in Mental health for people with aphasia (Aphasia PRISM): protocol and mixed methods analysis plan for two feasibility studies," *Discover Psychology,* vol. 4, no. 1, p. 153, 2024/10/24 2024, doi: 10.1007/s44202-024-00210-w.

[29] S. Corsten, E. J. Schimpf, J. Konradi, A. Keilmann, and F. Hardering, "The participants' perspective: how biographic–narrative intervention influences identity negotiation and quality of life in aphasia," *International Journal of Language & Communication Disorders,* vol. 50, no. 6, pp. 788-800, 2015, doi: https://doi.org/10.1111/1460-6984.12173.

[30] K. Hilari *et al.*, "Supporting wellbeing through peer-befriending (SUPERB) for people with aphasia: A feasibility randomised controlled trial," (in eng), *Clin Rehabil,* vol. 35, no. 8, pp. 1151-1163, Aug 2021, doi: 10.1177/0269215521995671.

[31] E. Sadler, S. Sarre, A. Tinker, A. Bhalla, and C. McKevitt, "Developing a novel peer support intervention to promote resilience after stroke," *Health & Social Care in the Community,* vol. 25, no. 5, pp. 1590-1600, 2017, doi: https://doi.org/10.1111/hsc.12336.

[32] R. Proffitt, A. Boone, E. G. Hunter, O. Schaffer, M. Strickland, L. Wood, and T. J. Wolf, "Interventions to improve social participation, work, and leisure among adults poststroke: A systematic review," *The American Journal of Occupational Therapy,* vol. 76, no. 5, 2022, doi: 10.5014/ajot.2022.049305.

[33] I. I. Kneebone, "Stepped psychological care after stroke," *Disability and Rehabilitation,* vol. 38, no. 18, pp. 1836-1843, 2016, doi: 10.3109/09638288.2015.1107764.

[34] F. A. S. Bright, J. Davison, and on behalf of the Psychosocial Working Group, "Supporting psychosocial well-being after stroke," National Stroke Network, Wellington, New Zealand, 2022. [Online]. Available: https://static1.squarespace.com/static/623a8069f9d2f75196b75b1b/t/637bfc412749627d280748b7/1669069947407/NSN+Psychosocial+toolkit++Doc_FINAL.pdf

[35] J. McClure and C. Leah, "Is independence enough? Rehabilitation should include autonomy and social engagement to achieve quality of life," *Clinical Rehabilitation,* vol. 35, no. 1, pp. 3-12, 2021, doi: 10.1177/0269215520954344.

[36] K. M. Brewer, C. M. McCann, and M. L. N. Harwood, "The complexities of designing therapy for māori living with stroke-related communication disorders," *New Zealand Medical Journal,* Article vol. 129, no. 1435, pp. 75-82, 2016. [Online]. Available: https://www.scopus.com/inward/record.uri?eid=2-s2.0-84999040005&partnerID=40&md5=a1574080e247fb2f8953d0a0ba6809ec.

[37] B. Bennett, "A culture of caring: how nurses promote emotional wellbeing and aid recovery following a stroke," *British Journal of Neuroscience Nursing,* vol. 13, no. Sup2, pp. S8-S17, 2017, doi: 10.12968/bjnn.2017.13.Sup2.S8.

[38] C. Rixon, "Connection: Stories not statistics," *Brain Impairment,* pp. 1-5, 2022, doi: 10.1017/BrImp.2021.37.

[39] A. F. Hannawa, A. W. Wu, A. Kolyada, A. Potemkina, and L. J. Donaldson, "The aspects of healthcare quality that are important to health professionals and patients: A qualitative study," *Patient Education and Counseling,* vol. 105, no. 6, pp. 1561-1570, 2022/06/01/ 2022, doi: https://doi.org/10.1016/j.pec.2021.10.016.

[40] K. Y. J. Sion, H. Verbeek, B. de Boer, S. M. G. Zwakhalen, G. Odekerken-Schröder, J. M. G. A. Schols, and J. P. H. Hamers, "How to assess experienced quality of care in nursing homes from the client's perspective: results of a qualitative study," *BMC Geriatrics,* vol. 20, no. 1, p. 67, 2020/02/17 2020, doi: 10.1186/s12877-020-1466-7.

[41] S. Thorne, *Interpretive Description: Qualitative research for applied practice*, 2nd ed. New York, NY: Routledge, 2016.

[42] K. Malterud, V. Dirk Siersma, and A. Dorrit Guassora, "Sample size in qualitative interview studies: Guided by information power," *Qualitative Health Research,* vol. 26, no. 13, pp. 1753-1760, 2016, doi: 10.1177/1049732315617444.

[43] S. Ly, F. Runacres, and P. Poon, "Journey mapping as a novel approach to healthcare: a qualitative mixed methods study in palliative care," *BMC Health Services Research,* vol. 21, no. 1, p. 915, 2021/09/04 2021, doi: 10.1186/s12913-021-06934-y.

[44] H.-F. Hsieh and S. E. Shannon, "Three approaches to qualitative content analysis," *Qualitative Health Research,* vol. 15, no. 9, pp. 1277-1288, 2005, doi: 10.1177/1049732305276687.

[45] F. A. S. Bright. "Research priorities from stakeholder consultation." https://cpcr.aut.ac.nz/__data/assets/pdf_file/0010/673984/Research-priorities-from-stakeholder-consultation-2021-website.pdf (accessed 18 November, 2024).

[46] J. Whitehead *et al.*, "Defining rural in Aotearoa New Zealand: a novel geographic classification for health purposes," *New Zealand Medical Journal,* vol. 135, no. 1559, pp. 24-40, 2022, doi: 10.26635/6965.5495.

[47] T. S. Jesus, C. Papadimitriou, F. A. Bright, N. M. Kayes, C. S. Pinho, and C. A. Cott, "Person-centered rehabilitation model: Framing the concept and practice of person-centered adult physical rehabilitation based on a scoping review and thematic analysis of the literature," *Archives of Physical Medicine and Rehabilitation,* 2021/07/03/ 2021, doi: https://doi.org/10.1016/j.apmr.2021.05.005.

