

Psychosocial well-being after stroke in Aotearoa New Zealand: A qualitative metasynthesis

Abstract

Introduction: Psychosocial well-being is key to living well after stroke, but often significantly affected by stroke. Existing understandings consider well-being comes from positive mood, social relationships, self-identity and engagement in meaningful activities. However, these understandings are socioculturally located and not necessarily universally applicable. This qualitative metasynthesis examined how people experience well-being after a stroke in Aotearoa New Zealand.

Material and Methods: This metasynthesis was underpinned by He Awa Whiria (Braided Rivers), a model which prompts researchers to uniquely engage with Māori and non-Māori knowledges. A systematic search identified 18 articles exploring experiences of people with stroke in Aotearoa. Articles were analysed using reflexive thematic analysis.

Results: We constructed three themes which reflect experiences of well-being: connection within a constellation of relationships, being grounded in one's enduring and evolving identities, and being at-home in the present whilst (re)visioning the future.

Conclusion: Well-being is multi-faceted. In Aotearoa, it is inherently collective while also deeply personal. Well-being is collectively achieved through connections with self, others, community and culture, and embedded within personal and collective temporal worlds. These rich understandings of well-being can open up different considerations of how well-being is supported by and within stroke services.

Introduction

Stroke has significant psychosocial impacts. The *psychological* impacts such as depression and anxiety affect many, with approximately one third of people experiencing depression [1] and one quarter experiencing anxiety [2, 3]. These rates are higher for those with aphasia [4, 5]. *Social* impacts see changes in social relationships amongst family and friends. It is not uncommon for people to report reduced social supports and networks, strain within family networks and social isolation [6]. The psychological and social effects are interwoven, with social isolation affecting mood, and vice versa [6, 7]. Together, these impact on quality of life [6], engagement in rehabilitation [8], participation in one's community [9] and stroke outcomes [10]. While the need to consider the psychosocial impacts of stroke has been recognised for decades [11, 12], this is not consistently integrated into practice [13]. After stroke, people continue to live with significant psychosocial disability [14]. They report that services fail to acknowledge and support their psychosocial needs [15] and in fact, can exacerbate the psychosocial impacts of stroke [16]. As a result, it is a leading area of unmet need [14, 15, 17].

An orientation to psychosocial *well-being*, as opposed to psychosocial *impacts* or needs, reflects a more positive, strengths-based approach to considering the psychosocial element of stroke and moves us beyond an impairment-based and biomedical orientation [18]. However, what constitutes well-being is not always clear or consistent across the literature or in practice [19]. Some authors have worked to develop more nuanced conceptualisations of psychosocial well-being that are grounded in the experiences of those living with stroke to better inform research and practice. Kirkevold's work is foundational in this area, suggesting that psychosocial well-being is comprised of four components: a mood of joy and the absence of sadness or emptiness; engagement in meaningful activities beyond oneself; good social relationships and a feeling of loving and being loved; and a strong self-concept with self-acceptance and self-belief [14]. These components resonate with findings in allied areas of 'living well' and 'living successfully' after stroke which highlight the roles of positive outlook, self-acceptance, sense of identity, hope, meaningful relationships and community participation in well-being [17, 20, 21]. More comprehensive understandings of psychosocial well-being and what supports well-being, grounded in the lived experience of those impacted by stroke may open up new possibilities for supporting people living with stroke, and ultimately, improved well-being.

Ideas around what constitutes well-being, and the ways in which people describe it, may be socioculturally located [22]. As such, we cannot assume that understandings from one location can be readily transferred to others. This paper seeks to understand psychosocial well-being in Aotearoa

New Zealand (referred to as 'Aotearoa' in the remainder of this paper). Stroke in Aotearoa is the third most common cause of death and disability, with approximately 9,000 New Zealanders being affected by stroke each year [23]. There are significant disparities in who experiences stroke, when, and what outcomes result. Māori, the Indigenous population are two to three times more likely to be affected by stroke than non-Māori and are on average, 15 years younger than New Zealand European stroke patients at the time of stroke [23, 24]. There are decades of research documenting inequitable care practices [25] and outcomes, with Māori experiencing greater disability and higher rates of death post-stroke [25-27], on a background of stroke services which are culturally unresponsive [28, 29]. In the context of well-being, relying on international conceptualisations may be problematic. These commonly focus on the individual who experienced stroke, while for Māori, well-being is centred in the collective and is multi-dimensional, including whanaungatanga (kinship relationships), uaratanga (values), tikanga (customs), and broader hauora (health and well-being) [30]. As such, international understandings may be problematic and not entirely applicable in Aotearoa. They may reinforce partial understandings of well-being and perpetuate inequities in care experiences and outcomes in Aotearoa. For services to be culturally responsive and not perpetuate inequities, locally-based understandings of well-being are imperative.

The aim of this qualitative metasynthesis is to understand how people living with stroke in Aotearoa, both Māori and non-Māori, experience psychosocial well-being by exploring existing empirical qualitative research. In doing this qualitative metasynthesis, we seek to develop "more comprehensive and integrated understandings" [31] of psychosocial well-being in our unique geographical and sociocultural context of Aotearoa, to inform research and clinical practice [32], and specifically, to underpin a programme of research to enhance psychosocial care practices and outcomes after stroke in Aotearoa

Materials and Methods

This metasynthesis was undertaken as part of a programme of study which utilises Interpretive Description, a qualitative approach that addresses practice-based questions in ways that generate knowledge that can be readily taken up in practice [31]. Within this paper, we use Qualitative Metasynthesis, an approach to literature review which seeks to generate a critically interpretive account of a body of knowledge, so that a phenomenon can be known "more deeply, more fully, and more convincingly" [33]. Core features include using multiple approaches to identifying included articles, engaging with included papers from a variety of disciplinary and methodological perspectives, asking analytic questions to further interpretation, and the requirement to produce a

deeply interpretive account, not simply an aggregation of primary studies, which advances theoretical, conceptual and/or praxis knowledge [32-35]. To honour the context of Aotearoa and Te Tiriti o Waitangi, the agreement of partnership between Māori (the Indigenous people of New Zealand) and representatives of the British Crown, we utilised He Awa Whiria (translated as 'Braided Rivers') [36] as a guiding framework to reflect and uphold this relationship as we conducted our metasynthesis. He Awa Whiria prompts researchers to engage uniquely with Māori and non-Māori knowledges; the latter based in western approaches to knowledge generation and interpretation. In He Awa Whiria, we conceptualise each approach to knowledge as a 'stream' that has mana (standing) in its own right. The approach, Māori or non-Māori, refers not simply to whether a paper is written about Māori experiences by Māori authors, but importantly, the knowledge system that we draw on in analysing and interpreting the paper for this metasynthesis. We refer to the Māori knowledge stream as the 'Māori' stream and the other as the 'General' stream. Reflecting the metaphor of braided rivers, we sought to bring each stream of knowledge together at different points through the research process to learn from all experiences, whilst also ensuring that nuance was maintained between streams and they were not collapsed into one. Each stream of knowledge stood in its own right with each informing the final analysis presented in this paper.

Recognising that our positions influence how we engage with, interpret and report data [35-37], the positionality and cultural diversity of our research team was integral in upholding He Awa Whiria . Having Pākehā (non-Māori) (FB and CIR) and Māori (BJW) researchers who are experienced clinicians and academics (speech-language therapy, FB; physiotherapy, CIR and BJW) with expertise in stroke care and research, psychosocial well-being and qualitative research (FB), programme evaluation (CIR) Māori health and kaupapa Māori research (BJW), and family members of people with stroke (FB and BJW), supported our approach. He Awa Whiria prompted essential team discussions, regarding our critical consciousness (personal and collective) to ensure responsive processes were maintained and culturally appropriate to each stream.

Search strategy

The search strategy was developed in conjunction with a health librarian to identify the relevant literature. The keywords for the search can be found in Appendix A. Searches were conducted in May 2021 in the EBSCO Health databases (CINAHL Complete, MEDLINE, SPORTDiscus), SCOPUS and the Australia/New Zealand Reference Centre. The search was supplemented by reference and citation searching of included articles.

