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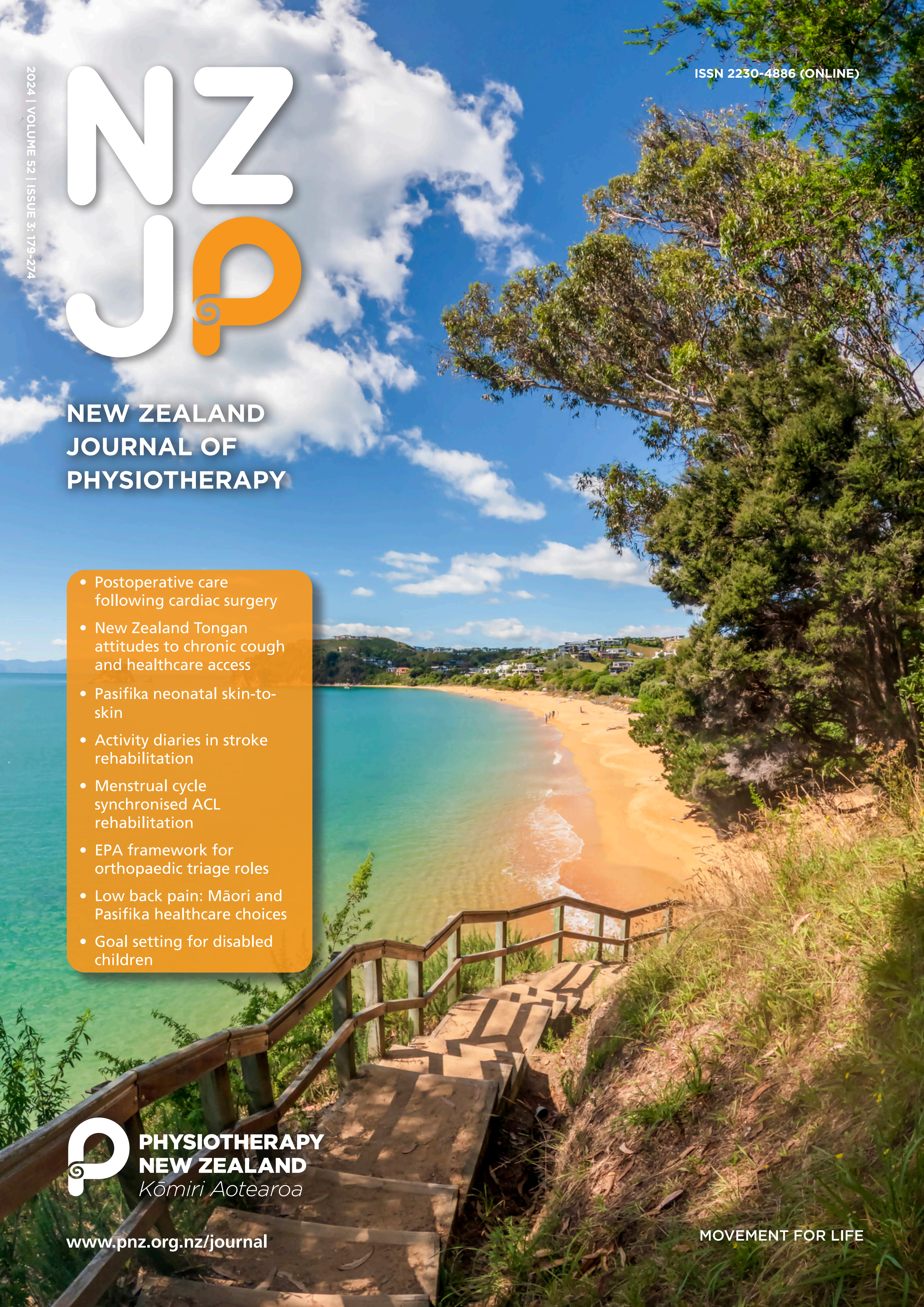

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A Paradigm Shift in Sternal Precautions and Postoperative Care after Cardiac Surgery: Are We There Yet?

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Gray, E., & El-Ansary, D. (2024). A paradigm shift in sternal precautions and postoperative care after cardiac surgery: Are we there yet? *New Zealand Journal of Physiotherapy, 52*(3), 182–184. https://doi.org.10.15619/nzjp.v52i3.451

Cardiac surgery via median sternotomy is the most common surgical incision performed globally for coronary revascularisation and valve surgery. It is estimated that over 1 million cardiac surgeries are performed globally (Vervoort et al., 2021), with approximately 2,500 cardiac surgeries performed in New Zealand public hospitals each year (New Zealand Cardiac Surgery Clinical Network, 2018). Cardiac surgery requires an incision that divides the sternum to access the heart. While the sternum is closed using plates or wires, significant complications such as infection, instability, and dehiscence can occur, which can treble the cost of care. Sternal wound complications have been reported to occur in approximately 1–8% of patients (El-Ansary et al., 2019), and may result in delayed recovery, hospital readmission, and increased risk of short- and long-term mortality (Filsoufi et al., 2009; Gaudino et al., 2021).

Historically, health professionals have encouraged patients to avoid upper limb movements, such as heavy lifting or pushing through the arms, based on cadaver and sternal replica studies that cautioned upper limb activity to avoid sternal complications (El-Ansary et al., 2019). Indeed, major restrictions that limit lifting to specific loads (anywhere between 2 kg and 10 kg) for a set time (up to 12 weeks) have traditionally been commonplace in clinical practice (Balachandran et al., 2014; Westerdahl & Moller, 2010). However, there is a lack of in vivo evidence linking loaded arm activities with sternal complications (Cahalin et al., 2011; El-Ansary et al., 2019). In addition, the recommended load restrictions are often less than the force required for many activities performed routinely and safely following cardiac surgery, such as opening a door (Adams et al., 2016). A further challenge to traditional load and time restrictions is robust evidence regarding the safety of early upper limb and trunk tasks, and early upper limb resistance training post-median sternotomy (Balachandran et al., 2019; Pengelly et al., 2022). As such, there seems to be no rationale for maintaining an outmoded restrictive approach to post operative care that delays functional recovery and daily activities.

Consequently, over the past 15 years there has been growing evidence to support a less restrictive approach based on biomechanical principles that reduce sternal loading, such as performing loaded arm activities bilaterally, with the arms close to the body and using pain to guide how much can be lifted, pushed, or pulled. With this approach, there is no specific weight limitation as long as the activity remains pain-free (Adams et al., 2016; Katijjahbe et al., 2018). The most well-known of these less restrictive biomechanical-based approaches is called “Keep Your Move in the Tube” (KYMITT) (Adams et al., 2016), with evidence demonstrating this approach is safe, does not increase the incidence of sternal complications, and leads to better early post-operative functional outcomes and greater patient confidence (Brown et al., 2021; Gach et al., 2021).

However, while a paradigm shift toward less restrictive sternal precaution approaches has occurred in the literature, has the same paradigm shift fully taken place in clinical practice? We would suggest not. In a 2019 survey of post-cardiac surgery physical activity advice provided upon hospital discharge in New Zealand, approximately half the hospital services that participated told patients about KYMITT. However, all these hospital services also told patients to limit lifting to a certain weight alongside the KYMITT advice (Gray et al., 2022). Thus, the intended messaging of KYMITT of using pain to guide how much can be lifted (rather than imposing a specific weight restriction) may not have been adopted by these services. Indeed, combining traditional load restrictions with the KYMITT approach (that is, keep your arms close to the body when lifting) likely places more restrictions on arm activity rather than less. In addition, encouraging the safe performance of upper limb activities and tasks facilitates active participation of patients in their recovery journey. It also ensures health professionals and carers can signpost recovery and postoperative care in a consistent and clear manner, avoiding confusion regarding permitted activities. A recently published scoping review of online information about returning to activity post cardiac events provides a more global indication of what is happening regarding sternal precaution implementation. This review found that out of the 17 included websites that provided advice about activity after cardiac surgery, only one website (from Australia) provided advice based on KYMITT principles, with the remaining 16 websites promoting traditional load- and time-based sternal precaution advice (Bennett et al., 2024). These findings suggest that evidence has not yet been widely translated into clinical practice, not just in New Zealand, but globally as well.

So, if a paradigm shift in clinical practice regarding sternal precautions has not completely occurred, the question is why not? We are currently undertaking a study exploring New Zealand health professionals’ knowledge and confidence of sternal precautions before and after watching an online educational video about KYMITT. One of the survey questions asks about perceived barriers to implementing KYMITT in clinical practice. Data collection is ongoing, but despite participants unanimously agreeing with the evidence and seeing the value in implementing KYMITT, the most common perceived barriers to implementation are that sternal precaution advice is dictated by the surgeons, and perceived difficulty in changing historical practices and mindsets within the wider team (unpublished data). If lack of awareness of the evidence regarding sternal precautions is a reason for surgeons aligning with historical advice, then a starting point for physiotherapists and other health professionals who would like to encourage a change in practice may be to take the lead by engaging in discussions and creating opportunities to present the current evidence around sternal precautions to the rest of the multi-disciplinary team.

Another potential reason for the lack of a paradigm shift in clinical practice could be that some clinicians may yet to be fully convinced by the evidence available. A recent scoping review identified 12 articles exploring the implementation of less restrictive sternal precautions such as KYMITT. The main conclusion from this review was that the available evidence suggests that such movement strategies are safe and allow patients greater engagement in activities that promote improved functional recovery and confidence. However, the authors also noted that most of the evidence was from lower levels of the evidence hierarchy, such as descriptive or retrospective cohort studies and identified only two quasi-experimental studies and one randomised controlled trial (Wiens et al., 2024). Further, while key arguments against traditional load and time sternal precautions include unnecessarily impeding engagement in activity and engendering fear of movement, to the authors' knowledge only one study has compared the effect of less restrictive precautions on kinesiophobia (and found no difference) (Katijjahbe et al., 2018) and no study has yet to explore differences in physical activity levels between traditional and less restrictive approaches. Thus, there is a need for further robust research to continue building the evidence base for this paradigm shift.

So, are we there yet? It appears that while we have travelled a considerable distance, we are yet to arrive at the final destination of having less restrictive sternal precautions embedded fully into clinical practice. The challenge for physiotherapists is to facilitate and implement knowledge translation by taking the lead to make the wider multidisciplinary team aware of the evidence to ensure clinical guidelines for sternal precautions are well founded rather than persisting with historical practices. It is now time to translate evidence into practice through the implementation of models of care that encourage patients to participate in their recovery and commence early moderate intensity exercise inclusive of the upper limb.

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Aotearoa New Zealand Tongan Residents’ Attitudes to Chronic Cough and Access to Healthcare

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ABSTRACT

Little is known about the unique attitudes of Aotearoa New Zealand Tongan residents to chronic cough and healthcare access. Chronic cough is synonymous with respiratory conditions and delayed assessment and management may result in detrimental effects on quality of life, hospital admission, and mortality. Talanoa were undertaken with seven Tongan adults to explore attitudes to chronic cough and healthcare access that may facilitate or inhibit diagnosis and management. Three key themes were constructed representing disruption to dimensions of the Fonua model of health and an imbalance between the interconnectivity of life’s dimensions: (1) “feeling the cold” and the “warmth of remedies”; (2) the multidimensional impact of cough and action/inaction taken; and (3) discrepancies between understanding and accessing cough care, including respiratory physiotherapy. Study findings highlight the importance of increased community understanding of chronic cough and why and how to better access care pathways. Appreciation of the unique cultural nuances and health models of diverse patient populations, including Tongan, is essential to enhance engagement and ensure culturally responsive practice is provided. The promotion and marketing of respiratory physiotherapy in cough management is also required so that people understand, access, and engage with therapies to optimise their respiratory health.