[48] C. Gordon, C. Ellis-Hill, B. Dewar, and C. Watkins, "Knowing-in-action that centres humanising relationships on stroke units: an appreciative action research study," *Brain Impairment,* vol. 23, no. 1, pp. 60-75, 2022, doi: 10.1017/BrImp.2021.34.

[49] C. Pound and L. R. Jensen, "Humanising communication between nursing staff and patients with aphasia: Potential contributions of the Humanisation Values Framework," *Aphasiology,* vol. 32, no. 10, pp. 1225-1249, 2018, doi: 10.1080/02687038.2018.1494817.

[50] N. M. Kayes and C. Papadimitriou, "Reflecting on challenges and opportunities for the practice of person-centred rehabilitation," (in eng), *Clin Rehabil,* vol. 37, no. 8, pp. 1026-1040, Aug 2023, doi: 10.1177/02692155231152970.

[51] A. Scheffelaar, N. Bos, M. Hendriks, S. van Dulmen, and K. Luijkx, "Determinants of the quality of care relationships in long-term care - a systematic review," *BMC Health Services Research,* vol. 18, no. 1, p. 903, 2018/11/28 2018, doi: 10.1186/s12913-018-3704-7.

[52] B. Graetz *et al.*, "KidsMatter: A population health model to support student mental mealth and well-being in primary schools," *International Journal of Mental Health Promotion,* vol. 10, no. 4, pp. 13-20, 2008/11/01 2008, doi: 10.1080/14623730.2008.9721772.

[53] M. Luisa Cantonnet, J. Carlos Aldasoro, and I. Rodriguez Oyarbide, "Well-Being through workplace health promotion interventions by European enterprises," *Safety Science,* vol. 151, p. 105736, 2022/07/01/ 2022, doi: https://doi.org/10.1016/j.ssci.2022.105736.

[54] N. J. Wilson and R. Cordier, "A narrative review of Men's Sheds literature: reducing social isolation and promoting men's health and well-being," *Health & Social Care in the Community,* vol. 21, no. 5, pp. 451-463, 2013, doi: https://doi.org/10.1111/hsc.12019.

[55] J. J. Evans, "Positive psychology and brain injury rehabilitation," *Brain Impairment,* vol. 12, no. 2, pp. 117-127, 2011, doi: 10.1375/brim.12.2.117.

[56] G. E. Mead *et al.*, "A systematic review and synthesis of global stroke guidelines on behalf of the World Stroke Organization," *International Journal of Stroke,* vol. 18, no. 5, pp. 499-531, 2023, doi: 10.1177/17474930231156753.

[57] M. Daem, M. Verbrugghe, W. Schrauwen, S. Leroux, A. Van Hecke, and M. Grypdonck, "How interdisciplinary teamwork contributes to psychosocial cancer support," *Cancer Nursing,* vol. 42, no. 3, pp. E11-E20, 2019, doi: 10.1097/ncc.0000000000000588.

[58] M. Lovatt *et al.*, "The provision of emotional labour by health care assistants caring for dying cancer patients in the community: A qualitative study into the experiences of health care assistants and bereaved family carers," *International Journal of Nursing Studies,* vol. 52, no. 1, pp. 271-279, 2015/01/01/ 2015, doi: https://doi.org/10.1016/j.ijnurstu.2014.10.013.

[59] A. Y. X. Yu, D. M. Bravata, B. Norrving, M. J. Reeves, L. Liu, and M. F. Kilkenny, "Measuring stroke quality: Methodological considerations in selecting, defining, and

analyzing quality measures," *Stroke,* vol. 53, no. 10, pp. 3214-3221, 2022, doi: doi:10.1161/STROKEAHA.122.036485.

[60] World Health Organisation, "Achieving well-being: A global framework for integrating well-being into public health utilizing a health promotion approach," World Health Organisation, 2023. [Online]. Available: https://www.who.int/publications/m/item/wha-76---achieving-well-being--a-global-framework-for-integrating-well-being-into-public-health-utilizing-a-health-promotion-approach

[61] J. K. Roddis, H. L. Liversedge, I. Ryder, and M. Woodhouse, "Incorporating the patient experience into clinical guidelines: recommendations for researchers and guideline developers," *BMJ Evidence-Based Medicine,* vol. 24, no. 4, pp. 125-126, 2019, doi: 10.1136/bmjebm-2018-111015.

[62] D. Aguiar de Sousa *et al.*, "European Stroke Organisation (ESO) standard operating procedure for white papers (expert consensus based clinical guidance)," (in eng), *Eur Stroke J,* p. 23969873251316430, Feb 4 2025, doi: 10.1177/23969873251316430.

[63] M. Manning, A. MacFarlane, A. Hickey, and S. Franklin, "Perspectives of people with aphasia post-stroke towards personal recovery and living successfully: A systematic review and thematic synthesis," *PLOS ONE,* vol. 14, no. 3, p. e0214200, 2019, doi: 10.1371/journal.pone.0214200.

[64] K. Brown, L. E. Worrall, B. Davidson, and T. Howe, "Living successfully with aphasia: A qualitative meta-analysis of the perspectives of individuals with aphasia, family members, and speech-language pathologists," *International Journal of Speech-Language Pathology,* vol. 14, no. 2, pp. 141-155, 2012, doi: 10.3109/17549507.2011.632026.

[65] L. Kidd *et al.*, "A realist evaluation of mechanisms and contexts for facilitating the implementation of supported self-management in community stroke care (The IMPETUS Study)," *Health & Social Care in the Community,* vol. 2024, no. 1, p. 9198768, 2024, doi: https://doi.org/10.1155/2024/9198768.

[66] V. Fu, K. M. Fernando, F. Bright, J. Riley, K. McPherson, H. McNaughton, and n. null, "Coming to my own wisdom: A qualitative study exploring the role of the Take Charge intervention in stroke recovery," *Clinical Rehabilitation,* vol. 39, no. 3, pp. 377-387, 2025, doi: 10.1177/02692155241310770.