Inclusion criteria

Papers were included in this synthesis if they were: qualitative empirical studies or qualitative reviews OR a mixed-methods study where the qualitative component could be clearly identified; conducted with people who experienced stroke in Aotearoa; considering people's experiences of psychosocial well-being; published between 1990 and 2021; and published in English. Studies were excluded if they only considered family perceptions of stroke survivor well-being or only considered *family* well-being after stroke; or if they addressed mixed aetiologies (e.g. traumatic brain injury or other acquired neurological conditions) and it was not possible to identify material specific to those with stroke.

---insert Figure One about here ---

Search process

The screening process is depicted in Figure 1. The search results (n=536) were downloaded into Endnote after duplicates were removed. The titles and abstracts were screened for eligibility by two student reviewers. The full text of the 50 papers which appeared to, or could possibly, meet the inclusion criteria were retrieved and reviewed by these reviewers who identified together if papers met, or possibly met the inclusion criteria. Through discussion with the lead author, the team identified 18 articles met the inclusion criteria (see Table One), three of which were solely focused on the experiences of Māori [28, 29, 43]. We then reviewed the reference lists and conducted citation searches to identify any additional articles that may have been missed, however no further articles were identified through this process.

--Insert Table One about here--

Data analysis

Analysis utilised reflexive thematic analysis [38, 39] and was jointly conducted by the three authors. He Awa Whiria prompted us to engage with material in ways that were appropriate for each stream. This is evident in how we considered: (1) whose perspectives constituted data for this metasynthesis, and (2) how our research team engaged with material from each stream. All 18 papers were analysed for the General stream by FB and CIR, reflecting that this analysis was done from a Pākehā perspective; the three Māori papers were also separately analysed in the Māori stream, from a Te Ao Māori perspective, by BJW. For the General stream, perspectives from the person who experienced stroke constituted data whilst for the Māori stream, we included material from whānau Māori (the person who had the stroke *and* those in their support network who

participated in the research). This difference reflects that in Te Ao Māori, mātauranga (knowledge and wisdom) is collectively held and therefore should be explored and engaged with, from an inclusive and collective perspective. In engaging with papers, we discussed them collectively as a team, however, the first four stages of analysis of papers in the Māori stream were led by our Māori researcher while the analysis of papers in the General stream was led by our Pākehā researchers. By first four stages, we refer to the first four steps of reflexive thematic analysis – familiarisation, coding, generating initial themes, and developing and reviewing themes [39]. Through this, we ensured that when themes, or aspects of themes, appeared unique to Māori, the analysis of these was led by our Māori researcher though as a team, we continued to explore areas of similarity and difference. By engaging uniquely with the Māori papers, we sought to ensure that these did not become invisible amidst the (majority) general papers. These similarities and differences were core topics of analytic discussions. This approach ensured each knowledge base was engaged with in its own right.

For the purposes of this metasyntesis, material in the Findings and Discussion constituted data, although the Introduction and Methods sections informed understanding of the context and underpinnings of the research, a core component of qualitative metasyntesis [35]. We engaged in iterative and recursive six-step approach to reflexive thematic analysis detailed by Braun and Clark, and Terry and Hayfield [38, 39]. The steps are marked with italics. After reading and creating a synopsis of each article to facilitate *familiarisation* with the literature, we engaged in a process of *coding the data* using semantic (descriptive) and latent (interpretive) codes. ‘Data’ constituted material which provided insight into understandings and experiences of psychosocial well-being. In determining what we attended to within the original papers, we oriented to data that related to aspects of the concept ‘psychosocial well-being’, with psychosocial referring to psychological, social, and/or emotional aspects of life after stroke, and well-being relating to their overall sense of wellness, and their inner self. Our coding was inductive not deductive, and so these acted as sensitising concepts to help us consider what was relevant ‘data’ for the metasyntesis. We collated the data excerpts and assigned codes in Microsoft Word then met together to discuss the initial codes. Using an online Miro board, we *generated initial themes* by grouping codes into candidate (potential) themes, assigning labels and generating thematic descriptors for the themes. To *develop and review themes*, we returned to the original articles, reviewing the coded material and contextual data surrounding it, and in some instances, refining coding with the candidate themes in mind. In doing so, our candidate themes were refined, for example, with ‘a sense of belonging and at homeness’ and ‘a sense of possibility’ being collapsed into one theme: ‘being at-home in the present while (re)visioning the future’. This process of moving back and forward through analysis and

between different knowledge sources reflects the recursive nature of reflexive thematic analysis [38] and the intent of He Awa Whiria [36]. At the fifth stage of *refining, defining and naming themes*, we integrated the general and Māori data and analysis within our analytic writing as we *wrote the final analysis*. Our Findings reflect the integration of the Māori and non-Māori knowledges.

The quality of the included papers was not appraised as articles are not excluded for lower quality scores in a metasyntesis [33] and because traditional appraisal tools are based on Western constructs of knowledge and quality and do not reflect the “heart and meaning” of mātauranga Māori (Māori knowledge) [40]. Throughout the process of review, we sought to ensure methodological and intellectual rigour by: staying grounded in the data and considering the data extracts in the context of the whole of the original work; maintaining records of analytic thinking which integrated memos, data, and recordings of discussion; integrating original data into the published report; utilising the different knowledges of the research team who have cultural, clinical, and methodological diversity which supports different ways of understanding primary data; and attending to how the data reflected particular research paradigms and privileged particular knowledges [33].

Results

We constructed three themes which provide insight into how people experience psychosocial well-being after a stroke in Aotearoa. These are: (1) *Connection within a constellation of relationships* which reflects that relationships, connection and belonging are central to well-being; (2) *Being grounded in one’s enduring and evolving identity* demonstrates how having a sense of identity which grounds people and contributes to the sense of well-being; and (3) *Being at-home in the present while (re)visioning the future* highlights that well-being was enabled when people had a sense of acceptance of the present, a vision of a desired future, and a sense of movement toward this desired future. Throughout the Findings, we have included direct quotations from the original papers which constituted data for this metasyntesis. If required for context, we have added brief material to ensure the meaning is clear. This is provided in square brackets.

Connection within a constellation of relationships

Central to well-being was connection: being in relationships and having a sense of belonging. Relationships were a resource; through them and what they brought about, came a sense of well-being. Well-being happened in relationships with others, people who provided support,

encouragement, and grounding. These relationships were commonly multiple, featuring family, friends, healthcare providers and others with stroke; something other authors have described as a “constellation of relationships” [41]. These different parties provided motivation [42], hope and positivity [42, 43], inspiration and validation [44], practical and emotional support [45, 46] and were seen to be pivotal in helping people move forward and progress after their stroke [28, 43]. Family and friends were perceived to be critical in recovery, supporting people to achieve more than they thought possible [28]. Family were often a constant form of practical and emotional support [28, 42, 47], described by one person as “the extra team you already had [even before the stroke]” [28]. The social connections and influence of these “nurturing relationships” [46] was not taken for granted. These were considered to have a preventative role, helping shield people from depression [48]. Relational supports helped anchor people and helped hold space for well-being at a vulnerable time in the person’s life.