Upsdell, A., Vaka, S., ‘Alatini, F. L., & Mooney, S. (2024). Aotearoa New Zealand Tongan residents’ attitudes to chronic cough and access to healthcare. *New Zealand Journal of Physiotherapy, 52*(3), 185–196. https://doi.org/10.15619/nzjp.v52i3.454

Key Words: Aotearoa New Zealand, Attitudes, Cough, Health Care Access, Tongan

INTRODUCTION

Cough is an essential and reflexive mechanism for protecting and clearing the airways (Andrani et al., 2018). An abnormal cough, e.g., persistent, ineffective, or associated with increased airway secretions, impacts on an individual’s quality of life in relation to negative social, psychological, and physical consequences (French et al., 1998; Jin & Kim, 2020; Morice et al., 2021). Cough is associated with a high global prevalence, affecting between 4% and 10% of the adult population (Çolak et al., 2017), resulting in a high health burden and significant morbidity (Song et al., 2015). Cough is also one of the most common symptoms that prompts individuals into seeking medical attention (Kaplan, 2019), in primary and specialist clinical areas, i.e., respiratory, cardiology, etc. (Chamberlain et al., 2015). While associated with multiple causes, chronic cough, that is, a cough lasting longer than 12 weeks (Irwin, 2006; Morice et al., 2020), requires investigation for potential causes, diagnosis, and associated management of, for example, asthma, lung cancer, or bronchiectasis (Farooqi et al., 2020). Chronic cough is characteristic of many respiratory diseases of which Pacific People bear the greatest burden (Telfar Barnard & Zhang, 2021). It is therefore relevant to explore attitudes and beliefs, from a Pacific People’s perspective, and specifically Tongan, around cough and better understand their health journey to influence understanding, access, and equity.

Access to health services is available to all New Zealanders; however, despite this, continued health inequities remain evident with Pacific People and Māori sharing the highest respiratory health burden (Telfar Barnard & Zhang, 2021). Barriers to primary care access include cost, transport, and language, in addition to family commitments, difficulty attending appointments due to inflexible work arrangements, not understanding the appointment purpose, and cultural discomfort when discussing issues with non-Pacific healthcare providers (Southwick et al., 2012). Risk factors for chronic conditions have also been found in Pacific People as evident early in life (Talemaitoga, 2010). For many Pacific People residing in Counties Manukau, low income, high unemployment, and overcrowding contributes towards poor health outcomes (Counties Manukau Health, 2017) and, by association, increased presentation of established and chronic conditions including, for example, respiratory disease.

Pacific People in Aotearoa New Zealand

Recognised as the fourth largest major ethnic group in New Zealand, 17 ethnic groups make up the total Pacific population (Ministry for Pacific Peoples, 2021). Samoan (49%) and Tongan (20%) are more represented (Pasefika Proud, 2016), with Tongan experiencing the highest percentage population increase in the last five years (Ministry for Pacific Peoples, 2021). Within Health New Zealand Te Whatu Ora Counties Manukau, Pacific People constitute 22% of the total population, of whom 25% identify as Tongan (Lees et al., 2021). While shared values and principles exist among Pacific People, each culture is unique and, as such, should be recognised and valued. Pacific People will be described in general; where available, Tongan-specific descriptions are made.

Pacific worldviews

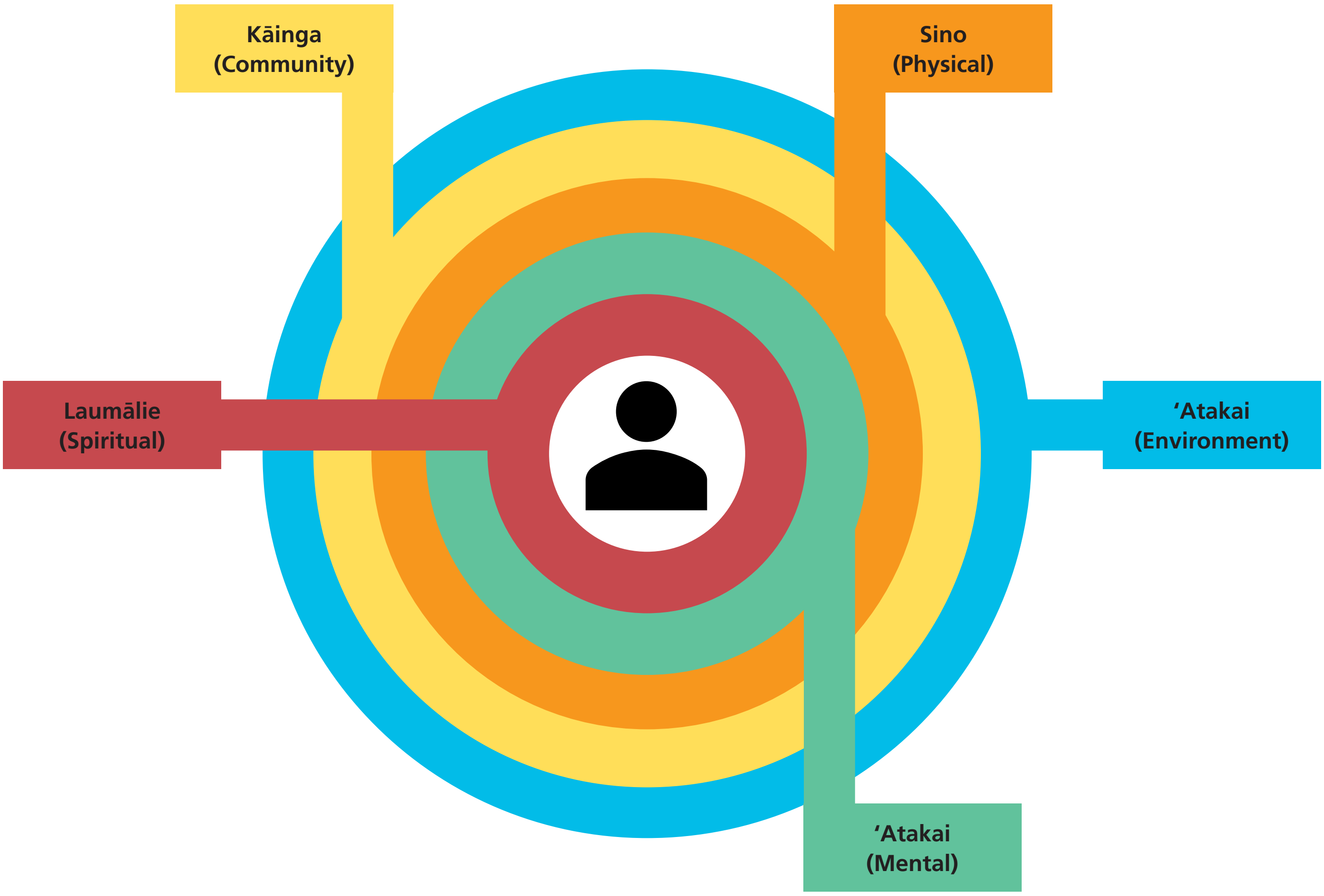
Tongan individuals have a unique worldview shaped by their profound connection to their place of origin, community, and their ancestral heritage (Ihara & Ofahengaue Vakalahi, 2011). Within this worldview, a sacredness exists of how things and people are related to each other. Relationships, for example, are shaped by social order with a shared belief in "good for all" (Fuka-Lino, 2018, p .48) rather than a focus on the individual. A positive and balanced interconnectivity between humanity and its ecology frames the Pacific view and is represented in health models such as Fonua (Figure 1). Sino (physical), ʻatamai (mental), laumālie (spiritual), kāinga (collective/community), and ʻātakai (natural and built environments) are presented as five interconnected dimensions (Tuʻitahi, 2007) representing health and harmony. Values of fe'ofaʻofani (love), fetokoniʻaki (reciprocity), fekaka'apa'apa'aki (respect), and fakapotopoto (wise leadership and management) collectively promote, sustain, balance, and harmonise health and wellbeing (Tuʻitahi, 2007). The unique Tongan worldview shapes the discourse between Tongan and others who are not Tongan. In the health context, understanding and valuing Tongan worldviews can impact on relationships, engagement with Pālangi ("white person", typically European) health professionals/physiotherapists (Crawford & Langridge, 2022), and, by association, chronic condition management including cough.

Cultural competency and physiotherapists

Cultural competency, defined as the ability of healthcare professionals to understand, respect, and effectively respond to diverse cultural beliefs, significantly shapes how patients and clients define their health, make health choices, and engage with therapy (Physiotherapy Board of New Zealand, 2018). Insufficient cultural diversity in the health workforce

Figure 1

Fonua – Pacific Model of Wellbeing



creates potential for tensions between cultural worldviews. However, culturally competent physiotherapists, possessing an understanding of and respect for cultural nuances, have been found to contribute significantly to ensuring equitable access and positive outcomes for health consumers (Physiotherapy Board of New Zealand, 2018). Beyond providing culturally meaningful physiotherapy services to Pacific People, these professionals also play a crucial role in influencing social policy and advocating for health equity at a socio-political level. In essence, cultural competency is integral to the role of physiotherapists, and extends beyond individual patient care to effect systemic changes for the benefit of diverse health consumers.

Tongan healthcare access and utilisation

While most Pacific People have a positive perception of their health and aspire to improved health and wellbeing (Ministry for Pacific Peoples, 2018), conflicting data exists. Pacific People utilise healthcare systems differently compared to non-Pacific counterparts (Ludeke et al., 2012; Toafa et al., 2001), typically at a lower rate than others, with consequences of advanced illness upon presentation (Ministry for Pacific Peoples, 2018). For Tongan people, unique beliefs influence chronic condition management (Barnes et al., 2004; Bassett & Holt, 2002; Reed et al., 2017), including accessing traditional Tongan healers (Faito'o faka-Tonga) (Reed et al., 2017; Toafa et al., 2001), often pre-empted by a quest for symptom relief and a cure. Dissatisfaction levels with "Western" medicine, namely traditional public healthcare, were found to be related to long waiting times, short consultation times, and, at times, ineffective treatment (Bassett & Holt, 2002). Time was valued and associated with relationship building and specifically trust (Ludeke et al., 2012; Toafa et al., 2001). Relationships and holistic focus on wellbeing underpinned by Pacific values and culture were also identified as important service dimensions to positively influence health outcomes (Ministry for Pacific Peoples, 2018). Self-management is integral to chronic respiratory condition management including bronchiectasis and relies on continued engagement and review (Chang et al., 2023; Hill et al., 2019; Polverino et al., 2017). Health professionals therefore should consider how best to engage with Tongan people to influence how practice and service delivery can be more culturally responsive, promoting review and investigation for symptoms such as chronic cough.

This qualitative study aimed to explore attitudes of Tongan adults resident in Counties Manukau to chronic cough and healthcare access, as a potential precursor to diagnosis and physician and physiotherapist management.

METHODS

Ethical approval was obtained from the Health and Disability Ethics Committee (reference 19/STH/27). Approval was also granted by the Counties Manukau Research Committee (registration number 612). Informed consent was obtained from all participants prior to the talanoa (conversation). A glossary that outlines Tongan words and their English translation is provided in Appendix A.

Research team

The research team included two non-Tongan (Pālangi) researchers (SM and AU) and two Tongan researchers (LA and SV), both of whom had experience in talanoa in health. Cultural oversight ensured Tongan worldviews, voices, and practices were visible and respected throughout the research. Both Pālangi, especially, given their cultural differences to the culture under review, engaged in personal, interpersonal, and methodological reflexivity, attending closely to their research position, interpretation, and relationship to the research process, talanoa, and transcripts.

Study design

This qualitative descriptive study explored the attitudes of Tongan adults resident in Counties Manukau about cough and healthcare access. Drawing on the Tongan cultural framework, talanoa, a Pacific research specific methodology was used to generate an authentic research process in addition to co-creating knowledge from participant narratives as a method (Vaioleti, 2016).

To preserve and safe-guard Tongan talanoa, each talanoa was undertaken by a Tongan researcher who promoted and encouraged conversation while listening, observing, and interpreting both verbal and non-verbal cues; the latter considered as important as verbal language (Le Va, 2020). Being "inside" the research, as Tongan, rather than New Zealand European (outside Tongan culture), and respectful of the culture, language, and values, was important to engage with participants through shared appreciation of cultural symbolism including the fale (house) representative of the family, the location of the fala (mat) or family context, and the conversation, as "participants shared talanoa from their loto (heart/soul)" (Vaka, 2014, p.111).

Participant recruitment

Eligibility criteria required participants to be Tongan, over 18 years of age, resident in the Counties Manukau region, and have had a cough for more than three months. Participants were recruited through purposive and snowball sampling through flyers circulated through Tongan community networks. Participation and engagement was enhanced through inclusion of an ethically congruent researcher (George et al., 2014) and research promotion by Tongan colleagues to negate the many barriers of ethnic minorities in health research, including lack of information, mistrust (George et al., 2014), and English proficiency (Stanaway et al., 2017). Tongan researchers discussed the research with potential participants, answered queries, and obtained informed consent. A mutually convenient time and venue were arranged, and informed consent was again obtained prior to each talanoa, which was then digitally recorded.