[67] C. D. Johnson *et al.*, "The Global Spine Care Initiative: model of care and implementation," (in eng), *Eur Spine J,* vol. 27, no. Suppl 6, pp. 925-945, Sep 2018, doi: 10.1007/s00586-018-5720-z.

[68] A. Ranta, B. Jones, and M. Harwood, "Stroke among Māori in Aotearoa New Zealand and solutions to address persistent inequities," (in English), *Frontiers in Stroke,* vol. 2, 2023-August-24 2023, doi: 10.3389/fstro.2023.1248351.

[69] Waitangi Tribunal, "Hauora: Report on Stage One of the Health Services and Outcomes Kaupapa Inquiry," Waitangi Tribunal, 2023. [Online]. Available: https://www.waitangitribunal.govt.nz/en/inquiries/kaupapa-inquiries/health-services-and-outcomes

[70] V. L. Feigin *et al.*, "30-Year trends in stroke rates and outcome in Auckland, New Zealand (1981-2012): A multi-ethnic population-based series of studies," *PLOS ONE,* vol. 10, no. 8, p. e0134609, 2015, doi: 10.1371/journal.pone.0134609.

Indicative questions

Stroke survivors and whānau

Māori stream

1. **Wellbeing after stroke**
   a. Can you tell us how things have been for you since you had your stroke?
   b. People often talk about the importance of wellbeing. What does wellbeing mean to you?
   c. Can you share your experience of wellbeing after stroke.
   d. People often talk about the importance of *psychosocial* wellbeing after stroke. What do you think of when you hear that term? Are there other kupu that you think are more appropriate?
   e. Do you feel you are experiencing psychosocial wellbeing at the moment? Why or why not?
   f. When you think about yourself just after you had the stroke, what was most important in helping your wellbeing at that time?
   g. How does wairua connect with wellbeing?
   h. What role do whānau play in your wellbeing?
2. **Stroke services**
   a. Can you tell me about the care you had after your stroke? (Map out care on a piece of paper – services, clinicians, gaps in care. Probe for care practices and processes such as family meetings, new therapists, referrals to other services
3. **Psychosocial wellbeing after stroke**
   a. When you think about how the stroke services supported your wellbeing, what went right, and what went wrong?
   b. When we look at each step in your care, can you tell me how the staff supported you with each of these areas?
   c. Was there any particular person who you felt helped? If so, what did they do?
   d. Were there times where services or staff focused on other things instead? Were there times when they could have looked more at supporting you to live well after stroke? Are there some examples you could share?
4. **Doing things differently**
   a. Other than stroke services, what helps or could help your wellbeing?
   b. If you felt your wellbeing was low, where would you go for help?
   c. In an ideal world, how could services better support your psychosocial wellbeing?
   d. Is there anything services and clinicians could do differently to support other people who experience strokes in the future?

Non-Māori stream: Individual interviews

1. **Wellbeing after stroke**
    a. Can you tell us how things have been for you since you had your stroke?
    b. People often talk about the importance of wellbeing after stroke. What do you think of when you hear that term?
    c. People often talk about the importance of *psychosocial* wellbeing after stroke. What do you think of when you hear that term?
    d. Do you feel you are experiencing psychosocial wellbeing at the moment? Why or why not?
    e. When you think about yourself just after you had the stroke, what was most important in helping your wellbeing at that time?
2. **Stroke services**
    a. Can you tell me about the care you had after your stroke? (Map out care on a piece of paper – services, clinicians, gaps in care. Probe for care practices and processes such as family meetings, new therapists, referrals to other services
3. **Psychosocial wellbeing after stroke**
    a. When you think about how the stroke services supported your wellbeing, what went right, and what went wrong?
    b. When we look at each step in your care, can you tell me how the staff supported you with each of these areas?
    c. Was there any particular person who you felt helped? If so, what did they do?
    d. Were there times where services or staff focused on other things instead? Were there times when they could have looked more at supporting you to live well after stroke?
4. **Doing things differently**
    a. Other than stroke services, what helps or could help your wellbeing?
    b. If you felt your wellbeing was low, where would you go for help?
    c. In an ideal world, how could services better support your psychosocial wellbeing?
    d. Is there anything services and clinicians could do differently to support other people who experience strokes in the future.

Stroke practitioners

Māori stream

1. **Supporting psychosocial wellbeing**
    1. What do you do within your role to support people's psychosocial wellbeing?*

        Prompts: How do you know this? Can you give an example? Are there things within your [service] that make it more possible or more likely that you will be able to do this? Think about different levels: Patient/therapist/service/profession? Within your discipline, what is your role?
    2. If I was shadowing you, what would I have seen you do and what would I have heard you do?

        Prompts: Who would you have talked to? What would you have talked about and when? What forms would you have filled out? What were the things you had to do?
    3. What is best practice for supporting psychosocial wellbeing?*

        Prompts: How do you know that? How do you stay up to date with best practice?
    4. What is best practice for supporting psychosocial wellbeing for Māori stroke whānau?

        Prompt: How do you know that?
    5. When you compare how psychosocial wellbeing is addressed in your current service with other services you have worked in?*

        Prompts: What is different? How did you learn this? How did you learn 'this is the way things are done'?

2. **Ideal vs. real practice**
    1. When you think about a person's rehabilitation care (across the continuum of recovery), when are the points that it is most likely that psychosocial wellbeing is addressed? Is this what you think it *should* be like?*
    2. When you reflect on your own practices, is there a difference between what you would like to do and what you *do* do in supporting psychosocial wellbeing? What stops you doing that right now?*
    3. What are the challenges in supporting psychosocial wellbeing?

        Prompts: Can you give an example? Are there things within your [service] that make it more difficult or more likely that you will be able to do this? Think about different levels: Patient/therapist/service/profession?
    4. If you were to build psychosocial wellbeing into your routine care, how would you do it? What would need to change?*
    5. If you were to build psychosocial wellbeing into routine care for Māori stroke whānau *in your service*, how would you do that? What would need to change?
    6. If you were to work in the way you would like to work, and you think would be most beneficial, what would need to change? What would make it possible for you to work differently?