Friendships were vulnerable to the impacts of stroke, more so than family relationships. Interactional patterns and ways of engaging with others could change. This could see people take a more passive role. A loss of friendships was not uncommon [28], particularly when people experienced aphasia [49]. Shared activities were not always possible because of the impacts of stroke; friends did not always make (or know how to make) the modifications needed to enable the person with stroke to participate [42], something particularly common in the presence of aphasia [42, 49]. People described withdrawing from their friends because of shame or stigma [28, 49], a loss of confidence [28] or because of the challenge of adjusting to the stroke [48]. Friends themselves may withdraw [49]. With the loss of friendships could come the loss of connection to people, activities and roles that supported well-being. Family support often became more significant as the physical, psychological and relational impacts of stroke become more evident [28, 47, 49, 50]. For those who perceived a ‘shrinking world’ [28, 49], family then become their main source of support with one saying “you just shrank down to your family” [49], who took on a role as a ‘connector’, helping people connect to other people and to rehabilitation, and to other sources of well-being. For Māori, *whānau* is an integral cultural construct which both includes, yet extends beyond commonly understood parameters of ‘family’, to those within a person’s wider network who they identify as important to them. Whānau Māori were actively involved in the care and treatment of the person with stroke [28, 29], acting as an anchor and source of well-being. Many assumed responsibility for their whānau member, which they described as “deep” and “almost spiritual” in nature [47]. This sense of responsibility was often taken up by others within the wider community [29]. Whānau Māori experiences reflected that people worked intentionally to support ongoing engagement in roles and to uphold their mana (standing) [29, 47], sometimes with implications for their own

personal relationships and well-being: “[I] Just let her enjoy as much as she can. I don’t care what I’ve gotta go through” [47]. Through active support of family, people could remain connected with others and with activities that supported well-being and recovery.

Being with others who had a stroke, connecting with others “in the same boat” [42] could be critical in providing a space for well-being to grow. These shared experiences helped co-create a space where people had a sense of belonging and of being understood, a sense that “we are all in the same boat” [51]. These new connections could substitute for previous relationships and activities and positively influence well-being [49]. For some Māori with aphasia, being with others with aphasia provided whanaungatanga (connections and a sense of belonging) [29]. In the early days after stroke, these connections set people at ease and provided a sense of belonging at a time of vulnerability [51]. Seeing or reading about other people’s progress and journeys provided hope [42, 51, 52], motivation [42] and helped people see that there were a range of future possibilities post-stroke [42, 52]. Being exposed “to others living active lives ... helped them both look for new possibilities and to ‘find’ a space where they belonged” [53]. Similarly, Kitt [51] found that “having the opportunity to relate to others may have offered the support needed to gain courage and trust in one’s new self and the motivation to engage in [therapy]” (p. 60). For those with aphasia, peer-facilitated groups provided a space for friendships and helped give a sense of community, as outside of these, many felt they “were the only one who couldn’t speak” [49]; a real feeling of aloneness. Being with others provided connections and a sense of being “part of the community again” [49].

Whilst the focus has been on what the constellation of relationships *gives* to the person with stroke, there is a risk that this positions the person as a passive recipient of support. It was clear that part of belonging was being able to offer that to others. The person with stroke was themselves a resource of support for *others* and contributed to the well-being of others, which in turn fuelled their own sense of well-being. This was particularly evident within relationships with others who had a stroke. Becker and colleagues [46] identified:

For some, [purpose in life] was achieved by ...offering their advice to other stroke survivors ... most participants regularly attended Stroke Club, where they would discuss their experiences with stroke or rehabilitation: as Joyce expressed “That is what made me tell it because I thought it may help. (p. 5).

People shared their experiences in the hope it would help – help give *others* a sense of belonging and help people navigate the world after stroke: “I really want to help people ... [when] I had a [stroke] no-one came to see me who knew what it was like” [49]. Talking about their own experiences not only enhanced their own well-being but contributed to the well-being of others.

Whilst one's social world often shrunk after the stroke, it was through making new connections, and strengthening existing connections, that people's world started to expand again, growing a sense of well-being.

Being grounded in one's enduring and evolving identities

Identity is multi-faceted, comprised of multiple strands, which together make up the person, many of which were disrupted by the stroke. For some, the stroke was seen to inherently impact on their entire being: "it's not just the brain eh ... It's the whole āhua'. Āhua is one's presence, being, or identity"[47]. Many of the strands which made people who they are were disrupted by stroke, resulting in a "loss of familiarity with the self" [53]. An inability to maintain previously valued roles and activities could be felt as a "loss of self" [51], impacting upon well-being [28]. This contributed to a sense of disconnection with their "former self" in the early days post-stroke: "... their former lives barely seeming real. Being unable to participate in the same way as prior to their stroke led to a loss of hope of recovering their former self" [51]. A sense of discomfort, and even self-stigma with regard to one's post-stroke self could leave people feeling disconnected from *themselves*, and could see them actively disconnect from *others*, from roles and activities that contributed to their sense of identity pre-stroke [28, 43, 49, 51]. When other people failed to recognise their personhood, it reinforced the disconnection from their sense of self. Health services could dehumanise people, failing to recognise their personhood in mechanistic interactions [51] and requiring people to fit in with inflexible services [54]. One whānau member described services as having "no Māori-ness about them", and that "by using a resource that Makere was not interested in, the [speech-language pathologist] was not acknowledging Makere's identity through her ties to her family and land. This was detrimental to the therapeutic relationship and, therefore, to the success of therapy" [29]. In contrast, "when the [therapist] tailored the therapy to their interests, it showed them that she recognized their individual personalities and identities" [29]. Having one's personal interests, values, cultural identity and language recognised and integrated into care created an engaging therapeutic space that supported and uplifted one's identity and well-being [29, 51, 55].

An important element that grounded many Māori living with stroke and their whānau post-stroke and supported well-being was their connection to their cultural identity. This gave them "the strength and resilience to tackle the challenges they faced" [28]. Māori with aphasia experienced particular challenges though, as language is central to identity. Indeed, for one woman, her loss of language was felt as "tragic". Her daughter described this: "Talking, articulating with voice is foundational to our peoplehood, to my mother's Aitanga-a-Hauti identity [her identity in her iwi or

tribe]. If you have no one to speak and represent one's peoplehood, then you die" [47]. Whānau were critical in upholding the person's identity as Māori and in supporting well-being in the context of services which commonly failed to recognise people's culture and worldview [29]. One son described himself as having to "jump through all the hoops" [29] to get support which was challenging in a monocultural system that had "no Māori-ness about it" [29]. Despite the central role of whānau in supporting well-being, it appeared that they are not consistently involved in rehabilitation [28, 29]. This reflects that services were Eurocentric, focused on the individual rather than the collective whānau as is central in Te Ao Māori. These failed to acknowledge let alone support cultural identity. This further reduced well-being as they further distanced people from their cultural identity, the very thing that grounded and supported them.

When people were able to (re)connect with "what makes me 'me'" as one person described [55], it fostered their well-being and helped them cope with the challenges that can result during life after stroke [53]. This sense of identity appeared intrinsically linked to well-being:

Those with a strong sense of self appeared able to sit with uncertainty. For example, Tony expressed a sense of peace with himself and his circumstances: 'I feel really at peace ... I just feel very confident with who I am' [53].

Central to this was engaging in previously valued roles and activities, which both reflected and contributed to an enduring sense of identity [47, 53]. One person with stroke described how important this is, stating "'I'm not fighting for my life, but I'm just fighting for my lifestyle, in other words what makes me 'me'" [55]. Roles that built identity related more to roles in relation to others within their family or communities [47, 48], such as "being the best Dad I can be" [43]. Grandparents relished caring for grandchildren. One person's daughter described facilitating this, even though this did cause her worry in case anything went wrong [47]. Contributing to communities through roles on the marae (meeting place) or in the community often required support from those within one's relational networks, who worked visibly or behind the scenes to support participation and contribution, seeking to uphold the mana (standing) of the person with stroke, recognising the importance of the person with stroke being, and feeling able to contribute to others [47]. This reinforces that one's 'constellation of relationships' is important in life post-stroke, and the (re)shaping of identity was frequently grounded in the social world [42, 47, 48].

The stroke also provided an opportunity for many to reshape their sense of identity, through necessity and through choice. While people's identities were commonly grounded in their pre-stroke identity, people rarely aspired to simply return to this. Many were unable to return to things that supported or reflected their identity. Instead, some viewed the stroke as an opportunity to be "a

new person” [53] as the stroke prompted them to revisit what was important in life. Moreover, many people worked through a process of “discovering their new self” following stroke [42]. This was commonly an ongoing process of adapting and recalibrating one’s self-understanding, reflecting on “what was important to them in their life, who they wanted to be and what they wanted to achieve in life” [44]. When people were aware that their identity was evolving but there was an underlying sense of self, and when this evolving identity was seen as acceptable and in many cases welcomed, this contributed to a sense of well-being.