Interview schedule

Initial introductions and general conversations took place to establish family, community, church, and Pacific heritage connections, aligned with values of reciprocity and respect that underpin the talanoa methodology and method (Vaioleti, 2016). Semi-structured questions in the interview guide (Appendix B) included probes about cultural values, attitudes about cough, what treatments were tried (natural/Tongan/pharmacological), who participants had received treatment from including GP/family doctor (Toketa fakafamili) or traditional healer (Faito'o faka-Tonga), and what factors influenced them in seeking treatment from healthcare providers. Finally, participants were asked if they had been referred to a specialist for cough management and if they had received treatment from a respiratory physiotherapist.

Transcribing and translating

Six of the seven talanoa were conducted in Tongan. The talanoa was opened with introductions and lotu (prayer). This introduction involved introducing places, families, and important milestones from Tonga and New Zealand. This helped with building relationships to enhance the talanoa and invited participants to tala (tell) stories from their heart and soul (noa) (Vaka et al., 2016). All Tongan talanoa were recorded and initially transcribed verbatim, and subsequently translated into English. Tongan researchers reviewed the transcripts to ensure the English translation aligned with Tongan translation and no cultural nuances were lost or misinterpreted. Recorded talanoa were saved in keeping with ethical requirements and respectful of safe Pacific data sovereignty practices (informed consent, confidentially and privacy, and appreciation of data ownership and control).

Data collection and analysis

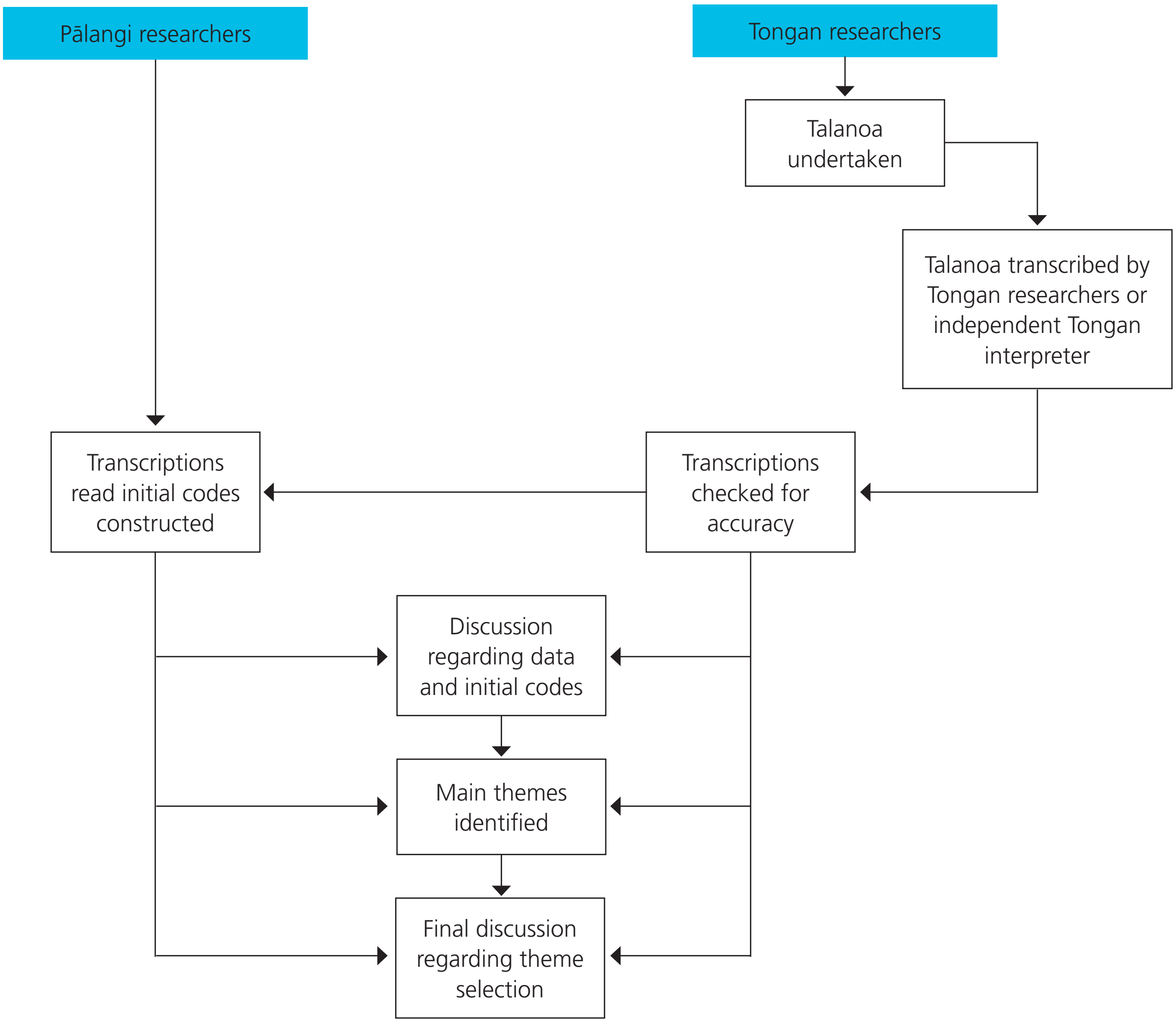
Seven talanoa were undertaken between March 2020 and February 2021 either face to face (participant's home) or by telephone. Six talanoa were undertaken in Tongan or interchangeably in English and Tongan, and one in English to accommodate participants' preference to speak in their native language (Finau et al., 2011).

Data were analysed using the six-phase thematic analysis outlined by Braun and Clarke (2020) and framed by the Fonua Model of Health, which highlights the interdependency of five life dimensions essential for harmony and health: Sino (physical), ʻAtamai (mental); Laumālie (spiritual); Kāingal (community); and ʻĀtakai (environmental) (Tu'itahi, 2007).

The roles of Pālangi and Tongan researchers in data analysis are presented in Figure 2. All researchers spent time engaging with reading and familiarisation of the transcripts. Initial coding was undertaken independently by both Pālangi researchers before a discussion to refine the codes and allow for all researchers' perspectives and insights to inform interpretation. Cultural nuances and linguistic terminologies (Faka-Tonga)

Figure 2

The Roles of Tongan and Pālangi Researchers in Data Analysis



that emerged from the analysis process were discussed by the research team. For example, while participants described the "cold", fu'u momoko (penetrating coldness) was not explicitly described; therefore, "cold" was retained in the final analysis. Miro Softwear© 2021 (https://miro.com/) was used to visualise codes and allowed researchers to collaborate digitally. These codes were organised into bigger and more meaningful groups to form themes. Candidate themes were compared and revised independently by researchers and finalised following group discussions.

RESULTS

Five interviews were conducted with women and two with men (average age 64 years, range 23–75 years) (Table 1). Participants' cough history ranged from three months to 24 years. Only one person had been admitted to hospital due to compromised respiratory health and two of the seven participants disclosed history of respiratory conditions, for example, bronchiectasis and asthma. Three participants did not visit their family doctor regarding their cough in the last year; one person was under the care of a respiratory team. Three people had experience of respiratory physiotherapy.

Three key themes were constructed that represented disruption to dimensions of the Fonua Model of Health and imbalance between the interconnectivity of life's dimensions: (1) "feeling the cold" and the "warmth of remedies"; (2) the multidimensional impact of cough and action/inaction taken; and (3) discrepancies between understanding and accessing cough care.

"Feeling the cold" and the "warmth of remedies"

The "cold" featured as a dominant theme in terms of temperature difference between Tonga and Aotearoa New Zealand, the temperature of their homes and between seasons, and their bodily temperature. All seven participants described the cold as being a cause of their cough or aggravating their cough. When Participant 3 (female, 77 years) was asked where she thought her cough came from, she explained:

> It's the cold, from being cold, from not having warm clothes especially around my neck … When I feel shivery or real cold I start to really cough … The biggest thing for me is to always make sure that I am warm and wearing warm clothes.

This connection between "cold", i.e., cold exposure and cough, aligns with the Sino dimension in the Fonua health model, where the physical environment (cold weather) has a direct impact on the participants' physical health (cough). Conversely, keeping warm and being "warm" through dressing and heating rooms at home were synonymous with improved health and wellbeing. Warm climate was also associated with health and happiness and was in contrast to the cold climate of Aotearoa New Zealand as described by Participant 1 (female, 68 years):

> It [cough] is because of the cold weather/or when I'm cold because this is a cold country. We came from Tonga, which was a warmer climate. When I travel to Tonga I never cough over there in Tonga, so I really think it's because of the colder climate/weather [here].

Participants found warmth-generating remedies effective in counteracting the cold. These remedies were perceived as providing immediate physical warmth and were used to gauge treatment efficacy. Remedies included ginger drinks, honey and lemon, steam therapy with lemon leaves, rum and coke, and Tongan oil (Lolo Tonga) made from coconut oil infused with a variety of flowers and plants including Ylang Ylang (mohokoi) and red ginger leaves (tevunga) and applied to the chest or body.

The multidimensional impact of cough and action/inaction taken

Cough was described negatively in various dimensions, encompassing physical, mental, spiritual, and social aspects

Table 1

Participant Details

Participant	Sex	Age (years)	Interview language	Interview location	Cough history	Healthcare utilisation
1	F	68	Tongan	Home	Several years	GP, respiratory specialist
2	M	70	Tongan	Home	"Since getting old"	GP
3	F	77	Tongan	Home	4 years	GP
4	F	23	English	Phone	"Whole life"	Hospital team during two admissions, GP, respiratory specialist, respiratory physiotherapist
5	F	70	Tongan	Phone	5 years	GP
6	M	75	Tongan	Home	5 years	GP, respiratory specialist, respiratory physiotherapist
7	F	64	Tongan	Home	6 years	GP, respiratory specialist, respiratory physiotherapist

Note. F = female; GP = general practitioner; M = male.

of their wellbeing. Sino (physical): cough was associated with tangible symptoms such as coughing up blood, which intensified negative emotions like manavasií (fear) and anxiety. ʻAtamai (mental wellbeing): participants spoke of fakamaaí (embarrassment) and described the experience as ikai makataki'i (unbearable). Laumālie (spiritual): the negative impact of cough extended to the holistic wellbeing of the individual. For example, for Participant 2, coughing interrupted their sleep, which affected their overall quality of life: "The only time I don't like coughing is when I go to sleep" (male, 70 years). Furthermore, the negative effects of cough reached beyond the individual to influence Kāinga (family and community). Participants described their coughing episodes as disrupting their ability to actively engage in community life, impacting on social gatherings and participation in public spaces. Participant 5 (female, 70 years), in particular, highlighted the social impact of cough, expressing a preference for staying home to avoid public coughing episodes during family gatherings:

> Like when we have a family gathering, I don't want to go in case I have a coughing fit and disturb people, so I just want to stay here, at times like this … It's better to stay [home] than having to constantly get up in public to go and cough.

Remedies were described by four participants as a means of managing cough, reducing or eliminating cough and delaying attendance at the family doctor. Remedies were trialled and perceived as a first-line treatment irrespective of the cough duration. Tongan remedies included the use of Tongan oil (Lolo Tonga) especially when cold, and distilling Tongan plants and drinking the infused liquid. Differing attitudes and beliefs represented a continuum from ''if there was a Tongan medicine, I'd be better" (Participant 7, female, 64 years), suggesting a strong belief in the efficacy and trust in Tongan remedies. In contrast, Participant 2 firmly stated "no Tongan medicine" (Participant 2, male, 70 years), indicating a strong personal view for other therapies and medications. Participant 1 (female, 68 years) expressed openness to using Tongan and traditionally prescribed medications for cough as both were perceived as beneficial:

> I believe that everything is good and think that with the Pālangi medication it's fast and heals quickly whereas with the Tongan medicine it works slowly but will eventually do the same healing as the medication given from the doctors … The great thing about the Tongan medicine is that there is no added chemicals in the medicine, it's all plant based and you can consume all you want but still be good for your body, whereas the Pālangi medication, there are times it becomes problematic to our stomach and bodies.