3. **Kupu**

We have been using the term ‘psychosocial wellbeing’ and our Māori advisors from Awhi Mai have suggested the kupu ‘oranga wairua’. What kupu do you think best reflects the notion of psychosocial wellbeing?

Non-Māori stream: Focus groups* and individual interviews

1. **Supporting psychosocial wellbeing**
    1. What do you do within your role to support people’s psychosocial wellbeing?*

        Prompts: How do you know this? Can you give an example? Are there things within your [service] that make it more possible or more likely that you will be able to do this? Think about different levels: Patient/therapist/service/profession? Within your discipline, what is your role?
    2. If I was shadowing you, what would I have seen you do and what would I have heard you do?

        Prompts: Who would you have talked to? What would you have talked about and when? What forms would you have filled out? What were the things you had to do?
    3. What is best practice for supporting psychosocial wellbeing?*

        Prompts: How do you know that? How do you stay up to date with best practice?
    4. When you compare how psychosocial wellbeing is addressed in your current service with other services you have worked in?*

        Prompts: What is different? How did you learn this? How did you learn ‘this is the way things are done’?

2. **Ideal vs. real practice**
    1. When you think about a patient’s episode of care in your service, when are the points that it is most likely that psychosocial wellbeing is addressed? Is this what you think it *should* be like?*
    2. Is there a difference between what you would like to do and what you *do* do? What stops you doing that right now?*
    3. What are the challenges in supporting psychosocial wellbeing?

        Prompts: Can you give an example? Are there things within your [service] that make it more difficult or more likely that you will be able to do this? Think about different levels: Patient/therapist/service/profession?
    4. If you were to build psychosocial wellbeing into your routine care, how would you do it? What would need to change?*
    5. If you were to work in the way you would like to work, and you think would be most beneficial, what would need to change? What would make it possible for you to work differently?
    6. Is there something you don’t have in your job that, if you did have, would help you support psychosocial wellbeing, or prevent it being an unmet need?*

Table S1: Quality domains with illustrative quotes

Quality domain	Illustrative data of how well-being *is* addressed	Illustrative data of how well-being is *not* addressed
Care supports people through uncertainty	**Uncertainty is explicitly acknowledged** "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* **The stroke, its causes and care processes, are explained as many times as needed** "She [nurse] pretty much broke it down to me about what I had, showed me pictures, and explained to me how a stroke works… It doesn't make any sense until someone explains it thoroughly and properly, it's like 'wow ok.'…It was only at that time I thought 'oh ok…I know what's happening'." *Person with stroke, Pasifika* **All the key people are included in conversations** "I just always like to touch base with whānau around how they're feeling about things…And part of that is to see whether they understand why they've come in and the family understand why they've come in – to make sure they've got a good understanding on the medical component. And you know, the doctors down here are great – they'll all come in with me and we'll just meet with the family." *Allied health, Māori*	**The impact of uncertainty is ignored or diminished** "Normalising is a good strategy but sometimes for patients it feels like minimising or downplaying, you know? Not normalising. For them to feel like that but then [to have someone] say 'Oh you'll be fine, it's normal, you'll get through it' I don't think it's helpful." *Nurse, Asian* **Information is not repeated or is unclear and people don't 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* **Information is only given to the person with stroke or whoever happens to be there at the time** "I was quite shocked when I went in [to visit husband in hospital] because nobody had actually contacted me or anything, so I didn't know what I was confronting. Then [husband] told me that he was going to have a scan and if this thing didn't go they would have to operate and he could end up a cabbage… And the fact that no one had actually been with him, family wise when he was told that." *Family member, Pākehā*

	Information given responds to the questions, priorities and life context of the person with stroke “Just base everything from what they feel, what they see, what’s going on, what they want to do, what help do they need, how they’re feeling, can they see the future or do they feel helpless…anything about them, what’s going on with them.” *Nurse, Asian* **Informative is given at appropriate times, in a relational way, with time to discuss, ask questions, and have these answered** "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* **People understand what to expect from post-discharge services, including contact timelines and details before leaving hospital** “[Community therapists meet patients on the ward before their discharge home] and we sometimes will get them in to do the home visits with the patients.” *Allied health, Pākehā* **People have a sense of what recovery, and what a ‘good life’ might look like in the future** [We need to know] “How do you live with strokes physically, mentally, spiritually? How do you do	**Only generic, not personalised, information is given** “They [health professionals] just about all say, 'every person's stroke is different'. I have heard that so many times. I would like to ask a question and get the answer to it rather than say ‘every stroke is different.' That’s not really the answer to the question, is it?” *Person with stroke, Māori* **People don’t know what to expect after discharge from hospital** “We somehow stumbled across, we kind of stumbled through quite a lot of it.” *Family member, Pākehā* **People don’t receive information about supports available and how to access them** “It’s like you need, like a ward nana or somebody to sit and just go through it all with you and just to actually be that person. It doesn’t have to be a medical person – just someone to say, ‘hey look you’ve arrived in this ward, this is available, and this is available…’ to try and help you through the situation.” *Family member, Pākehā* **Information doesn’t address the areas important to the person or whānau** “I think the support’s gotta be around the whānau and understanding what stroke is or understanding what brain surgery is and the effects afterwards, what could happen to the person. I never had any of that. I just got, you know, you get a leaflet and a