Being at-home in the present while (re)visioning the future

Following stroke, people commonly experienced disruption. Their present reality was somewhat unexpected and ever-changing; their assumptive future uncertain, disrupted by the impacts of the stroke. In a study of hope in people with aphasia, Bright and colleagues [53] suggested “people were living in the present while both looking forward to the future and reflecting on their past” (p.3). Uncertainty, change and unknown possibility were features of the time after stroke [43, 44, 50, 53, 55]. In this space, some people were able to sit with uncertainty, ‘be’ in the present, and perceive the potential for forward movement toward a possible future [42, 53, 55].

Finding balance and stability in the present

Well-being was associated with the ability to be grounded in the present, finding stability despite the uncertainty of life post-stroke [53]. This was commonly a space of hope[43]. Not hopes of specific recovery or defined hopes of what life would look like, but a space in which people had a sense of hope that the future will be good. It was also characterised by an openness to learning about one’s limitations, and adjusting and adapting to one’s new reality [42, 44, 48, 51, 52]. This involved making sense of what happened, a degree of accepting the changes brought about by stroke, and reflecting on what is important [44]. In learning to live with change, people drew on aspects of their ‘old normality’, returning to valued activities in order to (re)create patterns of living [46] whilst also engaging in new activities and relationships to create a new ‘normal’ [46, 49, 51].

Finding grounding in the present was not easy, however. Many people struggled with the process. A multiplicity of emotions were evident in people’s narratives of the time post stroke: despair [51], indifference [46], resignation [47], disempowerment [54], frustration [42] and mourning [51]. The sense of loss was palpable in comments such as “All those good things in my life are over and that is hard to come to grips with” [51]. Negative reactions from the community [42], or a sense of shame and stigma contributed to challenges in adjusting [47, 48]. With time, most were able to reach a

place where they could sit with uncertainty and accept their current situation [42, 48, 50, 56], aided by hearing the stories of others with stroke [52] which helped adjustment [52] and created a sense of gratefulness, positivity and possibility [42, 49]. Making sense of the stroke and why it happened were repeatedly highlighted as important in adjusting to one's new reality [44, 48, 50, 56]. Being given clear, appropriate information, and having the time and space for the person and their whānau to discuss what was happening appeared to assist the process of feeling more settled in the present [28].

Finding this point of 'comfort and stability' in the present did not mean letting go of the past. Even as people drew upon what was important to them during life pre-stroke, the grief, challenges and uncertainty brought about by stroke still remained [44]. Indeed, this was a place of many seemingly contradictory emotions and experiences – gratefulness amidst grief [42, 47, 49], hope amidst uncertainty [43, 53], a familiar self within an unfamiliar body, or a new and strange self within a known body [56]. Māori who had had a stroke identified that people could hold both grief for what was lost and recognition and appreciation of the current situation without this being inherently problematic [47]. Holding hope involved reflecting on past progress and priorities and integrating these with one's views and desires of the possible future. Bright and colleagues [53] found that people may continue to hold hope for a return to their 'old normal', while simultaneously holding hopes for new possibilities and a different, desirable future, holding both together without issue. They suggested that being able to hold onto aspects of the past, present and future in this way may contribute to a sense of continuity, and helps people to experience a sense of 'dwelling' in the present. Accordingly, we suggest well-being is associated with an ability to sit with these changes and contradictions, finding balance and stability amidst the uncertainty and challenges.

Holding a vision of the future

A feature of well-being was the process of future-making. Creating "an image of the future" [43] was often required because the person's assumptive future, the future they thought would unfold, was disrupted by the stroke. Instead, they needed to create a "new life" and "new patterns of living" whilst managing their "new selves" [42]. Active future-making required an ability to imagine and dream [46], to hold hope [53] and to re-envisage one's priorities and sense of self [44]. (Re)creating a vision of a possible future did not happen immediately after stroke. In fact, it appeared ever-changing:

At times, hopes and expectations for recovery dominated participants' views of the future, while at other times their uncertainty would dominate. When hopes and expectations

dominated, they expressed anticipation and positivity about the future. When uncertainty dominated, the future became restricted and the focus returned to the present, focusing on 'just getting through' [43].

Moreover, priorities shifted and evolved as people reflected and saw new possibilities [44, 53]. This saw people recalibrate their hopes and hoped-for life [53]. They created new patterns of living, engaging in new activities that reflect their new normal and their *desired* new normal [46]. There was both a desire for, and a sense of movement toward a new life and a new normal [42, 43, 46].

For some, moving forward required being able to clearly envisage their desired future and the pathway forward [55]. To assist this, some people wanted clarity on prognosis and what might be possible in the future [29, 55]. Some worked to re-establish normality by going back to known life activities and doing them again [46], while others set ambitious personal goals to aim for [52, 55] or articulated active hopes for the future, sometimes taking steps to realise these [43]). "Seemingly impossible goals" could bring comfort, although people considered this was under threat from staff who might classify them as "unrealistic" [55]. This highlights how well-being is not individually achieved, but is collectively developed, or diminished. Envisaging the future and pathways forward was commonly aided through goal setting as part of rehabilitation although achievement (or even the possibility of achievement) of said goals was not necessarily important – instead the important thing was that these offered a sense of direction and motivation [55]. For others, however, the path forward did not need to be defined or moving toward a discrete objective or destination. Rather, having a broad sense of looking forward to improvement, a sense of forward movement, perceiving that progress is being made, and having a sense that the future may be positive were key factors in maintaining momentum [45, 48, 53, 55].

Hope and purpose appeared important in enabling people to look to the future [46, 53]. People described holding a broad sense of hope following stroke which could provide grounding in the present, while also holding a hope for the unseen future that was revised and recalibrated in response to their changing circumstances. There was a recursive relationship between hope, progress, and future possibilities. Hope increased when people perceived progress [45, 48, 52, 53, 55] and when they had a view of a possible future [43]. Sitting alongside hope was purpose and meaning. People described trying to "find a purpose beyond the stroke" [42], sometimes through engaging in activities that helped create purpose in their lives and by contributing to others [46]. This helped people feel there was meaning in their lives, "which led to them being more positive and life-affirming" [46]; it also reinforced their own personal value and contributions, with people

“feeling valued and appreciated” [46]. Together, hope, purpose and possibility provided a reason for living [43].

Discussion

This metasynthesis, focusing on the psychosocial well-being of people living with stroke in Aotearoa, demonstrates that well-being is multi-faceted. Within our three themes, we show how well-being comes through an interweaving of connectedness with others, of personal, cultural and collective identities, of feeling at-home in the present, and of having a vision and sense of movement toward a desired future. At the core of this metasynthesis is an understanding that well-being is deeply social, personal, and temporal in nature. This offers a unique perspective on well-being, shifting beyond understandings of well-being as something situated within the individual, as often foregrounded in the literature [22], to understanding it as collectively achieved, through connections with self, others, community and culture. Well-being is inherently collective, grounded, supported and maintained through interactions and relationships with others, fostered through a sense of connectedness and belonging. At the same time, well-being is also inherently personal, experienced uniquely by each person, and deeply grounded in their enduring and evolving identities. This identity, ever-in-development, incorporates people’s enduring pre-stroke sense of self, and their evolving identity that grew and continued to develop after the stroke as people made sense of what happened and what matters to them. Well-being occurs within “overlapping temporalities” [57] of past, present and future, occurring when people could draw on their known and familiar past, whilst having a sense of comfort and stability in their present and looking toward a possible, desirable future. These strands are evident within all the themes presented in the Results, suggesting that well-being comes through the interweaving of personal, social and temporal worlds. While this analysis originates from the perspectives of people with stroke in Aotearoa, these areas also hold relevance, and speak to discussions happening internationally, as can be seen from the fact the remainder of the Discussion draws on literature from both Aotearoa and internationally. Within this discussion, we will focus on several aspects of the Findings which are particularly relevant to the aims of this metasynthesis: to develop understandings of psychosocial well-being in Aotearoa from the experiences of those impacted by stroke, recognising the need for locally-based understandings. Specifically, we focus on the social and temporal elements of psychosocial well-being that have been elucidated in this review.