Two of the seven participants commented on the importance of other people's opinions. Participants both listened to and trialled many recommendations from family members and friends as described by Participant 5 (female, 70 years):

> Someone would tell me they got better with this, I'd try it, someone else would say they got better with that and I'd try it. It's our way, when we look at it, from Tongan people, we think highly of people's opinions.

While Tongan remedies were considered less scientific and taking longer to take effect, they were perceived as more natural and with a holistic effect on cough and health. One participant discussed how Western medication was used for short-term symptom relief. There was disappointment that Western medication didn't "fix" or "cure" their cough, and concern over unwanted side-effects. One participant described being "given tablets for cough – a lot of tablets" (Participant 6, male, 75 years) to manage their cough and that they had tried "every type of cough mixture from the pharmacy" (Participant 5, female, 70 years). Medication adherence was also variable and was only taken when required, suggesting that participants self-determined when their health was compromised and required action.

Discrepancies between understanding and accessing cough care

All participants described accessing a GP/family doctor for cough management. Tongan healers (faito'o faka-Tonga) were rarely accessed; two of the seven participants described accessing a Tongan healer with one participant accessing the healer when they resided in Tonga. Three participants did not know how to access a Tongan healer and one participant expressed a preference for attending their GP over a Tongan healer.

Credibility of doctors trained in a "developed" country was aligned with increased knowledge, equipment, and research, and, by association, fast diagnoses were made and treatments instigated. Trust and respect were described as key to a shared investment in participants' health. Yet, at times, sessions were described as rushed with awareness of the doctor's large caseload. Several participants described a unique relationship with their GP as the "only one I trust", with a relationship developed over several years. Genuine care for participants and empathic listening were recognised as important bonds in the patient/doctor relationship and the inter-generational relationship with their family doctor (toketā faka-fāmili). Participant 1 (female, 68 years) explains why she and her family see their current Pālangi family doctor:

> He's been a doctor for a very longtime serving in the community … He is familiar with me and the history of my health from the beginning up to now and I believe that it's fair to stay with him … He is always smiling and very caring.

None of the seven participants attended a Tongan doctor. There was a preference expressed for attending a doctor of their birthplace for reasons including a shared understanding of "the Tongan way". This was expressed in terms of communication by Participant 1 (female, 68 years) namely through the "use of stories/illustrations" and to explain "tell it how it is" (Participant 3, female, 77 years). Cultural sensitivity in relation to finances (pa'anga) was also appreciated, which inferred less embarrassment in asking for payments to be paid in instalments.

> …whereas the Tongan doctor, we would be able to ask for help with regards to payment, I would ask if I can make part payments in order for my family member to see the doctor because that is the island way. (Participant 1, female, 68 years)

Shared language and culture were also described as facilitating a reciprocal relationship, creating an important connectivity, relative to the participant's health and cough management. This connection is described by Participant 1 (female, 68 years) and how this impacted medication adherence:

> (Tongan doctors) they tell you the truth straight up and that they stress the importance of why the medication is important to take. Whereas the Pālangi doctor, you don't tell him your lifestyle, what you do in your spare time, no, you just go to them and just tell them what they want to hear and leave out other important things.

In contrast to attending GPs, two participants described care provided by respiratory specialists. Specialist care was viewed positively and associated with tests, for example, lung function tests, "specialist tests", and different treatments such as using equipment. The role of respiratory physiotherapy was less clear. Three participants who had experience of respiratory physiotherapy described associations between physiotherapy and their lung health, using equipment and breathing exercises. Participant 3 (female, 77 years) described receiving equipment related to "breathing": "she gives me equipment … the things to use to breathe in". This contrasts with the equipment purpose, i.e., airway clearance techniques. In general, physiotherapy was associated with musculoskeletal injury and rehabilitation, as described by Participant 5 (female, 70 years): "I don't really know (what the role of physiotherapy is). I thought they're the person you go and see for exercising, no?".

DISCUSSION

This qualitative study explored New Zealand Tongan residents' attitudes to cough and access to healthcare. Emergent themes represented a disconnect between the five dimensions of health in the Fonua health model. Cough was symbolic of an imbalance between the sino (physical), and ʻātakai (environment), which then impacted on the other dimensions of health in the Fonua model: emotional, spiritual, and community.

Cough was perceived as a complex issue with multidimensional causes, strongly tied to the environment, particularly the ātakai. Living back in Tonga was associated with a healthier, simpler lifestyle, linked to warmth (māfana) and happier times (Faletau et al., 2020). Māfana (warmth), for example, is referred to in cultural dance performances and spiritual activities as a state of elation, joy, excitement, and much satisfaction (Johansson-Fua, 2023). In contrast, Aotearoa New Zealand was described as "cold", both physically and environmentally, contributing to housing issues like cold, dampness, and mould that are more prevalent among non-owner-occupiers. These housing conditions are recognised factors impacting health vulnerability (Camaira & Mafile'o, 2019) and, specifically, respiratory health (Telfar Barnard & Zhang, 2021). Notably, Pacific People, including Tongan, face challenges in housing quality and affordability, creating vulnerabilities. Encouragingly, recent government initiatives that retrofit insulation into existing homes have shown improvements in respiratory health outcomes for Pacific populations (Fyfe, 2021), highlighting the importance of health professionals including physiotherapists advocating for such policies and funding to improve health equity and outcomes.

The study also shed light on the perceptions of individuals living with cough from a healthcare perspective. Cough was associated with stigma and was found to impact various dimensions of an individual's quality of life, including laumālie (spirituality). This both impacted on participants' ability to attend church and social gatherings. While healthcare communication often adheres to the biomedical model, focusing on anatomy, physiology, and pathophysiology (Thornquist, 1997), findings from this study emphasised the need for incorporating cultural and spiritual aspects into care models as previously recognised as beneficial for this community (Vaka et al., 2022). Health professionals, particularly those outside the Pacific community, should aim to understand what "wellbeing" means to different cultures, enabling better engagement in managing not only cough but also chronic conditions.

Building rapport and good communication were deemed vital by participants to establish rapport and relationships with health professionals and were also described as fundamental, given their influence on patient experiences and high-quality health services (Ministry of Health, 2022). Unrushed appointments and time to welcome and get to know people were valued and set the scene to further discuss cough and cough management. However, challenges existed due to high caseloads, affecting patient satisfaction. For people living in Counties Manukau, access was further challenged by a disproportionally smaller serviced population by primary care (Medical Council of New Zealand, 2021). Addressing these challenges requires not only individual health professionals' efforts but also broader service and policy reviews. Study findings highlight the concerning rates of unmet care needs among Pacific People in New Zealand as seen in the New Zealand Health Survey (Ministry of Health, 2022), indicating the need for improved access, especially for those with cough. In addition, health professionals are challenged to be active in advocating for health and social policy reform, and addressing population health determinants is crucial for promoting equitable respiratory outcomes as outlined by Heaps (2023).

The global burden of chronic cough in general populations is recognised (Song et al., 2015) with cough of any duration being the most prevalent presenting symptom in primary care (Achilleos, 2016). When cough was present in participants' lives, it was tolerated; medical advice was not always sought. In a study of Italian adults with cough, Dal Negro et al. (2016) found that cough was considered a "disease" that warranted a "cure". Tongan participants in this study also sought a cure. The disjuncture between expectations of cough "cures" and chronic cough management were evident. The former represents a one-off, cost effective "cure"; the latter requires engagement and attendance at multiple appointments to initiate a chronic cough pathway (Morice et al., 2020) and access specialist care. Current health models put the onus on individuals to fund appointments with primary care, essential for future referral and access to specialist care. Access to appointments including investigations continues to be limited by transport issues and specifically petrol costs. Unmet health needs were found to relate to cost (Ministry of Health, 2022), indicating that current funding models do not support the most vulnerable populations in accessing healthcare. It is not surprising therefore that ambulatory sensitive hospitalisation rates for Pacific People are higher compared with the rest of the population (Ministry of Health, 2022). Hospitalisation rates for respiratory disease are also disproportionate for Pacific adults and children compared to other ethnic groups (Bibby et al., 2015), suggesting that chronic respiratory conditions are sub-optimally managed. The current health systems, left unchanged, will continue to neglect the health needs of Pacific People.

Lack of improvement in cough impacted on continued engagement with health professionals. In contrast to medicines, Tongan remedies were more readily available, commonly sourced from plants and trees and grown locally. These provided temporary relief that could be accessed at any time and hence cost was minimal in comparison and was readily shared. The longer-term and natural Tongan remedies were perceived as more holistic, promoting a background wellness. This contrasted with medicines perceived to "cure" cough. Prescriptions costs continue to deter collection by Pacific People (Ministry of Heath, 2022); however, recent policy changes (i.e., free prescription charges) may redress this balance in terms of access to medicines.

Little is known about Tongan traditional healers in Counties Manukau. Indeed, concern has been raised by Tongan traditional healers in Aotearoa New Zealand regarding their role by western health professionals (Toafa et al., 2001). In this study, only two of the seven participants engaged with Tongan healers. There is an increased need to better understand the role of other complementary health providers such as Tongan traditional healers to ensure therapies that may be received complement advice rather than conflict with it.

The role of respiratory physiotherapy was unclear to all participants, including three of the seven participants who experienced respiratory physiotherapy. Physiotherapy was associated with musculoskeletal injury and rehabilitation. This mirrors findings in a survey of New Zealand public awareness whereby sports injuries and bad posture issues were considered core areas of physiotherapy (Physiotherapy New Zealand, 2021). Of the 437 respondents, only 1% self-reported as Samoan, suggesting the survey did not capture the unique views of the wider Pacific population. Interestingly, 91% of the 437 respondents indicated they would seek advice from a doctor regarding "feeling breathless/asthma" compared with physiotherapists (3%) (Physiotherapy New Zealand, 2021) highlighting a paucity in the public's understanding of the role of respiratory physiotherapy. The inequity of respiratory services in Aotearoa New Zealand continues to exist. Only 10 District Health Boards (DHBs) employed dedicated respiratory physiotherapists, with "generalist" physiotherapists employed by other DHBs including three large DHBs (Meyer et al., 2022). Marketing strategies to date have not increased the role and scope of respiratory physiotherapists. Wider and more inclusive marketing would not only extend the understanding and value of respiratory physiotherapy but may also empower people with cough to seek treatment.

Pacific People remain underrepresented in the health workforce. Pacific physiotherapists constitute 1% of the physiotherapy workforce compared with 50% New Zealand European (Physiotherapy Board of New Zealand, 2022). The lack of cultural diversity in the health workforce creates opportunities for clashes of cultural world views. Similarly, intergenerational clashes may be evident between young workforces such as physiotherapy with over half of physiotherapists who held a practicing certificate in 2021/22 aged under 44 years (Physiotherapy Board of New Zealand, 2022), and a growing, aging population from cultures such as Tongan, in which elders are valued and afforded faka'apa'apa (respect) (Havea & Alefaio-Tugia, 2018). Elders in the Pacific community are recognised for their important role in the family and community, yet their ability to fulfil their responsibility of linking the past, present and future of families and communities is compromised when their health and wellness is at risk (Ihara & Ofahengaue Vakalahi, 2011). In this study, participants with an average of 64 years spoke of how their health was impacted in relation to cough, with two of seven participants diagnosed with respiratory illnesses. The growth and maturation of Pacific healthcare workforce is therefore essential. In the interim, cultural support workers and advisors can enable non-Tongan health staff to mediate between two potentially different world views and are therefore essential in the tripartite relationship. These essential services, where they exist, are commonly overloaded and under-resourced (Ministry for Pacific Peoples, 2021). Financial support to fund cultural services lies with organisations to ensure the health as well as cultural needs of their population are effectively met.