	that? What tools are there to give us to help us manage those aspects of stroke?” *Person with stroke, Māori*	pamphlet and a booklet and a what not to read and you can ask questions of the neurosurgeon but they’re procedural sort of medical questions, they’re not around the wairua, or the, how will a person be?” *Person with stroke, Māori*
Care fosters a sense of belonging	**Services provide a welcoming, age-appropriate environment for people with stroke** “It’s an amazing [gym], like it really is, you know and they didn’t have to put lycra on, they would just go along in whatever they were comfy in. It’s a very sociable, sporty...it’s actually really nice...it’s just a family, it’s a very much a family feel to it.” *Family member, Māori* **People are offered facilitated connections with others impacted by stroke, for example through peer support or community groups, or simply through introductions on the ward** "They [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* **Whānau Māori are offered a connection with other Māori** "It’s lots of fun when we’re together because we acknowledge each other’s confusion sometimes,	**People with stroke do not have a welcoming physical space where they can feel settled** " That’s the first time I’ve had to wait in the assessment area for the amount of days that I stayed in. So I just thought ‘oh maybe I am not important? ...It was just after hearing that I’d had a stroke and I thought, just to have, it was frustrating the fact that, I think it was just there wasn’t a room, I didn’t have a room to myself and a sense of belonging...[I thought] am I just an 'assessment'?" *Person with stroke, Pasifika* **There is little reflection of te ao Māori in clinical spaces** “[There was no support for elements of wairua] at the hospital. I don’t know how long I was over there for but it was sort of sterile and even when I’d go back to have post appointments and that, it still was, it was not a nice place to go.*” Person with stroke, Māori* **The environment is confronting or isolating, where there is little in common with others** "I was in the aged caring unit with people who were about 80 years old, you know, old people. That was horrible, I hated it, I hated it, and I was just

	but we don’t have to justify it. You know, we just sit there and crack up and laugh and it’s fun and I think that’s the healing part for me personally, so I don’t have to justify and explain myself. That’s the part that’s really really healing." *Person with stroke, Māori* **Services enable a holistic sense of belonging, reflecting people as people not just patients with strokes** “[We] went fishing just recently. We just do different things, we go for a picnic or a barbeque somewhere and those, you know, things that you kind of have started to exclude out of your life because you can’t do them, yourself anyway.” *Person with stroke, Māori*	desperate to get out of there. I was depressed, yeah." *Person with stroke, Māori* **Services offer little flexibility, and care feels like a ‘one-size-fits-all’ approach** “We are somewhat limited in really being able to fully evidence that sometimes with the under 65 patients especially when we’re looking at what cares and supports are available it tends to be done on more the physical need, ‘Do you need showering? Do you need dressing? Do you need your dinner made?’ And sometimes some of the questions that don’t get asked but should be are ‘How are you going to parent again? How are you going to look after your children, how do you get kids to drop-off?’ And how do we get that individual a bit more involved in that? So that’s the other cohort of patients that I think we really struggle with getting an appropriate plan for discharge with.” *Allied health, Pākehā* **There are few opportunities to connect with others impacted by stroke** "All of them that I was with at [hospital] when I was doing the painting therapy thing had all had some sort of brain operation or something that happened, but they were all Pākehā and we’re just different, you know, and while I enjoyed it, it was funny. I don’t know how to explain it." *Person with stroke, Māori*
Care prioritises relationships and connecting ‘as people’	**People feel that staff want to know them which helps build trust**	**People feel ‘invisible’ when staff are disengaged or focus on the stroke, rather than the whole person**

	“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* **Staff get to know people by asking about their lives, interests and what matters to them** “This particular nurse, she come in and I noticed that she had a, there was an aura about her that I could feel that she was caring. The way she spoke, very gentle. And so I connected with her straightaway... And she always [said], ‘Excuse me, would you like to do this, would you like, is there any way we’d do...’ So she spoke like that. 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* **Staff share of themselves** "We had quite a bit in common. She [allied health therapist] was a twin too. We’d talk about our sisters, and it was good like that because she was very positive, and she never put me down. Yeah so, I would say she had a big impact in my recovery of that [depression]." *Person with stroke, Pākehā*	“I notice they’re just so quick to pump them full of drugs and get them out the door, but you know, they are not talking to them... you don’t trust people and I’ve seen it...you don’t trust people in the way they might treat you.” *Family member, Māori* **Staff don’t share of themselves, increasing a feeling of vulnerability and power imbalance for people and whānau impacted by stroke** “The doctors tended to breeze in and breeze out. They’d hmm and ha and write notes and you didn’t really know what was going on.” *Person with stroke, Pākehā* **The relationship with staff focused on the technical aspects of care, not people’s wider relational needs or well-being** “Some of them would come in, do what they had to do, go... As I say, some of the nurses were wonderful and some of them were good technicians. It wasn’t that the care wasn’t good, but it was a different sort of care. And you notice the difference when you’re sitting in the bed.” *Person with stroke, Pākehā* **Staff don't ask about nor create time for people to talk what is important for them** “There were a couple [of staff] that were barely just there for the pay check and didn’t engage. And staff that don’t engage when you have had something like this happen, that’s just annoying ...I could see how if you were lying in bed, no income, no certainty about their future, not knowing whether they were going to

	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 "There was just something about their relationship that I think helped him a lot. Like she [specialist] 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." *Family member, Māori* **People feel comfortable reaching out to staff anytime, and are given a point of contact to make this easier** “[The specialist] said ‘If ever there’s anything comes up, contact me, I’m happy to go back into it’. So, there was something there that’s…yeah she was an excellent source [of support] for me.” *Family member, Māori* **The relationship with staff supports people’s confidence and self-belief** "Her [physio] strength became my strength." *Person with stroke, Pākehā*	have another one, I could see how service like that would really drag you down.” *Person with stroke, Pākehā* **The time pressures of the service mean staff don’t get to know people** “They’ll be in and then they’ll be out…there’s no, ‘Oh how’s your family?’ You know, it’s just business.” *Family member, Māori* **Rigid service processes result in people feeling unheard and having to fit the needs of services** “There was no follow-up or anything, it was just like, ‘Ok you’ve done your six weeks’ or eight weeks or six months or however long it was and tick and off you go and that’s what I said to them, ‘Oh I ticked that box and now I’m out of here, what do I do now?’” *Family member, Māori*
Care attends to the emotional aspects of stroke	**The emotional impacts of stroke are acknowledged in care** “They would let you say, ‘I have had a shitty night’ or ‘I’ve had a bloody horrible day’ and they will agree with you, or they will let you say it” *Person with stroke, Pākehā*	**Physical recovery is prioritised with little acknowledgement of the emotional impacts of stroke** “Sometimes we tend to not speak the truth because we feel like lots of expectancy, sometimes we are afraid, or I felt like I was afraid. Because they would be ‘oh you are looking good’ after maybe the second,