Our review makes clear the pivotal role of social relationships in psychosocial well-being. These relationships were important in and of themselves because of the sense of belonging and

connectedness that they brought about. Beyond that though, these underpinned other aspects of well-being. One's social world was integral in one's identity and self-concept, as expressed in our theme 'being grounded in one's enduring and evolving identities'. Rather than seeing one's self-concept and social relationships as separate components of well-being [14], our review demonstrates how these are entwined; that one's self-concept is inherently social, supported and formed through one's collective and cultural identities. For many, these externally-mediated identities carried people through times when their self-concept was threatened or fractured by the stroke. Viewing psychosocial well-being as being embedded within one's cultural and collective identities and entwined within the interactions with one's social world, rather than something individually achieved, affirms the crucial role of social relationships in well-being after stroke [14, 18, 20, 58, 59]. In particular, our review demonstrates the critical role of family, whānau and others who had experienced stroke. Within Te Ao Māori (a Māori worldview), whānau are recognised as a pillar of well-being [60] and the well-being of an individual is viewed as 'indivisible' from that of their whānau [61]. The centrality of others in well-being perhaps contrasts with more individualistic Western cultures, and in biomedical health systems which focus on the individual with stroke, not recognising the critical role family and whānau have in supporting well-being and recovery beyond the designated role of 'carer', or not attending to specific well-being needs of family members [62, 63]. Our review shows how social relationships with others with stroke can be particularly important in well-being. These created a sense of belonging which in turn, helped develop a person's identity as a person living with stroke, and their post-stroke identity, and supported them in looking toward the future [29, 49, 51]. This aligns with other literature which demonstrates the critical role of peer relationships in creating spaces of support and belonging [64] and facilitating well-being [65, 66]. Our review suggests that social relationships – with family, friends and others with stroke – are generally not facilitated by stroke services across the continuum of care. Instead, it was family members, or the person's own efforts that built and sustained relationships. In fact, services could inhibit or place significant pressure on relationships, something particularly evident in the experiences of Māori whānau who reported not being recognised or supported, and at times, actively excluded in service design and delivery despite whānau being a source of hauora (health and well-being) [60]. At an institutional level, this represents a form of racism which is a negative determinant of health and well-being [67]. Given that well-being is socially achieved, and that whānau, friends, and people's wider communities are key in supporting well-being, this needs attention and support within services. By considering the collective(s) who are key in supporting people's on-going well-being, services can enact a proactive approach to care, sustaining relationships and preventing losses of social networks after stroke [68].

This review prompts us to consider the temporal element of well-being: the interwoven past, present and future. Occupational science literature argues we are always in an ongoing process of being *and* becoming [69]; this is particularly evident in our theme which considers how identities that are enduring *and* evolving. Considering well-being as situated within a person's "overlapping temporalities" [57] of past, present and future reflects Leder's [70] argument that, after illness, richness in life comes from weaving together temporalities – "remembering the past, anticipating the future and presencing, that is, living fully in the here and now" (p. 99). Others outside stroke rehabilitation have proposed that well-being comes when one has a sense of dwelling-mobility: a sense of dwelling (or 'at homeness') in the present and a sense of movement toward the future [71], evident in our theme 'being at-home in the present whilst (re)visioning the future'. For Māori, looking to one's past involves looking beyond one's own history, to draw on the strengths from those who have gone before them as people's identity sits within a wider sense of belonging within their hapū (sub-tribe) and iwi (tribe) [72], and reflects Māori perspectives of time in which the past, present and future are entwined and the past is central to, and shapes one's present and future [73]. This further illustrates how collective and cultural identities are important in well-being and how personal, social and temporal domains are entwined. Acknowledging and building on the strengths of a person's past and present to support people as they create visions of, and move toward their desired future, may be one way to take a person-centred and strengths-based approach to supporting well-being and recovery. Viewing the future as one that is ever-being-made highlights the important role that services can play in supporting future-making, creating opportunities for "new futures ... to grow into being" [57].

Whilst our discussion has focused on the social and temporal aspects of well-being, there are other findings which need discussion, in light of how they add nuance to existing conceptualisations of psychosocial well-being. Like Kirkevold [14], our findings reflect the importance of engaging in meaningful activities. This appeared to both *support* well-being (e.g. when completing activities and roles that supported one's identity [47]) and reflect an *outcome* of well-being (e.g. when people experienced a sense of well-being, they were more likely to engage in activities [49]). Of note, in many instances it was not so much that *doing* activities was important, but what the doing brought about – the sense of making a contribution, of reinforcing a sense of self, of whanaungatanga in being connected with others (whanaungatanga stems from Māori worldviews, referring to developing meaningful connections and relational linkages). This further reflects how the facets of well-being are interconnected. Perhaps the area of greatest difference from the existing well-being after stroke literature is the place of positive mood in well-being. Whilst Kirkevold and colleagues found that positive mood and "the absence of sadness or a feeling of emptiness" [14] was an aspect

of well-being and others talked of the value of positive outlooks [20, 21] , this metasynthesis suggests it is not simply having a positive mood or the absence of psychological sequelae. Instead, we identified that both positive and negative emotions could exist. People could report experiencing well-being whilst also describing loss, grief and uncertainty, to name some emotions. When people had a sense of identity and a degree of being at peace with the past and present, it appeared to enable them to hold multiple emotions without these conflicting or being distressing. Our review suggests that what matters is a sense of equilibrium which allows different emotions to co-exist. This reflects wider understandings of well-being, which propose that well-being is inherently dynamic and that continued movement and change is a feature of well-being [74]. In fact, some suggest that the ability to manage ups and downs is considered to reflect the “true level of well-being” [74].

A strength of this metasynthesis is our use of He Awa Whiria [36] which highlighted particular features for Māori which we might have missed had we not uniquely engaged with the Māori literature – the importance of cultural and intergenerational identity, and the critical role of whānau and of community in well-being, as two examples. This also prompted us to look for evidence of these themes in other papers and thus facilitated a deeper analysis. This is a strength of our research approach which was designed to enable a deeper understanding of diversity in experience, supported through the research team composition and use of He Awa Whiria. At the same time, we also are aware of mātauranga Māori (Māori knowledge) that exists outside Western academic publications [40], and as such, were not captured within our search strategy. As a result, we are conducting a wider review of well-being for Māori, engaging with a range of materials and knowledges to develop our understandings. Our review has focused on the perspectives and experiences of people with stroke, although for Māori, we included the perspectives of whānau. Given our review has demonstrated the collective and relational nature of well-being, there would be benefit from further understanding family and whānau perspectives. Indeed, these may have offered deeper, or different insights into well-being in this review, however we wished to give primacy to the voices of those who had had a stroke. Our use of He Awa Whiria and our specific focus on experiences of people in Aotearoa has ensured that we generated findings that reflect “local understandings” [75] of what constitutes and creates well-being. As such, this offers an example of research practice that engages with, represents, and contributes to Indigenous communities. However, the findings of this metasynthesis are limited by the published material from Aotearoa. Few studies explicitly explored psychosocial well-being. Our search was conducted in May 2022; several papers have been published whilst analysis was occurring [e.g. 76, 77] which may be considered in future work in this area as they offer insight into Māori experiences after stroke. Moreover, studies generally reflected an Interpretive approach focused on understanding individual

experiences of life after stroke. There was little consideration of the wider social, structural and material factors which impact on well-being which highlights an area for future research. Willen and colleagues [22] recently asked “who has the opportunity to live a flourishing life, who does not, and why?” (p. 1) and suggested this also applies to well-being. Critical public health research is demonstrating that an individual’s well-being cannot be seen apart from their personal social world and the broader material world they live within. In the context of New Zealand, a country founded through colonisation, in which Indigenous people experience significant marginalisation and disparities in stroke incidence, service provision and outcome [24, 25] and institutional and interpersonal racism in health services [78], it is critical to attend to how well-being is impacted by the wider societal context, and how this might be exacerbated when someone has a stroke. It also suggests that supporting well-being after stroke needs to take wider contexts and experiences into account. This public health perspective will be woven into our future work.