Pacific People's culture is unique and distinguishes them from other groups in Aotearoa New Zealand. The Fonua health model provides Pacific as well as non-Pacific healthcare professionals and service providers with an understanding of what is important for Tongan people. The Pacific Wellbeing Outcomes Framework (Ministry for Pacific Peoples, 2022) also provides an integrated picture of the needs of Pacific communities, what is perceived by the communities as important to their wellbeing, and captures strategies and plans for the government to improve their outcomes, informed by Pacific for Pacific communities. Lalaga potu (Pacific values and principles), fale fono (partnership and governance), vaka moana (performance and improvement), and te kupega (capability) are four interconnected focus areas that inform the Pacific Wellbeing Strategy (Ministry for Pacific Peoples, 2022). It is the responsibility of the Government to not only listen to the voices of Pacific People but also to ensure strategies are enacted. For health professionals as individuals and professions, it is important to not only ensure they are culturally competent, but also to advocate for under-represented populations, social policy, and health reform. This advocacy is crucial so that, for example, social determinants that influence cough can be addressed, and people with cough can better access health care including respiratory physiotherapy.

Strengths and limitations

Strengths included a unique collaboration of Tongan and Pālangi researchers who mirrored the mutual reciprocity and respect afforded to study participants. Cultural governance was provided by two experienced Tongan researchers (LA and SV) who contributed to all aspects of the study including working with SM and AU as Pālangi researchers.

This study was framed by the philosophies of talanoa research methodology and method led by Tongan researchers. This strength allowed for participants to experience an authentic talanoa that would be culturally safe and relevant to them. However, both researchers were male and significantly younger than the majority of participants, who were older women. This dynamic could have been a barrier to allowing researchers to probe deeper during the talanoa due to perceived lack of respect. Lack of participant diversity in age and gender also requires consideration, as older Tongan women may have more traditional views than other members of the Tongan community.

Data collection occured over the COVID-19 pandemic throughout non-lockdown periods. Cough is a common symptom of COVID-19 with associated stigma (World Health Organization, 2020). This may have inhibited discussion and open dialogue about cough, and impacted on participant recruitment.

CONCLUSION

In conclusion, the impact of cough extended across the interconnected dimensions of the Fonua health model, perpetuating imbalances that could affect health journeys. Access, engagement, and quality of experiences were pivotal in managing cough, influenced by trust and rapport with health professionals. This study emphasised the need for better understanding of cultural nuances by healthcare providers and the importance of integrating Pacific health models. Findings also highlighted the need for advocating for policy changes, addressing social determinants, and increasing awareness about cough management. Ultimately, collaborative efforts are crucial to harmonising health dimensions and improving the health and wellbeing of Pacific People, including Tongan, living in New Zealand.

KEY POINTS

1. Cough was seen as an imbalance between the physical body and the environment, and largely managed with remedies.
2. Cough impacted on quality of life by affecting other dimensions of health, particularly in social situations.
3. Tongan people may have difficulty initiating chronic cough pathways due to perceived need to tolerate and barriers to accessing primary healthcare services.
4. Limited understanding of the role of healthcare professionals (including respiratory physiotherapist) exists in the management of chronic cough.

DISCLOSURES

Funding was received from the Physiotherapy New Zealand Scholarship Trust. No conflicts of interest exist that may be perceived to interfere with or bias this study.

PERMISSIONS

Ethical approval was obtained from the Health and Disability Ethics Committee (reference 19/STH/27). Approval was also obtained from the Health New Zealand Te Whatu Ora Counties Manukau Research Committee (research registration number 612).

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CONTRIBUTIONS OF AUTHORS

SM and AU conceived the study and study design. LA worked on the design concept and initial Talanoa, and SV on the remaining Talanoa and data analysis. LA and SV provided cultural oversight and guidance. SM and AU undertook data analysis and wrote the initial manuscript draft. All authors contributed to the revisions and approved the final manuscript draft submission.

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APPENDIX A

GLOSSARY OF TONGAN WORDS AND ENGLISH TRANSLATION

Tongan word	English translation
'Ātakai	Natural and built environments
'Atamai	Mental wellbeing
Fakamaaí	Embarrassment
Fakapotopoto	Wise leadership and management
Fakatonga	Tongan language terms
Fekaka'apa'apa'aki	Respect
Fe'ofa'ofani	Love
Fetokoni'aki	Reciprocity
Ikai makataki'i	Unbearable
Kāinga	Collective/community
Laumālie	Spiritual wellbeing
Lolo Tonga	Tongan oil made from coconut oil infused with a variety of flowers and plants
Manavasií	Fear
Momoko	Deep penetrating cold
Pa'anga	Finances/money
Sino	Physical wellbeing
Toketa faka-famili	GP/family doctor

Note. Translations acquired from: https://tradukka.com/translate/to/en/fakatonga.

APPENDIX B

INTERVIEW SCHEDULE

Cough parameters. Tell me about…

- How long have you had a cough?
- What do you think causes your cough?
- How does it affect you?
- Does it worry you?
- What does health mean to you?

Treatments (natural/Tongan/medication/etc.). Tell me about…

- What treatments have you tried? Why?

Initial treatment provider. Tell me about…

- Who have you seen about your cough?
- Why did you see them?
- What was your experience?
    - What information or tests did you receive/undertake?
    - What treatment did you receive?
    - Were you satisfied with treatment received?
    - If appropriate, did you tell them that you had seen a Tongan healer?
- What stopped you from seeing them earlier?
- Did you attend again for a follow up? If no, why? If yes, why?
- Would you see a Tongan healer in preference to your family doctor? Why?
    - What methods of healing did they use?
- Is your family doctor Tongan?
- Do you take any Tongan medicines?

Follow up treatment provider. Tell me about…

- Have you seen a specialist doctor, physiotherapist or health practitioner at Manukau Super Clinic?
- What was your experience?
    - What information or tests did you receive/undertake?
    - What treatment did you receive?
    - Were you satisfied with treatment received?
    - Did you attend again for a follow up? If no, why? If yes, why?
    - If appropriate, did you tell them that you had seen a Tongan healer or taken Tongan medicine?
- Did you continue to attend? If so/not … why?
- Could anything be changed to make your experience more positive?
- If you had a family member with a cough…
    - Who would you recommend they see? And why?

Pasifika Parents' Experiences of Neonatal Skin-to-skin: Insight into Culturally Responsive Care

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ABSTRACT

Infants who survive prematurity have greater risk of neurodevelopmental impairments. Skin-to-skin during the neonatal period can improve infant outcomes. Greater understanding of Pasifika parents needs in implementing skin-to-skin could inform better implementation of skin-to-skin. This study explores Pasifika parents' experiences of skin-to-skin with their preterm infants in New Zealand-based neonatal units to inform culturally responsive care and service delivery. Pasifika parents of preterm infants born less than 33 weeks gestation were eligible to take part in interviews. Recruitment and data collection occurred in neonatal units across Auckland. Interpretive Phenomenological analysis informed by Talanoa and Tui Kakala research methods informed the interview format and data analysis. Five themes were identified: "overcoming fear and anxiety", "connection", "words matter", "actively managing racial bias", and "spirituality and religious beliefs facilitate resilience". Skin-to-skin promoted connection and strengthened all four pou of the Fonofale model. Communication styles of individual clinicians greatly influenced the Vā (relational space) experienced by families, which subsequently affected their experience of skin-to-skin. Findings indicate the need for Pasifika cultural competence training in order to provide culturally safe care when supporting an intervention like skin-to-skin. Intentionally encouraging and facilitating Pasifika parents' spirituality within the neonatal intensive care unit could optimise skin-to-skin. Clinician communication has the potential to affect the initiation, uptake, and experience of skin-to-skin.

Taylor, C., Brown Purcell, A., Elder, D., & Graham, F. (2024). Pasifika parents' experiences of neonatal skin-to-skin: Insight into culturally responsive care. *New Zealand Journal of Physiotherapy, 52*(3), 197–205. https://doi.org/10.15619/nzjp.v52i3.455

Key Words: Cultural Competence, Cultural Safety, New Zealand, Neonatal Intensive Care Unit (NICU), Pasifika, Pacific Peoples, Prematurity, Racism, Skin-to-skin

INTRODUCTION

Prematurity, defined as birth before 37 weeks' gestation (World Health Organization, 2023), is currently the leading cause of death worldwide in children under five years of age. An estimated 15 million infants are born prematurely worldwide each year and, of these, 9,000 die before the age of five due to preterm birth complications (Chawanpaiboon et al., 2018; Liu et al., 2016). The majority of infant deaths in New Zealand are infants born < 28 weeks' gestation with a death rate of 2.1 per 1,000 live births (Ministry of Health, 2019). Within New Zealand, infant death rates vary by ethnicity with significantly higher rates for Māori (5.9%) and Pasifika (6.2%), compared to European (2.8%) and Asian (2.5%) ethnic groups, with Pasifika infants < 28 weeks experiencing the highest death rates (Ministry of Health, 2019). Within the Neonatal Intensive Care Unit (NICU) environment, 13% of mothers are Pasifika (Malatest International, 2019), compared with 8.1% in the total population (Stats NZ, 2019), indicating compounded negative outcomes for Pasifika infants.

Preterm infants have a greater risk of neurodevelopmental impairment compared to full-term infants, including motor impairments, cognitive deficits, poor academic achievements, and behavioural disorders (Chawanpaiboon et al., 2018, Twilhaar et al., 2018). Parents of preterm infants are at higher risk of experiencing postpartum depression (PPD), post-traumatic stress disorder (PTSD), and anxiety disorders (Lefkowitz et al., 2010) due to separation from infants and medicalised post-partum experiences (Caporali et al., 2020). Pasifika parents are at greater risk of these sequelae, given their over-representation as parents of premature infants. Understanding the experience of Pasifika families during the inpatient post-partum period may inform more supportive care for Pasifika parents, thus improving parent and infant long-term outcomes.

Skin-to-skin (also known as Kangaroo care) is a non-invasive, parent-mediated intervention for preterm infants that significantly reduces infant mortality and morbidity including infection, sepsis, severe illness, and respiratory issues (Conde-Agudelo & Díaz-Rossello, 2016). Skin-to-skin is defined as "early continuous and prolonged skin-to-skin contact, exclusive breastfeeding and early discharge" (Conde-Agudelo & Díaz-Rossello, 2016) and involves placing an infant vertically on their mother or father's chest wearing only a nappy. Skin-to-skin is associated with better infant self-regulation, cognitive outcomes (Akbari et al., 2018), lower pain responses and infection rates, positive parent–infant experiences, and higher rates of breastfeeding (Akbari et al., 2018; Boundy et al., 2016). Skin-to-skin appears to provide infants with a dose-dependent neuroprotective effect by promoting and protecting structural brain development (Casper et al., 2018, Charpak et al., 2022; Head, 2014; Schneider et al., 2012), and reduces stress in parents (Vittner et al., 2015).

Low rates of implementation of skin-to-skin in NICU in New Zealand mirror low international uptake (Chan, 2016), with many eligible infants receiving very low doses of skin-to-skin (Bear, 2019) or none at all (Taylor, 2023). Internationally, barriers to implementation expressed by parents include insufficient physical space or social support, limited time, medical concerns for the infant (Seidman et al., 2015; Smith et al., 2017), and negative perceptions of staff (Blomqvist et al., 2013; Seidman et al., 2015). Variable support by nursing staff to implement skin-to-skin has been reported internationally, with differences noted with non-white mothers reporting receiving less support than white mothers (Hendricks-Muñoz et al., 2013). The role of the specialist neonatal physiotherapist within the interdisciplinary team has become increasingly important, as survival rates of preterm infants have increased, shifting the focus on developmental care and supporting long-term neurodevelopmental outcomes (Sweeney et al., 2009). The role requires advanced training to meet the neurodevelopmental and musculoskeletal needs of physiologically unstable infants, as well as supporting parents emotionally and practically, and providing culturally safe care in a highly stressful environment (Doğan et al., 2022; Sweeney et al., 2009). With all the neuroprotective effects skin-to-skin has, neonatal physiotherapists therefore play a vital role in supporting the uptake, thus mitigating some of the downstream neurodevelopmental concerns.

Whānau Ora envisions prosperity for all Pasifika families in New Zealand by supporting and building family capability (Ministry of Health, 2014). The umbrella term Pasifika has been used to describe all migrants from the Pacific Islands and their descendants now residing in New Zealand, while acknowledging there is substantial heterogeneity within this population (Winter-Smith et al., 2023). Increased uptake of skin-to-skin for premature Pasifika infants is a specific, low-cost, and evidenced-based strategy for improving infant mortality. Greater understanding of the experience of Pasifika parents with skin-to-skin is a key step in designing tailored health initiatives facilitating access to this intervention and thus improved health outcomes. The aim of this study was to explore Pasifika parents' lived experience of skin-to-skin with their preterm infant while receiving care in a New Zealand neonatal unit.