	People feel their experiences are validated, and not minimised “Normalising is a good strategy but sometimes for patients it feels like minimising or downplaying, you know? Not normalising. For them to feel like that but then [to have someone] say ‘Oh you’ll be fine, it’s normal, you’ll get through it’ I don’t think it's helpful. I’d probably say, ‘This is very very common but for you, this is the first time you’ve been through this so it must be very very difficult for you’. I would say common for them to see that ‘oh I’m not the only person that’s going through this’.” *Nurse, Asian* **Staff show empathy and are unhurried in their interactions** “She [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* **Staff provide opportunities for people to share their emotions if they choose** “They [nurse] picked up on how the person was feeling and were always available for a chat.” *Family member, Pākehā* **People are asked how they are coping, and what they feel would be helpful for their well-being**	third week they would say ‘oh you are looking much better’ but I felt physically better, but it doesn’t mean to say that I was mentally better. I just sometimes went ‘oh I am good, I am ok’.” *Person with stroke, Pasifika* **People feel their experiences are minimised or dismissed** “After three sessions [with the psychologist] he was like, “Oh you’re fine now.’ And it was like okay, obviously I’m fine but I don’t feel fine.” *Person with stroke, Pākehā* **Staff appear rushed, inhibiting people with stroke from reaching out to them** “Either they’re [staff] too busy or, I don’t know exactly what the problem was, it’s just that… getting to people’s mindset of where they are to understand them, put that work in to… sit down and see where that person’s, state they’re in and then make a plan around that. That’s probably the biggest help people need.” *Person with stroke, Pākehā* **People feel pressured to mask their true feelings and stay overtly ‘positive’** “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’. Which in itself is what people do, the majority of people must do? I don’t know. But it is one thing that we totally get pissed off hearing. ‘It’s going to be

	“Just base everything on what they feel, what they see, what’s going on, what they want to do, what help do they need, how they’re feeling - can they see the future, or do they feel helpless?...Anything about them, what’s going on with them.” *Nurse, Asian* **Care recognises and supports people emotionally** 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* **People and whānau have access to counselling or psychological support if they choose** "It’s good [talking to psychologist], I find, like I say... If I talk about stuff and get it off my mind that normally eases my mind – I don’t think about it all the time." *Person with stroke, Pākehā*	alright, so you’ve had a stroke’. And it’s not.” *Person with stroke, Pākehā* **Staff avoid or ‘skirt around’ emotionally challenging conversations** “For myself personally, I need it [anxiety] labelled and then I can work out ways around it or how to deal with it or what to do with it and [staff could help by saying] ‘This is the outcome and this is what you can do to get around it or these are the systems you can use or find for yourself.’ Whereas I have had to do it by myself, reason to myself, working out what it might be, working out what I can do.” *Person with stroke, Pākehā* **There is no access to culturally safe emotional or mental health support** “I didn’t know that that was going to happen, like bouts of depression, I wasn’t a psychiatrist, I didn’t know what to do, they never gave any instr... I didn’t even know where to go with her [wife] when she was like that. I had to sort it out and was just my spiritual stuff that helped me counsel her through... “ *Family member, Māori*
Care centres people’s preferences and supports people to have choice and control	**People and whānau are asked their perspectives and opinions about what would they like to see happen in their care.** “What I really liked about the community team, it’s all about the...like coming here [home] and doing stuff and you know, it’s like, ‘okay what is it that we	**Staff ignore or diminish the knowledge and experience people have** “[It was important to have] patience to wait until the doctors listened to what you were saying.” *Person with stroke, Pākehā*

	can help you figure out how to do?" *Person with stroke, Pākehā* **Staff work with whānau Māori to identify how care can align with areas of meaning for them** “Once [dad] was out of the immediate danger zone, we 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* **Staff encourage people to challenge themselves** “Try to encourage people that they can do it even if just trying to walk one foot in front of another is impossible. Standing on my weak leg was impossible but the physiotherapist said, ‘you can do it’. So, it’s helpful if staff say you can do it and encourage you and say, ‘other people have been able to do it but it did take a struggle and they had to change their thinking, you can do it.’ Not in a judgmental bossy way but as an encouragement, with enthusiasm for it.” *Person with stroke, Pākehā* **Staff acknowledge the effort and problem solving that people put into their recovery** “[The neurologist] would say ‘you are doing really well, you are a miracle. Things are working, keep on going.” *Family member, Pākehā*	**There is a lack of interest or respect for the opinions and perspectives of people with stroke and whānau** “They have their best intentions but it’s like the old, 'well I know what you need and I’ll give it to you ‘cause I know what you need.' No-one asked me ‘well what do you need or what would you like?’ Because I wanted to go swimming and they said, ‘oh no you can’t do that’ and I went ‘oh, ok’. ‘You can just go and see the psychologist’...” *Person with stroke, Māori* **Whānau Māori perspectives are unheard or overridden** “[Health professionals had no understanding] from a Māori perspective.” *Person with stroke, Māori* **Staff appear too busy to answer the questions of people and whānau** “[I didn’t tell them that I was hoping to discharge to see my daughter renew her wedding vows]. Why load them up with trouble? They were all already loaded up and stressed out anyway.” *Person with stroke, Pākehā* **Care feels directed by staff and service processes** “It ends up a waste of time having counselling ‘cause you’ve gotta go through their professional process before they get to you...Talk about what is actually happening for the person, why they’ve come to you that day, not the background stuff...you’re crying out for help now, not six weeks or ten weeks