Through this metasynthesis, we identify a number of implications for practice. While these are grounded in research in Aotearoa, these recommendations are relevant to stroke care beyond Aotearoa, and indeed, are aligned with stroke research conducted internationally. First, we demonstrate the significant psychosocial impacts of stroke that clinicians and services need to take into account, that people with stroke report are not consistently being addressed. The time that most services are provided is a time of significant grief and a myriad of emotions as people make sense of the stroke and come to realise its impacts [44, 79]. While for some this might require specialist psychological support, for many, this requires attentive listening, information, normalising, and support as they navigate through this process [80], developing a sense of equilibrium [74]. Second, this review might prompt clinicians and services to reflect on what is prioritised and supported in care. It clearly demonstrates the importance of social relationships, identity, knowing and building on people’s past, and supporting people to ‘be’ in the present and to look toward a desired future. The unique needs of family as a source of well-being, and as people whose own well-being is often threatened by stroke, are not well-addressed [15, 81]. Yet services commonly focus on the individual with stroke, on people’s physical needs and their impairments and basic activities, on short-term outcomes and on helping people move between stroke services [13]. This reflects broader healthcare pressures and a Western, individualistic orientation to health and rehabilitation, but can mean services can themselves be a barrier to well-being [28, 29]. Processes such as goal-setting have great potential to support future-making and are nearly ubiquitous within strokes services. However, our review highlights existing processes can see people’s visions of possible futures shut down, or not disclosed for fear of staff reactions. Reflecting on what and who is supported in services, and considering the unintended consequences of dominant practice models

may help identify areas for practice development. One aspect of this might be considering how services might create a therapeutic milieu, a physical, social and relational environment that fosters well-being whilst in services and beyond. However, having identified the implications for practice and services, we do not want to give the impression that well-being is the sole responsibility of services. Indeed, this review shows the critical role of one's social world in well-being. Our own Māori advisors have cautioned us about suggesting the answers to well-being all sit within the healthcare system. Instead, they suggest that services need to consider how they can support whānau and communities to support well-being.

Conclusion

This metasynthesis advances understandings of how psychosocial well-being is experienced, and what supports well-being in Aotearoa. Through grounding our analysis in the experiences of those with living experience of stroke [16], we have come to see that well-being is deeply personal yet inherently collective. It is grounded in social connectedness, personal, collective and cultural identities, and sits within and across experiences and visions of the past, present and future. These findings will be tested and developed through future research to build more comprehensive understandings of psychosocial well-being. Integrating knowledge of well-being into services and into support for those impacted by stroke can help foster better experiences and outcomes.

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Declaration of Interests

We have no declarations to declare.

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79. Salter, K., et al., *The experience of living with stroke: A qualitative meta-synthesis*. Journal of Rehabilitation Medicine, 2008. **40**(8): p. 595-602.

80. Kneebone, I.I., *Stepped psychological care after stroke*. Disability and Rehabilitation, 2016. **38**(18): p. 1836-1843.
81. Denham, A.M.J., et al., *The long-term unmet needs of informal carers of stroke survivors at home: a systematic review of qualitative and quantitative studies*. Disabil Rehabil, 2020: p. 1-12.

Appendix A: Search terms

1. stroke OR "cerebrovascular accident" OR "cerebrovascular disease" OR CVA OR hemiplegia OR aphasia (Title-Abstract-Keyword) AND
2. adjust* OR identity OR recovery OR rehabilitation OR "life after" OR "quality of life" OR "self-management" OR "self management" OR experienc* OR satisfaction OR hope OR wellbeing OR identity OR psychosocial OR "well-being" OR "lived experience" OR "liv* well" OR impact OR relation* OR "social support" (Title-Abstract-Keyword) AND
3. qualitative OR "grounded theory" OR phenomenolog* OR ethnograph* OR interview* OR "focus group*" OR "thematic analysis" OR "content analysis" OR narrative OR "lived experience" OR "interpretive description" OR wananga OR hui OR "mixed methods" OR "Kaupapa Maori" (Title-Abstract-Keyword) AND
4. aotearoa OR "new zealand" OR Māori OR "pacific island*" OR Pasifika OR Indigenous OR fiji* OR samoa* OR tonga* OR native (Title-Abstract-Keyword) AND
5. Aotearoa OR "New Zealand" OR Maori (all text)