METHODS

Methodology

This study employed an Interpretive Phenomenological Analysis (IPA) (Smith et al., 2009) method, informed by Talanoa and Tui Kakala methods (Thaman, 1997; Vaioleti, 2006). Through IPA, knowledge and values of caregivers' experiences of skin-to-skin were explored. Data collection and analysis were guided by Talanoa principles of relationality and reciprocity, enabling cultural safety during interviews, and Tui Kakala methods ensured the cultural authenticity of analysis. Two Pasifika cultural advisors (GL, ABP) provided extensive guidance in adhering to Talanoa principles throughout the study. Ethics approval was obtained through the University of Otago Ethics Committee (reference H20/069). Locality approval was provided for each study site alongside Māori consultation.

Participant selection and recruitment

Inclusion criteria were Pasifika parents receiving neonatal care from one of the three study sites for a preterm infant born < 33 weeks' gestation. Exclusion criteria were infants with health issues that would preclude the provision of skin-to-skin (e.g., unrepaired surgical conditions, major surgery, requiring ventilation or muscle relaxants). Participant recruitment occurred by consecutive purposive sampling between November 2020 and July 2021 with invitation to the study offered verbally by onsite nurses and neonatal physiotherapists working with families. Following consent, parents were contacted for interviews.

Data collection

Consistent with IPA and Talanoa methods, open and flexible interviewing structures were employed in which a semi-structured interview guide was used to prompt reflections, while focusing on a respectful and reciprocal discussion that ended when points already discussed were being revisited. Interviews were recorded using Zoom videoconferencing software version 5.4.3 on two password protected devices. Interviews were transcribed verbatim.

Analysis

Data analysis followed the six steps of IPA (Smith et al., 2009) while being informed by the Tui Kakala process described by Vaioleti (2006) and Thaman (1997). After reading and re-reading the raw data, initial noting took place, and then emergent themes were developed. Tui is the process where the knowledge gained through the rich Talanoa discussions are woven together, authentically arranging the data to ensure the relevance and usefulness of the research produced (Thaman,1997; Vaioleti, 2006). When developing emergent themes and seeking connections across those themes, cultural and technical skill were of utmost importance to ensure the essence of participants' experience was fully captured and support from cultural advisor ABP was enlisted to oversee each step of the data analysis.

RESULTS

Seven families (seven mothers, four fathers) were interviewed in person, with all but one still in a neonatal unit at the time. One interview took place over the phone within a week of discharge. Families represented a range of Pasifika ethnicities, with parents aged between 20 and 40 years, and four families having other children at home (Table 1). Most infants were singleton, with one set of twins and one set of triplets (with one of the triplets deceased). Eight of the 10 infants were born extremely premature, less than 28 weeks' gestation. Data analysis produced five superordinate themes and 13 subordinate themes (Table 2).

Theme 1. Overcoming fear and anxiety

This theme reflects the emotional context in which families experienced skin-to-skin with their infant, and the impact fear and anxiety had on their experience. Fear related to concern about harming their vulnerable infant during handling for skin-to-skin. Anxiety was described as worry and unease regarding their infant's medical stability when first doing skin-to-skin.

It's a rollercoaster

Parents shared extreme variations of experiences through different stages of the NICU journey. These experiences were turbulent fluctuations between extreme highs and lows related to their infant's medical progress and the psychological adjustment of parenting an infant in a foreign environment, as Participant 5 describes:

> They say that it's a roller coaster. There are lots of lows and you have a little bit of a high and then there'll be another setback. That's exactly the best way to describe the NICU experience actually. You never get over it.

Longing met with fear

This subtheme describes parents' experience of their first skin-to-skin contact with their infant. For all parents, their first

Table 1

Participants' Demographic Data

Participant	Role	Ethnicity	Age range (years)	Infant	Gestation (weeks)	Birth weight
1	Mum	Hawaiian	26–30	Singleton	28	VLBW
2	Dad	Rarotongan				
3	Mum	Samoan/ NZ Māori	MD	Triplets	24	ELBW
4	Dad	NZ Māori				
5	Mum	Fijian Indian	36–40	Singleton	24	ELBW
6	Mum	Samoan	21–25	Singleton	26	ELBW
7	Dad	Tongan				
8	Mum	Samoan	26–30	Singleton	29	LBW
9	Dad	Tongan				
10	Mum	Tongan	36–40	Twins	25	ELBW
11	Mum	Tongan/ Rotuman	31–35	Singleton	26	VLBW

Note. ELBW = extremely low birth weight (< 1000 g); LBW = low birth weight (< 2500 g); MD = missing data; NZ = New Zealand; VLBW = very low birth weight (< 1500g).

Table 2

Overview of the Superordinate and Subordinate Themes Developed

Superordinate themes	Subordinate themes
1. Overcoming fear and anxiety	1.1. "It's a rollercoaster" 1.2. Longing met with fear 1.3. Moving from fear to confidence
2. Connection	2.1. Heart to heart 2.2. Touch in lieu of skin-to-skin 2.3. Becoming parents
3. Words matter	3.1. Reassurance and encouragement 3.2. Do not do that
4. Actively managing racial bias	4.1. Differences in care 4.2. Being an advocate for your infant 4.3. Culturally supportive care
5. Sprituality and religious beliefs facilitates resilience	5.1. Pillar of strength 5.2. Spiritual connection with your baby

skin-to-skin was one of anticipation and longing met with fear and hesitancy in an emotional context of anxiety. The longing to physically hold their infant was reported by all parents and was described as a significant part of parenthood in the Pasifika community by many, representing a gateway to nurturing their infant, both practically and emotionally. In contrast, the first experience of skin-to-skin was described by Participant 11 as "nice but nerve-wrecking".

> Yeah. Scary and just I did not move. I held her for two hours just like a statue because you just do not want to move around with her in case anything happens. I enjoyed it, but then I also was like yeah, how do I explain it. It was nice but it was nerve-wrecking at the same time.

Moving from fear to confidence

Families were reliant on the clinical team initially to be able to start having skin-to-skin with their infant and then the process by which they started to build comfort and confidence. Skin-to-skin was described as a new skill parents had to learn, and the provision of step-by-step support appeared to provide a bridge from fear to confidence. This learning support started with nurses transferring infants, showing parents how to do this, then supervising, and finally enabling parents to do it independently: "They would break it down to how you want it to be explained to you. That helped me and my partner a lot because we learnt a lot of things" (Participant 9). Parents described a gradual reduction in the support provided and the feeling of pride and accomplishment as they implemented skin-to-skin, with several parents describing this as moving into their parenting roles.

Theme 2. Connection

Heart to heart

Skin-to-skin was perceived by parents to facilitate and encourage connection with their infant. Several parents used the term heart to heart in reference to skin-to-skin. Parents' descriptions of 'heart to heart' not only included the physical component of their infant being placed on their chest, thereby aligning their hearts, but also included a description of deep emotional connection. The physical components of connection experienced by parents included improved breathing and sleep, as well as the emotional component of bonding.

> Bonding. Feeling comfortable with each other … There are a lot of communication [sic] between skin-to-skin between baby and mum that cannot be interpreted. For me and my baby, it was her breathing. Because she had difficulty breathing, putting her on me helped regulate her breathing. So, the calmer she was on me, the better her breathing would be. The benefit of that is they sleep deeper, and they heal. (Participant 11)

Touch in lieu of skin-to-skin

Touch became a valuable source of connection when parents could not implement skin-to-skin and provided a way for parents to move from feeling disconnected to connected with their infants. Parents of extremely preterm infants, less than 28 weeks' gestation, particularly described feeling disconnected from their infants and were more often unable to implement skin-to-skin due to their infant's unstable condition. These parents described the connective impact of simply touching their infants as they lay in their incubator. One of the participants described the impact of touch from a cultural perspective.

> In my culture and my religion, it is very important to hold the baby so that was something that I was very passionate about. Holding, talking and any form of interaction. There was [sic] a lot of times that I could not because of the way he was. (Participant 5)

Becoming parents

Skin-to-skin allowed parents to take up their parental roles in the NICU environment, thus enabling deeper connections to develop. It provided an opportunity for relationship building and a way to get to know the unique attributes and preferences of their infant. Skin-to-skin was described by parents as a way to protect, nurture, and comfort their infants. Participant 4 describes:

> But yeah, I don't really think it comes down to a cultural thing it's just more being a parent … you do what you have to do to look after them, protect them. Yeah, parenting because I don't think any parent would just come in and cuddle with anybody's baby.

Theme 3. Words matter

Communication styles used by staff had a significant impact on the parent's comfort and confidence when doing skin-to-skin with their infants. Individual staff members appeared to have more impact on the parents' experiences of skin-to-skin than the experience of being in a particular neonatal unit.

Reassurance and encouragement

Parents described how much they valued reassurance and encouragement from staff, which played a pivotal role in the process of moving parents from fear to confidence during skin-to-skin and was even more critical after a negative experience of skin-to-skin. As Participant 8 shared, words had the ability to provide comfort, even when their infants were not progressing:

> And you know even though, like your baby's not progressing and stuff like that they make it into a positive thing … Again, never make you feel like, sad like you just know that their words are comforting and stuff … that's how I feel when they tell us information.

When having an infant on the NICU, what came across is the vulnerable position parents are in and how much they rely on their medical team for support. Participants therefore shared how vital a trusting relationship was with their medical team and when reassuring and encouraging language was used, this helped to build trust.

Don't do that

In contrast to the first subtheme, when parents experienced a more direct and judgemental communication style, they shared not feeling comfortable requesting support, which then impacted on their ability to do skin-to-skin with their infants, as Participant 6 relayed:

> I go off energy so if the energy doesn't feel right, I feel uncomfortable even doing anything to baby. I think there are sometimes where there are nurses that were kind of demanding, where they like do not do this. This will make him de-sat or what not.

Theme 4. Actively managing racial bias

Differences in care

Several parents expressed experiences of being treated differently to other families while on the NICU or witnessing lower levels of support to other Māori or Pasifika families. Parents attributed these differences in care by some nurses to racial bias, whether intentional or not. Participant 10 explains this was a familiar experience as a Pasifika woman:

> I know from experience and just growing up as a Tongan in the [New Zealand] community that there definitely are stereotypes of how people talk and communicate. You get treated like that [dismissively] whether people realise they are doing it or not.

Specific examples where differences in care were experienced were relayed by parents, including inconsistent visitation guidelines. For example, Participant 5 shared her experience where they received different instructions:

> Oh, they're allowed. Just to see that [proactive support from nurses for some (white) families regarding having extended family visit on the unit] and then you suddenly just get rejected [in your request to have family visit]. It makes you question, is this racial?

Differences in care the parents described included culturally insensitive care (e.g., making inappropriate jokes about their infants), and an experience of being unsupported when they had culturally related needs or observed these in other parents (such as language barriers). Participant 11 described an example that highlighted the importance of having a cultural understanding of how a Pasifika person might respond agreeably when unsure and in need of support: "Yeah, language, and how to communicate with them because they may say yes, yes, yes, but really, they do not know, or they do not feel worthy to ask for help because they are uncomfortable to open up."

Being an advocate for your baby

Parents described the impact of racially biased care from nurses on their experience of skin-to-skin with their infant. Parents described feeling less comfortable asking for help and some mothers shared examples where they had to strongly advocate to be involved in their infant's care in the absence of support from nurses. Parents varied in taking a subtle or more assertive approach to actively ensuring their needs and those of their infant were met. Participant 10 shared her experience where she had to actively advocate for an additional chair to be able to have skin-to-skin as a family with their twins. Her husband, who is Palagi, had commented to her at the time that she was being treated differently compared to himself. She described the use of an assertive approach as a lifelong strategy she had learned for responding to racial bias in all spheres of life but recognised that it was needed while on the NICU to optimise the care she received, including facilitating skin-to-skin:

> There are little babies that you are having to help right now. If you're not confident for them then who will be? Until they have their own voices you have to be that person. Especially as a brown person because I feel there are [sic] always going to be unconscious bias. (Participant 10)

Culturally supportive care

This subtheme reflects contrasting experiences of care that were supportive of their culture, in which parents felt respected and encouraged to engage in skin-to-skin. Culturally supportive care included support to pray, the importance of including and accommodating the wider family system, and being able to express their values and beliefs at their infant's bedside. Being able to express their culture within the NICU was referred to as "necessary for survival" when navigating the NICU journey, as Participant 5 shared:

> You have to understand; people have to survive there so you have to make sure that their values are incorporated otherwise that family system will not survive. It will be hard for people to cope if the health system starts changing the family's ways.