	People see staff taking action on things they have discussed together "If you asked for something, you noticed she actually did it...Like a lot of people listen to you and go away and say they'll do something and nothing ever happens..." *Person with stroke, Pākehā* **Care feels like a process of shared problem solving about what will work best for the person and their whānau** "She'd say, you know, 'Okay so if we showered you earlier in the morning, we've got this staff member that starts at this time – would that make you happier?' And [husband] would go, 'actually yes, that would make a huge difference'. *Family member, Pākehā* **When a person's wishes cannot be upheld, alternative options are discussed together** "If they're unable to go home for various reasons and they're going to residential care, I think it's about still having control in some way around that. We had a gentleman here, I asked him 'what would you like to do?' He said, 'I'm not going to go back to my house, what I want is to go back, sit in my sunroom and have a cup of tea for the last time'. He said, 'because I built that house, all my babies were born there, my wife died there'. So, I said, 'come on, let's do that'. I spoke to the doctor, and we did that." *Allied health, Māori*	down the track when they finally get to your issue and other issues have popped up after that so you've built up issues that you can't talk about because the process lets you down." *Person with stroke, Māori* **When people try to exercise autonomy, this is not well received because of concerns about risk** "That was always a major issue was having someone there. You had to depend on them, whenever they were ready to take you to do certain things. And they made that quite clear that you had to do it with a nurse, and I had quite a few arguments about that." *Person with stroke, Māori*

Care honours Māori knowledges and practices	**Staff and services recognise their own cultural perspectives and how these might influence care.=** “I think it’s really important that we are aware that we are just part of a journey and it’s the patient’s journey, not ours. I think we’re still very much in transition from clinician-driven to patient-centred care. And I think just like what the cultural advisor’s talking around is we’re still very much in process to transition to genuine patient-centred whanau-centred care.” *Nurse, Pākehā* **Care is underpinned by tikanga** “[We] start and finish with karakia, whanaungatanga, then we tell them about who we are and what we’ve experienced as a stroke survivor. Then we’ll get them to share their experiences...And before the end are their goal setting and that’s when I’ll be talking to them about tinana, hinengaro and wairua and I [say] ‘Now, you need to have goals for all of them’ because ...the support has to be balanced.” *Person with stroke, Māori* **Whanaungatanga is prioritised, and care is provided in ways that reflect te ao Māori - recognising that western concepts of health and well-being are different to those in te ao Māori** “She was a kapa haka 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	**Little recognition of culturally grounded concepts of well-being, nor the deeper connections that foster well-being for many whānau** “You can’t look after the hinengaro without looking after the wairua and the tinana, 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* **While there are opportunities for karakia, there are few other indications that tikanga is respected** “[It has to be a holistic approach all of the time] and I won’t assume that everybody understands that so it’s vital that it’s spoken. It’s vital otherwise it’s just an assumption that people make, ‘Oh no they’re ok, they had a karakia, everything’s cool.’ But the other parts haven’t been taken care of.” *Person with stroke, Māori* **Interactions feel transactional, with limited time for whanaungatanga. This isn’t enough for people to feel safe and comfortable.** “It’s all about relationships so how much time do you need to do that? Every whānau are different. Every individual in that whānau are different so unfortunately, you’ve just gotta make sure that you have enough time to give.” *Person with stroke, Māori* **There are few Māori clinicians** “The service is very much not built for Māori...they were lovely people, but it’s very much a service for

	words. We've done that with various cultural parts – weaving, another person was into arts. So, it was tapping into that activity that they've been doing for many, many years." *Allied health, Māori* **Whānau Māori have space to determine their own healthcare journey, and are supported in ways that they choose** "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 feel listened to and understood**. "We're always telling our stories and the more that I do, I found that the less I will cry and be emotional and then I can see the real facts from what's going on in my heart and [the Kaupapa Māori group] allows us to do that because we continue to always talk about our stories." *Person with stroke, Māori*	Pākehā people...there was no Māori staff or volunteers." *Family member, Māori* **Therapy resources are designed by and for Pākehā, and do not reflect different cultural concepts or languages** "They had a lady who would come and help dad read. She was an old Pākehā lady and things that she would bring for him to read were written in Old English...there was nowhere that we could see to help, because it wasn't until he got home we realised not only could he not really read or speak English, he actually could do neither in Māori and how are we going to get him back to speaking Māori and understanding, reading, writing it when the only people that can help are Pākehā old people?" *Family member, Māori* **Interactions are time-bound, and people and whānau cannot choose when they receive input nor what that looks like** "If there's a health provider service out there that I could benefit from, they give me a timeframe to get back to them if I want the service. If I don't get back to them in two months, then they'll probably think 'oh no she doesn't want it' but I'm not ready yet for that." *Person with stroke, Māori*
Care responds to the strengths and needs of friends and whānau	**Staff learn who key whānau members or friends are and don't make assumptions** "When we engage with the whanau, don't make assumptions. Look, listen, see. Then try and figure	**Staff do not introduce themselves nor get to know whānau or friends** "I didn't...didn't really get to see them [staff] much." *Family member, Māori*

	out what strengths are there within this whanau. Everybody will quickly identify what the negatives are … Let's focus on what is shining. That's what you have to build, that's what you've gotta try and include if you're looking at rehab." *Person with stroke, Māori* **Staff introduce themselves and maintain regular contact with whānau** 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* **People are supported to engage in family meetings that are designed around their needs and concerns** "Today we had a meeting this morning and it's like what do they need to carry on to make my life easier" *Person with stroke, Pākehā* **Staff are attuned to family and work to elicit and address their concerns** "I like to manage the [family] meetings because I like to read the whanau's body language. Sometimes when something's been said, afterwards I say, 'oh so and so, I could see your body language was telling me something's not right. I picked up something from your body language – what were you thinking?' And she'll say, 'well I disagreed with what they were going to do for my whoever because he doesn't work like that'. [I'd say] 'Okay, have you got any ideas of	**Staff assume the roles that whānau will play in the person's care** "Sometimes I sort of had to say to staff do you mind giving [her brother] a shave 'cause that's something I wasn't going to do … it was never a problem but they didn't think to do it because I was there … like an assumption was made." *Family member, Māori* **Whānau members are only peripherally included in information sharing, and don't feel able to ask questions** "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 are only included in therapy activities and care when they happen to be there** "There was space [for family] but there wasn't active inclusion as much I don't think." *Person with stroke, Pākehā* **Staff don't seek out the perspectives of whānau, nor recognise their strengths** "I think it'd be good for them [stroke services] to have someone available…that is able to sit and talk and say, 'Hey, these are options, and you don't have to accept what's given to you if you have another