Figure One

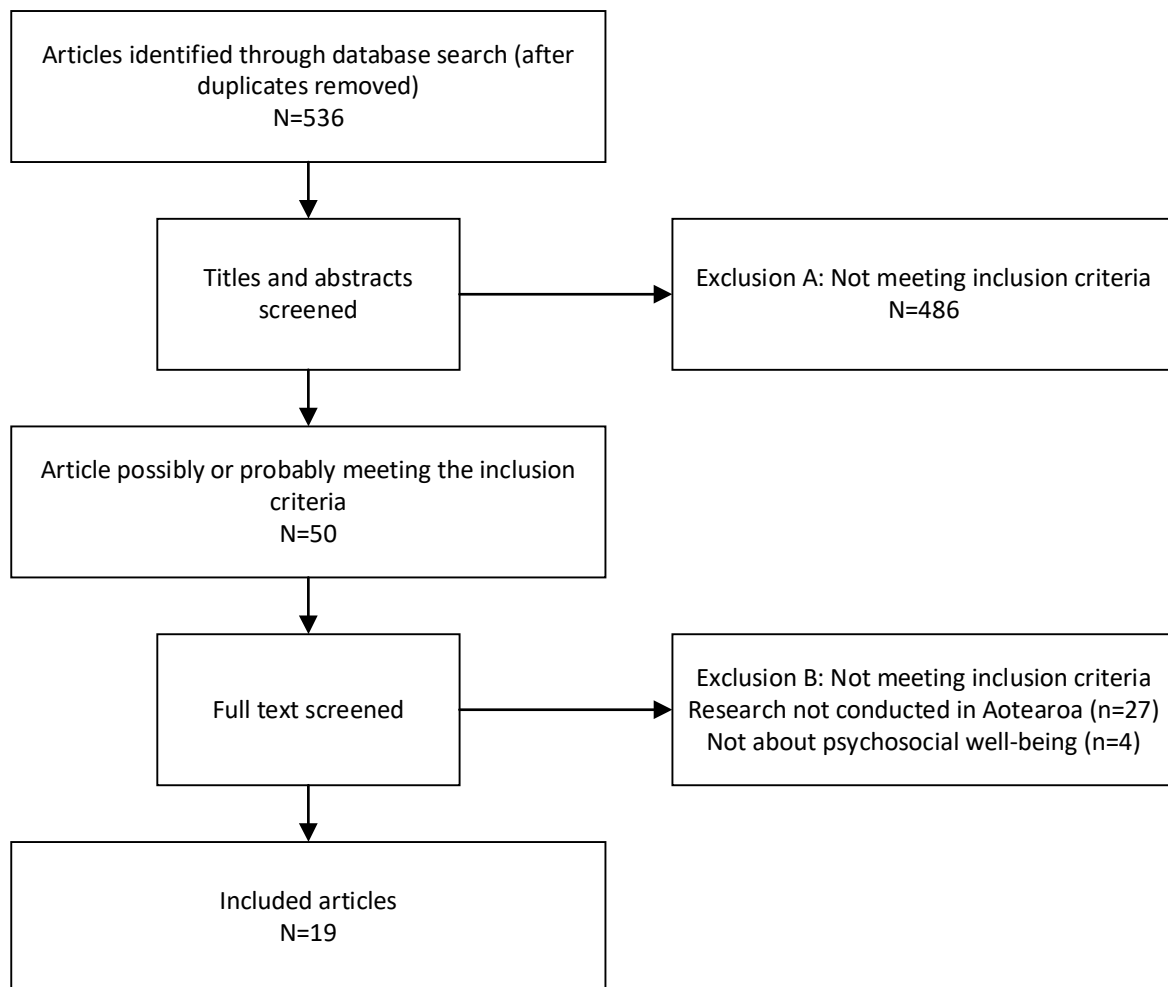


Table One

Table One: Summary of included papers

Author	Research aim	Methodology	Participants	Setting	Findings in relation to understanding psychosocial well-being
Ahuja, Clark, Morahan, Mulligan & Hale (2013)	Identify and discuss the experiences, perceptions and challenges faced by those living with stroke, to provide health professionals with an insight into the journey to recovery following stroke	Methodology: Qualitative Data collection: Semi-structured interviews Data analysis: General Inductive Approach	N = 11 (1F, 10M) Aged 49 – 72 years Time since stroke = not reported	Community	People described a journey to a “new me” after their stroke. This journey involved frustrations and challenges and was an ongoing process of learning about one’s limitations, developing coping strategies and adapting to new realities to work towards acceptance. Crucial aspects to recovery included a positive attitude, control over goal setting, adapting and adjusting to new limitations, and receiving support from family/community. When these factors were accepted into the process of their journey, it helped propel them towards their “new me” and allowed for improvements in wellbeing.
Becker, Maleka, Stewart, Jenkins & Hale (2020)	Explore the perceptions of stroke survivors living in the southern region of the South Island of New Zealand with regards to their reintegration into their communities	Methodology: Qualitative Data collection: Semi-structured interviews Data analysis: General Inductive Approach	N = 8 (2F, 6M) Aged 50 – 80 years Mean time since first stroke = 6.5 years	Community	Key factors that supported successful community reintegration included involvement in meaningful activities, and reduced reliance on others whilst maintaining or developing supportive, respectful, and caring social relationships. Re-establishing normality, whether that be returning to one’s ‘old’ normality, or finding a ‘new’ normality, along with finding purpose in life also promoted well-being.

Author	Research aim	Methodology	Participants	Setting	Findings in relation to understanding psychosocial well-being
Boland, Levack, Graham & Perry (2018)	Identify the adaptive equipment (AE) that people typically use after a stroke and the outcomes achieved as a result, and to explore people's experiences obtaining and using AE	<p>Methodology: Grounded theory</p> <p>Data collection: Semi-structured interviews</p> <p>Data analysis: Coding and constant comparative methods of grounded theory</p>	Interviewees: <i>N</i> = 15 Aged 49 – 90 years Time since stroke = 18 – 24 months	Community	Trusting, respectful relationships with therapists promoted AE use for people after stroke. AE that allowed for engagement in meaningful activities and community participation were reported to benefit aspects of psychosocial well-being.
Bright, Kayes, McCann & McPherson (2013)	Explore how hope was experienced by people with aphasia following stroke during the post-acute period of rehabilitation, and to identify factors influencing the experience of hope	<p>Methodology: Interpretive description</p> <p>Data collection: Semi-structured interviews</p> <p>Data analysis: Multiple approaches including coding, thematic analysis, and narrative construction</p>	<i>N</i> = 5 (2F, 3M) Aged 41 – 62 years Time since stroke = 2 - 5 months	Community	Hope was experienced both through 'simply having hope' – a passive, constant sense of hope; and 'actively hoping' – an intermittent, future focused hope. Hope was considered essential by people with aphasia and could provide stability, and support them to think positively about the future.

Author	Research aim	Methodology	Participants	Setting	Findings in relation to understanding psychosocial well-being
Bright, McCann & Kayes (2020)	Identify how people with aphasia experience hope 1 year after stroke and how hope may change in the year after stroke	<p>Methodology: Interpretive description</p> <p>Data collection: Semi-structured interviews</p> <p>Data analysis: Content analysis</p>	<p>N = 4 (2F, 2M) Aged 42 – 63 years Time since stroke = 14-18 months</p>	Community	<p>Early post-stroke hopes were recalibrated through an ongoing process of reflection on past progress, one's current reality, and what a person desired for the future. People continued to hold an underlying broad hope for the future. Having a sense of progress, engaging in meaningful roles and activities, feeling socially supported, and having a sense of identity facilitated hope and helped people to develop a sense of a positive, desirable future.</p>
Brown, Levack, McPherson, Dean, Reed, Weatherall & Taylor (2014)	Explore patient experiences with goal setting in post-acute stroke rehabilitation to further understanding of its application to practice	<p>Methodology: Qualitative</p> <p>Data collection: Semi-structured interviews</p> <p>Data analysis: Thematic analysis</p>	<p>N = 10 (3F, 7M) Aged 33 – 85 years Time since stroke = 3-7 months</p>	Community	<p>Maintaining forward momentum was identified as vital to recovery and promoting well-being. This could be achieved in different ways. Some people found short term goals useful, others drew motivation from setting ambitious goals without necessarily needing to achieve them, while others simply needed to feel they were making progress. An individualised approach to engaging patients in goal setting is required to ensure that both the process of goal setting, and goals themselves are patient centred and meaningful.</p>
Dyall, Feigin, Brow & Roberts (2008)	Identify issues important to Māori stroke survivors, providing Māori-specific qualitative information to complement the quantitative results	<p>Methodology: Qualitative</p> <p>Data collection: Semi-structured interviews</p>	<p>N = 15 Stroke survivors = 8 (4F, 4M) Caregivers = 7 (6F, 1M) Females aged < 60 yrs Males aged > 60yrs</p>	Community	<p>Māori cultural identity, and the support of whānau were identified as important facilitators to recovery post stroke and promoted well-being. People spoke of challenging experiences within health services that negatively impacted upon well-being, including care that was not culturally appropriate, a lack of clear and appropriate information, and whānau frequently being excluded from care. The experience of</p>

Author	Research aim	Methodology	Participants	Setting	Findings in relation to understanding psychosocial well-being
	from the 2002/03 Auckland Regional Community Stroke (ARCOS) study	Data analysis: Transcripts coded to predetermined schedule	Time since stroke = not reported		stroke had ripple effects, including both socially and financially, which impacted the well-being of the wider whānau.
Hale, Jones, Mulligan, Levack, Smith, Claydon, ... Alcock (2014)	Describe the adaptation of the UK-developed Bridges stroke self-management programme (Bridges SMP) into a version relevant and acceptable to the NZ context	Methodology: Qualitative Data collection: Semi-structured interviews Data analysis: General inductive approach	<i>N</i> = 6 (3F, 3M) Aged 46 - 68 years Time since stroke = 3-12 months	Community	Connecting with others with a shared experience of stroke, being supported to set personally meaningful targets broken down into achievable steps, reflecting on progress made, working towards acceptance, and taking responsibility for rehabilitation were seen as important in recovery and life after stroke. These factors supported people to overcome feelings of isolation and loneliness, to connect with family, and provided encouragement and positivity for the future.
Kitt, Wang, Harvey-Fitzgerald, Kayes & Saywell (2016)	Explore the perspectives on participation on group rehabilitation in the inpatient setting for people with moderate to severe stroke	Methodology: Qualitative descriptive Data collection: Semi-structured interviews Data analysis: Conventional content analysis	<i>N</i> = 6 (2F, 4M) Aged 76 – 93 years Time since stroke = < 3 months	Inpatient	People expressed frustration and at times despair at the sense of loss experienced following stroke. Some people experienced a loss of identity, or of meaningful roles and activities post-stroke which negatively impacted upon well-being. Hope, support and encouragement was gained through connecting with others with a shared experience of stroke. Creating relationships with peers or therapists, and being seen and respected as an individual created a sense of belonging, and could improve confidence and engagement.
McLellan, McCann, Worrall &	Describe and interpret the experiences of Māori with aphasia and	Methodology: Kaupapa Māori research and	Stroke survivors <i>N</i> = 11 (7F, 4M) Aged 50-79 years	Community	Stroke resulted in complex changes to the lives of those who had a stroke and their whānau, with ripple effects felt throughout the wider whānau. Cultural identity,