Theme 5: Spirituality and religious beliefs facilitate resilience

Pillar of strength

This subtheme describes the firm foundation faith provided the parents in the unpredictable NICU environment. Parents' spirituality and religious beliefs, both Christian and Muslim, ultimately assisted families to overcome their anxieties and provided hope to manage a journey where their infant's health was fluctuating and encouraged parents to persist with skin-to-skin. Parents also shared how they relied on their faith particularly when things weren't going well: "Um, you know, sometimes she side-tracks, and we're just like come on baby like [sic], we just pray upon her and just, yeah, just keep her going" (Participant 8). Two key components of parental spiritual beliefs were their personal relationship with God/Allah, as well as a community of faith in which family and friends were also praying for their infant. While experiencing the turbulence of the emotional rollercoaster, their faith and spirituality provided peace and assurance amid the turbulence.

Spiritual connection

Parents would engage in prayer while having skin-to-skin with their infant. They described how this deepened their connection with their infant: "For me when I was doing skin-to-skin, I was totally connected with him. I would pray. Those are the things that was particularly very important for me" (Participant 5).

DISCUSSION

This study explored Pasifika parents lived experience of skin-to-skin with their preterm infant while receiving care in a New Zealand-based neonatal unit. Parents reported they "overcame fear and anxiety" to implement skin-to-skin. While not unique to Pasifika people (Forcada-Guex et al., 2011; Galea et al., 2021; Hall et al., 2016; Provenzi et al., 2016), the experiences of fear and anxiety for these Pasifika parents were compounded by needs related to their language and cultural beliefs and practices that often went unmet by staff. Collectively, these experiences amplified parents' experience of a loss of choice and control over the care and connection with their infants. Despite longing to touch their infant (including implementing skin-to-skin), a fear of harming their infant and being reprimanded by staff inhibited parents from doing so.

Like most parents of infants in NICU, Pasifika parents needed support to initiate skin-to-skin, and to reconcile their expectations as new parents, with the lived experience of having a preterm infant in the NICU (Maastrup et al., 2018; Vazquez & Cong, 2014). Skin-to-skin offers an important opportunity for this reconciliation process, enabling touch and connection to occur in a way that was experienced as safe for both parent and infant. Once initiated, skin-to-skin facilitated "connection" and relationship building with their infant and increased confidence in their parenting role within the NICU context. Parents' references to connection included bonding and attachment. Some described how engaging in skin-to-skin helped them to move from a place of disconnection with their infant to one of connection, consistent with previous research (Gooding et al., 2011).

Culture greatly affects how stressful or traumatic events (such as NICU admission) are perceived and managed (McCubbin et al., 1998); therefore, culturally safe care (Adcock et al., 2023) that upholds parents' mental wellbeing in the NICU setting is a critical element of optimising parent and infant outcomes. A multilayered approach to culturally safe care has been suggested with specific interventions focused on supporting both maternal and paternal mental wellbeing (Treyvaud et al., 2019). The Fonofale model is a Pacific model of health developed by Fuimaono Karl Pulotu-Endemann in 1984 (Pulotu-Endemann, 2001), where Samoans, Cook Islanders, Tongans, Niueans, Tokelauns, and Fijians were able to share their values and beliefs as part of workshops held. Although not a part of the data analysis process, the Fonofale model provided a powerful illustration of how skin-to-skin contact synergised many components of health for infants and parents, as described by parents in this study, to create a cascade of positive health effects. In this model the concept of family is foundational and represented by the floor. Culture is depicted as the roof that provides shelter or protection. The four pou or poles represent spirituality (traditional or any other religion), physical (biological wellbeing), mental (emotions, thoughts, feelings), and other (personal factors such as age, sex, sexual orientation). These pou connect and support the relationship between culture and community, including a continuous interaction with one another (Pulotu-Endemann, 2001). Pasifika parents articulated perceptions that skin-to-skin enriched infant's physical pou by improving their breathing and sleep; infant and parent mental pou through the calming effect of skin-to-skin; and infant and parent spiritual pou through the opportunity for spiritual connection during skin-to-skin.

Skin-to-skin created an experience of being together as a family unit as parents stepped into the role of parenting. Given family is the foundation of the Fonofale model, skin-to-skin became a substantial vehicle for shaping early family relationships and the foundations of health for the infant and family. Distinctively, Pasifika parents shared how their spirituality and religious beliefs facilitated their initiation of skin-to-skin by replacing thoughts of fear with thoughts of hope and trust in a higher being. Without practical support from staff, or a sense that to pray with their infant was acceptable, some parents felt uncomfortable attempting skin-to-skin. In these instances, parents and infants missed opportunities for higher dose skin-to-skin, but also missed the opportunities for deeper spiritual connection with their infant.

The first stage of skin-to-skin for many parents is characterised by overcoming conflicting emotions through professional support and experience (Maastrup et al., 2018). As reported by Pasifika parents in this study, initiation and sustained uptake of skin-to-skin was significantly influenced by nurses, as facilitators of the process (Vazquez & Cong, 2014). Conversely, the absence of nurse support, when this occurred, was also keenly felt. The Pasifika cultural concept of Vā, a positive relational climate (Anae, 2016; Ioane & Tudor, 2017), explains the impact of nurses' words and actions during parent attempts at skin-to-skin, and provides direction in improving the support provided to improve implementation of skin-to-skin among Pasifika families. Vā has been described as a space that can be fruitful or, conversely, dangerous and unsafe if not well supported (Ioane & Tudor, 2017). Parents experienced a wide range of communication styles from clinicians, varying from warm and encouraging to critical and judgemental. While trust and supportive relationships are fundamental to family-centred care (Gooding et al., 2011), maintaining the Vā was particularly significant for Pasifika parents who, culturally, view individual identity (such as their identity as a parent) through the relationships with others (Anae, 2016). Parents in this study experienced both extremes of Vā, which directly impacted on their participation in skin-to-skin. Although other studies report nurses' intention to provide the best care to infants and families, staff shortages and sustained high workloads may have impact on the quality of their care, including their communication with parents (Malatest International, 2019). Authentic relational communication by health professionals is difficult to imagine in a setting operating at or near crisis levels for sustained periods. In order to facilitate a culturally safe and clinically positive relational space (Vā), nursing burnout and compassion fatigue may need to be explored and addressed (Tabakakis, 2019).

Given Pasifika culture has hierarchical relational structures that affect engagement with health professionals (Medical Council of New Zealand, 2010), ways of involving Pasifika parents in decision making within the NICU may need to be tailored for Pasifika parents. A communication framework for NICU proposed by Wreesmann et al. (2021) may provide a starting point for culturally safe communication training and service development that will support the uptake of skin-to-skin. This framework proposes structured regular updates to parents about their infant's medical status as a strategy to decrease parental anxiety and improve their relationship with medical staff (Vazquez & Cong, 2014). Similarly, support from nurses that was instrumental in the uptake of skin-to-skin described by the parents in this study included the provision of clear information, being shown the skin-to-skin process step by step, and gradually transitioning from hands-on modelling from nurses to verbal coaching and encouragement. Although nurses spend more time at the bedside, with neonatal physiotherapy often only present on a part-time basis, the communication approach and information provided needs to be consistent. Any communication training would therefore have to include the wider interdisciplinary team. A co-design pilot of structured strategies to enhance bilateral communication with Pasifika parent partners could clarify if these kinds of communication structures enhance the uptake of skin-to-skin for Pasifika parents.

Findings indicate that racially differential care is a barrier to skin-to-skin and a priority for service improvement to achieve more equitable outcomes for Pasifika preterm infants. Self-reported experiences of racism, including by health professionals, are higher for Māori and Pasifika peoples compared to other ethnicities, suggesting this phenomenon is not limited to NICU settings or this study (Health and Disability System Review, 2020). The differences in care expressed by participants in this study may have impacted Pasifika parents' help seeking on the NICU, such as requesting support to initiate regular skin-to-skin. Pasifika people accessing NICU services in New Zealand experience a "summative disadvantage" (Graham et al., 2022), of negative social determinants of health and inequitable or absent culturally safe care despite cultural safety training having been embedded into nursing curricula for decades (DeSouza, 2008; Jones et al., 2020). Investment into mitigating social determinants that result in Pasifika infants needing NICU care as well as those that impact on Pasifika parents' ability to be present on the NICU, and therefore have skin-to-skin with their infants, should be part of any solution for improving outcomes for Pasifika families.

To address the health inequalities and poor health outcomes experienced by Pasifika peoples, a culturally safe and competent health service in which cultural practices, concepts, and diverse world views are integrated into high-quality, evidence-informed health services is essential (Betancourt et al., 2003; Ministry of Health, 2020). Pacific health models like the Fonofale model may be helpful in informing such health services that enable Pasifika parents to fully experience all the benefits of skin-to-skin with their infants.

Strengths and limitations

Confidence to participate in interviews in English rather than participants' first languages excluded parents whose experience is impacted by language barriers with nursing staff. Inclusion of non-English-speaking Pasifika parents in the study may have provided greater nuance in the knowledge gained about traditional cultural practices, as families may be more deeply embedded in Pasifika cultural beliefs and practices than those born and raised in New Zealand. Further investigations would require culturally safe and sensitive practices acknowledging that Pasifika parents are more likely to have had a heightened experience of fear and anxiety. Research of Pasifika communities should involve Pasifika researchers in the first instance and, where possible, in the research process (Health Research Council of New Zealand, 2014). Future research done by Pasifika researchers including ethnic-specific research within the Pacific populations may add depth and clarity to the experiences of Pasifika parents of NICU. Recruitment predominantly relied on in-person contact so parents who could not be present on the NICU for various reasons are not represented in this study, thereby not fully capturing Pasifika parents who may be more exposed to important social circumstances that contribute to health disadvantages. Future studies that specifically aim to recruit parents who have difficulty attending NICU are an important next step in understanding and addressing the uptake of skin-to-skin with Pasifika families.

In relation to the strengths of this study, the qualitative design provided rich description and insights into the experiences of attempting skin-to-skin on NICU settings in New Zealand. The rich descriptions achieved relied heavily on the valuable contributions from the cultural advisors who participated in this research throughout all phases. Their guidance informed the ways interviews occurred, including, for example, taking time to connect and provide a safe relational space before starting the interviews and data analysis informed by Pasifika perspectives, although led by a Palagi researcher. Strong links with Pasifika NICU staff enabled recruitment of the planned sample size and the documentation of a diverse range of experiences including parents who had experienced different infant birth and health journeys. Four fathers participated in interviews, both individually and in interviews of couples, providing rare insights into the experiences of Pasifika fathers. A future study focusing centrally on the needs and experiences of Pasifika fathers is warranted.

CONCLUSION

Pasifika families highly valued skin-to-skin with their preterm infants and, from a Pasifika perspective, it was found to synergise many cultural components of health, as represented in the Fonofale model. As such, skin-to-skin was a catalyst for a cascade of positive health effects for Pasifika infants and parents and when spirituality and religious beliefs were supported by medical staff, this further enhanced their implementation of skin-to-skin. Vā, the Pasifika concept of the relational space, illuminates the relationship between experiencing cultural safety, clinician communication, and the uptake of skin-to-skin.

KEY POINTS

1. Pasifika parents valued skin-to-skin with their preterm infants and described its impacts on all components of the Fonofale model, thus facilitating a cascade of health benefits.
2. Spirituality and religious beliefs enabled Pasifika parents to overcome their fear and anxiety and experience spiritual connection with their infants during skin-to-skin when this was supported by the nursing staff.
3. Vā (relational space) impacted on parents' comfort and ability to undertake skin-to-skin, thereby highlighting the importance of cultural safety training for health professionals and their use of empowering communication styles.
4. The Fonofale model is a helpful guide to developing culturally safe NICU environments that enhance early engagement of Pasifika parents in skin-to-skin and other infant interactions.

DISCLOSURES

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PERMISSIONS

This research was approved by the University of Otago Ethics Committee (H20/069).