	what we could do to make it different?' 'Yeah, why don't you try this'." *Allied health, Māori* **Whānau or key friends are asked what is important to them and how they want to be involved in care** "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* **The needs of whānau and friends are understood and supported in the service** "I would always be able to ask questions and bring things up and they were always very forthcoming. And one day, I can't remember what it was, something had really upset me, something financial…and the OT picked up on that straight away and asked me what was wrong and talked me through…I felt like I could ask her anything." *Family member, Pākehā* **There are comfortable spaces for the person with stroke to spend time together with their loved ones** "They had like a little unit there, self-contained unit for people to sort of, you know, just check out their	plan'. So, they need someone available that can discuss how [the person and whānau] might want to see things happening." *Family member, Māori* **Staff don't understand the broader context of whānau lives, and the wider impacts of stroke on them** "There's too much expectation that ok, a family member can take care of the person, but that family member probably needs to work to help support the rest of the family so if we take care of the person that can't, who doesn't get paid well then, you know…money's needed." *Family member, Māori* **Services are not resourced to support whānau needs** "I don't really feel like there was a lot of [support for families], yeah, the posters were up on the walls and there was this and that but yeah, I wouldn't really say that they're equipped to deal with [families]." *Family member, Pākehā*

	own capabilities…[and] I had my child with me, they were onsite, so I was gonna be ok”. *Person with stroke, Māori*	
Care attends to people’s holistic long-term well-being	**Staff seek to find out what supports a person’s well-being and integrate this into care** “It’s just tolerance for stuff like ‘this man’s not coping today. Look that’s absolutely fine, and that’s really normal, let’s awhi him more today. And what can we do to awhi him? What does that look like?’ Like [a patient] who’s had a dense stroke. Her cat came in yesterday. For her that’s critical. That’s all that she wants, you know?” *Nurse, Pākehā* **Care is holistic, focusing on what supports people to be and stay well in themselves** “I encourage therapy to think outside the box. It’s not always just medical and psychological, it’s about whānau, skin on skin, reconnecting, stimulating the body, using things that [person with stroke and whānau] were doing previously…It’s about feeling connected, feeling loved, feeling accepted, even though my body’s like this”. *Allied health, Māori* **Goal setting is an individualised process, revisited often as people progress through care** “People set rehab goals, they’re the ones setting the goals, so it’s based around their own aspirations… So, I think we have that collaborative thing to start with and align with their aspirations, their passion and their dreams.” *Manager, Māori*	**Care focuses on what is ‘broken’ – the impairments from the stroke** “It’s the silo mentality, and that irritates the heck out of me because you are a whole person – you’re not just ‘a plastics’ entry or ‘a stroke’.” *Person with stroke, Pākehā* **Goal setting discussions are the only opportunity to discuss the future, but often feel like a ‘tick box’ exercise** “Only superficially they’d come around with a form and say, ‘what are your goals?’ I am like, ‘What do you mean what are your goals? I want to get out of here.’” Person with stroke, Pākehā **An orientation toward discharge focuses staff and those with stroke on short term tasks rather than looking to a future in which the person can flourish** “So, [in hospital] I think the thing is walking, so just walk – doesn’t matter how, [just] walk so you can go home really.” *Person with stroke, Pākehā* **There is little consideration of what roles people hold and what supports their well-being in the community** “There was no awareness from any of the services that put any weighting on his ability to reconnect on the marae or in any other space apart from getting

	Staff actively support people to engage in activities, roles, relationships and social contexts that support their well-being “The manager lady she came and talked to me once and because she knew I was a teacher, the Catholic school was on the corner so she offered if I would come and be a teacher aide.” *Person with stroke, Māori* **An environment is created where people’s strengths are recognised and fostered** “[As a] therapeutic community [people] have things like shared responsibility, they have peer to peer problem solving, joint problem solving. So, you provide opportunities for clients themselves to try and troubleshoot and to share their expertise. We find that the clients have the answers to a lot of the stuff themselves and… everybody’s an expert on themselves because, you know, we’ve known ourselves for the longest, haven’t we?” *Manager, Māori* **Services reflect a holistic understanding of well-being, where people feel able to draw on the supports they need - including from outside formal services** “We had a young lady who had quite a severe stroke… she had children including a young toddler. The doctors basically said she’s not participating, and they didn’t think there was any cognitive response. So, I went and spoke to the husband about what was she like prior, what did she like to	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 for an Iwi. 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* **There is an implicit sense that well-being equates to physical independence, and that once people’s physical function has improved, then they have achieved sufficient recovery for discharge** “Correct me if I’m wrong but I feel that the aim of community rehabilitation is to get functionality back…feels like in our case, and I could be completely wrong, ‘can you walk well enough?’ Tick… ‘What can you do around the house with your arm? How can you make your own cup of tea and your toast? Okay that’s fine.’ Tick.” *Family member, Pākehā* **People don’t feel able to express what is important to them and their well-being** “I think [acknowledging differing spiritual and cultural beliefs] is lacking in hospitals…whether the nurses and everybody that works for DHBs and that have a more open mind to things that people might believe in or may not believe in, just to be, just to

	do? One of the key things he said to me was ‘our girl’s struggling because she always slept by her mum every night, since she was born’. So, I organised one weekend to put her in the hospital flat with her whānau. Afterward I asked her husband ‘how did it go?’ And he just burst into tears. He said, our baby just loved being near her mother, kissed her during the night, would hug her and she would touch her skin like she used to. With that skin on skin, she started to respond. So, it’s about what other ways can we use for treatment to get some response.” *Allied health, Māori*	acknowledge that somebody’s thinking like that and they shouldn’t end up in the psychiatric unit or something, which would’ve happened, you know?” *Person with stroke, Māori*