Author	Research aim	Methodology	Participants	Setting	Findings in relation to understanding psychosocial well-being
Harwood (2014a)	their whānau to inform service delivery for this population	<p>interpretive description</p> <p>Data collection: Semi-structured interviews</p> <p>Data analysis: Inductive thematic analysis</p>	<p>Time since stroke = not reported</p> <p>Whānau members $N = 25$</p>		engaging in meaningful roles, and the indivisible nature of the person with stroke and whānau were central to well-being. Whānau took responsibility for the well-being of the individual who had a stroke and were deeply involved in their physical and emotional care. Individuals and whānau actively managed recovery and life after stroke, choosing how best to respond to challenges faced.
McLellan, McCann, Worrall & Harwood (2014b)	Explore Māori experiences of aphasia therapy, with a view to ascertaining what makes a service culturally safe as well as “accessible to and culturally appropriate for” Māori with aphasia and their whānau	<p>Methodology: Kaupapa Māori research and interpretive description</p> <p>Data collection: Semi-structured interviews</p> <p>Data analysis: Inductive thematic analysis</p>	<p>Stroke survivors $N = 11$ (7F, 4M) Aged 50-79 years Time since stroke = not reported</p> <p>Whānau members $N = 25$</p>	Community	<p>Having a good therapeutic relationship between person with stroke, whānau and clinician was vital to successful, valued therapy.</p> <p>People valued therapy that was respectful, tailored to the individual and their whānau and what was meaningful to them, and was communicated clearly and appropriately. Of central importance was the recognition of cultural identity and worldview, and the inclusion of whānau in the rehabilitation process. The use of culturally appropriate resources, and the delivery of services in an appropriate setting supported engagement in therapy.</p>
Rotherham, Howe & Tillard (2015)	Explore the benefits for adults with aphasia of all the groups they had chosen to participate in post-stroke, as	Methodology: Qualitative descriptive	<p>Stroke survivors $N = 10$ (2F, 8M) Aged 51-83 years Time since stroke = 7 months – 4 years</p>	Community	Groups provided valued opportunities for social connection. Connecting with others who had a stroke, and in particular others with aphasia, provided people with a sense of belonging and assisted in overcoming feelings of isolation.

Author	Research aim	Methodology	Participants	Setting	Findings in relation to understanding psychosocial well-being
	perceived by the individuals with aphasia and their family members	Data collection: Semi-structured interviews Data analysis: Qualitative content analysis	Family members <i>N</i> =6		Groups also boosted confidence, provided hope and encouragement, supported people to engage in meaningful roles within family and community, and to develop a positive post stroke identity.
Rutherford, Hocking, Theadom & McPherson (2018)	Explore challenges that are experienced at 6 months after stroke to inform the ongoing refinement of self management programmes	Methodology: Qualitative descriptive Data collection: Minimally structured interviews Data analysis: Thematic analysis	<i>N</i> = 53 (27F, 26M) Aged 38-94 years Time since stroke = 6 months Significant others <i>N</i> = 26	Community	People highlighted the need for health professionals to recognise and acknowledge the impact of stroke on a person's life, regardless of the severity of stroke. They highlighted the need to be supported to make sense of what had happened, in a way that was meaningful to them as an individual. To promote well-being and support people to manage post-stroke, services must be person-centred and timely, providing on-going services particularly following discharge from acute care.
Singh, Mani & Hale (2021)	Explore the unique culture and ethnicity specific experiences of Indian people living in New Zealand with stroke, focusing on self-management and facilitators and challenges to recovery	Methodology: Qualitative Data collection: Semi-structured interviews Data analysis: General Inductive Approach	<i>N</i> = 8 (4F, 4M) Aged 28-76 years Time since stroke = 3 months to 18 years	Community	Working towards small milestones, being open to new experiences, persevering and adopting a positive attitude were strategies used by people to manage the challenges of life post-stroke. Support from both family and health services, social connectedness, engaging in meaningful roles and activities, and accepting and embracing the changes in oneself following stroke were factors that promoted recovery and facilitated well-being.

Author	Research aim	Methodology	Participants	Setting	Findings in relation to understanding psychosocial well-being
Stretton, Mudges, Kayes & McPherson (2020)	Explore what real-world walking means to people after stroke and how they think it could be better	Methodology: Interpretive description Data collection: Semi-structured interviews Data analysis: Thematic analysis	N = 8 (4F, 4M) Aged 36-85 years Time since stroke = Ranged from < 6 months to >12 months	Community	Walking provided a sense of freedom and independence for people with stroke as it allowed some control and choice over their situation. This sense of freedom could reduce negative emotions experienced following stroke. Seeing progress made in walking increased hope for progress in other areas of life, and led to improved confidence, enhanced motivation, positive emotions, and a sense of achievement. Social connections often underpinned progress made in walking, which in turn promoted increased social interactions, thus facilitating well-being.
Theadom, Rutherford, Kent, McPherson & A.IV.G (2019)	Explore people's experiences over the first three years post-stroke and identify what helped or hindered recovery	Methodology: Qualitative description Data collection: Semi-structured interviews Data analysis: Coding and constant comparison	N = 55 (29F, 26M) Median age 71 years Time since stroke = 48 interviewed at 6 months 52 interviewed at 12 months 47 interviewed at 24 months 37 interviewed at 36 months	Community	Adjusting to life post-stroke was an ongoing process. People reflected on their past, their present reality and what was important to them to establish a 'new normal'. Being well supported, and engaging in meaningful activities facilitated this process. People described the need for health professionals to provide clear information about their stroke at a time when they were able to process this as important to facilitating adjustment. Services that recognise the psychological impacts of stroke and are more flexible and responsive to a person's needs were recommended to support adjustment post-stroke; as was better support to navigate the health system.
Timothy, Graham & Levack (2016)	Gain an in-depth understanding of embodiment for people after stroke while	Methodology: Grounded theory	N = 7 (2F, 5M) Aged 66-89 years Time since stroke < 4 months	Community	People were in a constant state of flux between a sense that their body and self were one and feeling that their body was separate from themselves. Regaining control over one's body, and aspects of life more generally,

Author	Research aim	Methodology	Participants	Setting	Findings in relation to understanding psychosocial well-being
	transitioning from the hospital to home	<p>Data collection: Semi-structured interviews</p> <p>Data analysis: Constant comparative method of grounded theory</p>			reflected a sense of wholeness, with participants associating bodily control with self-assurance and feelings of progress. Experiencing freedom of bodily movement and having freedom of choice also contributed to a sense of 'wholeness'. Those with a strong self-identity did not appear to be as negatively impacted by changes in bodily ability compared with others. Knowledge of stroke, and of one's post-stroke body, a positive attitude, and a supportive environment helped to ground and reassure people during life early post-stroke.
Turner (2012)	Understand stroke patients' perspectives of hospital-related psychosocial and environmental factors contributing to post-stroke depression	<p>Methodology: Grounded theory</p> <p>Data collection: Interviews (one unstructured and one semi-structured per participant)</p> <p>Data analysis: Constant comparative method of grounded theory</p>	<p>N = 6 (4F, 2M)</p> <p>Aged over 65 years</p> <p>Time since stroke = Not stated</p>	Inpatient	Dependence on others and a lack of control contributed to feelings of disempowerment in people after stroke, as did feeling enclosed in the hospital environment, disconnected from the outside world. Feeling as though one must 'fit in' to the routines of the ward led to feelings of decreased self-value and self-esteem. People described feeling separation from loved ones due to a lack of privacy during visits. A lack of meaningful activity, particularly for women, contributed to low mood. Mitigating factors to depression included supported home visits and car outings, and cheerful staff who provided encouragement and listened to their needs.