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CONTRIBUTIONS OF AUTHORS

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Inpatient Stroke Rehabilitation Activity: Barriers, Enablers, and Changes in Activity Behaviour with Diary Use

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ABSTRACT

The Australian Stroke Foundation guidelines recommend participation in at least 3 hours of physical and occupational therapy daily during stroke rehabilitation. The majority of services in Australia do not currently meet this guideline. This study explored the usefulness of activity diary implementation in increasing activity during inpatient stroke rehabilitation and identified barriers and enablers to activity level guideline adherence, as perceived by clinicians. Using a mixed-methods, longitudinal embedded-design study, two participant cohorts were recruited: people undergoing inpatient stroke rehabilitation and stroke rehabilitation clinicians. Behaviour mapping pre- and post-implementation of activity diaries measured inpatient activity levels. Clinician surveys assessed enablers and barriers to inpatient activity level guideline adherence, both pre- and post-implementation. Twelve adults undergoing inpatient stroke rehabilitation were included. Trends toward reduced time spent sedentary ($d = -0.797$, 95% confidence interval (CI) [–1.811, 0.217]), increased independent ADL practice ($d = 0.861$, 95% CI [–0.159, 1.88]), and lower limb active practice were noted after diary implementation ($d = 0.778$, 95% CI [–0.234, 1.791]). Sixteen clinicians completed 14 pre-diary implementation and nine post-implementation surveys. The main themes identified as clinician-perceived barriers to activity level guideline adherence included de-prioritisation of activity, staff shortages, caseload demands, lack of family and patient-friendly resources, and stroke-related factors. The facilitators included activity diaries, behaviour change, and multidisciplinary communication. Active time among people undergoing inpatient stroke rehabilitation increased after implementation of the diaries. Despite the identified institutional barriers to inpatient activity engagement, activity diaries may assist in promoting an increase in activity among people undergoing inpatient stroke rehabilitation.

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Key Words: Barriers and Enablers, Behaviour Mapping, Clinical Practice Guidelines, Implementation, Stroke Rehabilitation

INTRODUCTION

The Stroke Foundation provides evidence-based, living stroke rehabilitation guidelines for Australia and New Zealand (Stroke Foundation, 2024). The guidelines recommend that people undergoing inpatient stroke rehabilitation participate in at least three hours of scheduled physical and occupational therapy daily, with at least two of these hours being active task-practice (Stroke Foundation, 2024). Continued active task-practice outside of scheduled therapy sessions is also recommended (Stroke Foundation, 2024).

The 2020 Stroke Foundation rehabilitation services audit showed that only 25% of the 111 participating Australian rehabilitation services met the guideline for therapy intensity (Stroke Foundation, 2020). The audit report outlined barriers to engagement in physical activity among people in inpatient stroke rehabilitation, including patient factors such as dependence, capacity to engage, and comorbidities, and staff limitations such as time, skill, and experience (Stroke Foundation, 2020).

Higher activity levels during rehabilitation are associated with greater functional improvement (Foley et al., 2012; Stroke Foundation, 2020). Repetition of functional activities and task-specific practice can facilitate recovery of movement, activity of daily living (ADL) function, language, cognition, and perception (Saunders et al., 2021; Stroke Foundation, 2024). Despite evidence supporting a high volume of task-practice, and widespread knowledge of stroke guidelines among clinicians, activity-level recommendations are not consistently met in clinical practice (Barrett et al., 2018; Foley et al., 2012; McLaren et al., 2020). Barrett et al. (2018) reported that most people in stroke rehabilitation were sedentary during their awake hours (12.75 hr, 85.6% sedentary), with greater sedentary behaviour on weekends (13.5 hr, 89.8% sedentary), highlighting the need for strategies to increase engagement in physical activity outside of formal rehabilitation hours. Bernhardt et al. (2007) reported that people undergoing inpatient stroke rehabilitation were more likely to engage in activity during interactions with visitors. The COVID-19 social distancing protocols and inpatient visiting hour changes during the lockdown periods in Australia and New Zealand likely compounded barriers to engagement in activity due to staffing shortages related to self-isolation requirements, reduced engagement with visitors, cancellation of group therapies, and restrictions on use of inpatient common areas such as dining rooms, meaning inpatients spent more time alone (Angus et al., 2023; Australian Government, 2020; New Zealand Government, 2023). These limitations enhanced the need for promotion of self-directed activity for people undergoing stroke rehabilitation (Vadas et al., 2021).

Prior studies have identified barriers such as lack of time to implement change, highlighting additional challenges of staff shortages, staff turnover, and high workloads (Alsop et al., 2023; Lynch et al., 2017). The integration of non-therapy team members into rehabilitation, self-directed therapy guides, group therapy sessions, and therapist availability across a seven-day period have been demonstrated to increase the amount of activity performed by people in stroke rehabilitation (Gittins et al., 2020; Lynch et al., 2017; White et al., 2014; Wong et al., 2022). Alsop et al. (2023) conducted a systematic review and thematic synthesis, which highlighted a lack of prioritisation of physical activity in inpatient settings including rehabilitation. A shift in culture, in which physical activity promotion is an interdisciplinary responsibility, was recommended (Alsop et al., 2023). Therefore, implementation strategies that are tailored to health-care professional groups and guided by theory-informed interventions to improve adherence to clinical guidelines are needed (Wong et al., 2022). Understanding barriers and enablers to stroke guideline adherence, specific to the context of the service, can inform targeted implementation strategies to increase the success of delivery of evidence-based practice.

This project aimed to:

1. Map all task-related activity performed by people undergoing inpatient stroke rehabilitation pre- and post-implementation using activity diaries, and on-site “activity champions” at the Osborne Park Hospital (OPH) stroke rehabilitation unit (SRU) in Western Australia.
2. Explore barriers and enablers to activity diary implementation and activity level guideline adherence, perceived by SRU clinicians.

METHODS

Design

Reporting of this mixed-methods, longitudinal embedded design study conformed to the STROBE statement (von Elm et al., 2008). Behaviour mapping was conducted pre- and post-diary implementation to evaluate inpatient observable time spent in active practice. A clinician survey evaluated pre- and post-implementation perceived enablers and barriers to diary implementation and activity level guideline adherence.

Setting

The study was conducted over one month in February 2023 at the OPH SRU. The SRU has 13 dedicated stroke rehabilitation beds with approximately 150 admissions annually.

Ethical considerations

The project was approved by Osborne Park Hospital (QI44008) and by the University of Notre Dame Australia Human Research Ethics Committee (2022-162F). All participants provided informed consent.

Participants

Two participant cohorts were recruited to address the two study aims. Cohort 1 included people admitted for stroke rehabilitation on the SRU. An a priori power calculation (based on Janssen et al., 2014) determined a minimum sample of n = 12 to detect a change in activity from baseline to post-implementation.

The inclusion criteria for Cohort 1 were aged ≥18 years; able to provide informed consent or available appropriate proxy to provide consent; had a diagnosis of stroke and admitted for rehabilitation; and expected to remain on the SRU for at least two weeks from study enrolment. People involved in episodes of care outside of rehabilitation (acute or palliative) were excluded.

Cohort 2 included clinicians who worked on the OPH SRU during the study period and who could influence the structure of rehabilitation (physiotherapists, occupational therapists, speech pathologists, and clinical nurses).

Outcomes of interest

The outcomes of interest across both cohorts in this study were:

- time spent engaged in physical activities
- barriers and enablers to diary use
- barriers and enablers to physical activity on the SRU.

The data collection methods included a pre-implementation clinician survey, post-implementation clinician survey, and a behaviour mapping tool.

Procedures

Stakeholders from the multidisciplinary team including physiotherapy, occupational therapy, speech pathology, and nursing participated in two meetings prior to the commencement of this study. The overarching goal of the project (increasing activity among people undergoing inpatient rehabilitation on the SRU), roles and responsibilities of team members, and activity diary implementation strategies including appointment of an "activity champion" who was responsible for diary implementation, daily reminders at interdisciplinary board rounds, and visual reminders in rooms of inpatients using the diaries, were discussed and agreed upon during these meetings.

The study timeline is presented in Table 1. A lead clinical implementor ("activity champion", SRU physiotherapy clinician) was responsible for the diary implementation process. An aphasia-friendly version of the activity diary was developed by two senior speech pathologists. Standard and aphasia-friendly activity diaries are presented in Appendix A. The lead clinical implementor ("activity champion") was interviewed and discussed the implementation process and their perceived barriers and enablers to intervention implementation of the activity diary to increase post-stroke activity levels.

Table 1

Study Timeline

Week	Activity
1	Cohort 2: Pre-implementation survey distributed
2	
3	Cohort 1: Pre-implementation behaviour mapping
4	Implementation of diary intervention
5	Cohort 1: Post-implementation behaviour mapping
6	Cohort 2: Post-implementation survey distributed
7	

Note. Study commenced in February 2023.

Cohort 1

The design and methodology of the behaviour mapping tool (Appendix B) was based on methodology reported by D'Souza et al. (2022) and planned in conjunction with the SRU team. Behaviour mapping measured participant activity engagement (observation at 10 min intervals) before and one week after implementation. During each observation period (pre- and post-implementation), participants were observed in two separate groups across five days. Participants from each group were observed for two blocks of 3.5 hours on weekdays and one block of four hours on the weekend. Participant activity was observed by GM, a physiotherapy honours student, and recorded at a single time-point every 10 min across each block. Table 2 presents activity variables that were recorded.

Cohort 2

Surveys were created using the Qualtrics programme, based on a previously validated survey (Harmsen et al., 2005) that explored clinician-perceived barriers and enablers to health service improvement. The survey used in the present study is presented in Appendix C. Two people with experience of providing stroke rehabilitation on the OPH SRU collaborated in survey development. Eligible clinician participants were invited to complete the surveys via email pre- and post-implementation. Two reminders, in addition to the initial invitation, were sent via email to eligible clinicians to enhance participation.

Table 2

Participant Demographics

Cohort 1	*n*	%
Participants	12	
Age (years), *Mdn* (range)	75 (39–90)	
Sex		
Male	7	58.0
Female	5	42.0
Oxford stroke classification		
Lacunar stroke	2	16.6
Posterior circulation stroke	2	16.6
Partial anterior circulation stroke	6	50.0
Total anterior circulation stroke	2	16.6
Side of stroke		
Right	8	66.7
Left	4	33.3
Cohort 2		
Participants	16	
Allied health	13	81.3
Clinical/coordinating nurse	3	18.7
Age (years)		
25–35	9	56.0
35–45	2	12.5
> 45	5	31.3
Sex		
Male	1	6.3
Female	15	93.7
Experience in stroke rehabilitation (years)	3	19.0
< 1	5	31.0
1–5	3	19.0
5–10	5	31.0
> 10		
Experience on OPH SRU (years)		
< 1	7	44.0
1–5	3	19.0
5–10	4	25.0
> 10	2	12.0

Note. OPH SRU = Osborne Park Hospital stroke rehabilitation unit.

Data analysis

Cohort 1

Behaviour mapping data were organised using Microsoft Excel with the outcome variables calculated pre- and post-implementation. Active observations were calculated as the observed occasions spent performing activity relative to total number of observations. Data were imported into IBM SPSS v29 for analysis with mean and interquartile ranges of each variable from all participants and pre- and post-implementation calculated. Normality was assessed using the Shapiro Wilk test. Pre-post differences were assessed with Paired sample *t*-test and the non-parametric Wilcoxon signed-rank test, with the standardised test statistic and 2-sided *p*-value reported. Effect sizes were reported as Cohen's d point estimates with lower and upper confidence levels.

Cohort 2

Qualitative thematic analysis (Braun & Clarke, 2006) was conducted by one author (GM) and ratified through discussion with two co-authors (JN and PC). Themes and subthemes were identified based on survey data. Further analysis compared qualitative data from a sub-cohort of participants who completed both surveys (*n* = 7) to explore change in knowledge and perceptions about meeting activity guidelines pre- versus post-implementation of diaries. Analysis was conducted manually using tables, after responses were exported from Qualtrics to Microsoft Excel. Pre- and post-implementation data were analysed separately prior to comparison. Themes were separated by pre- and post-implementation responses. Subthemes were identified where main themes did not capture the full scope of information from responses.

RESULTS

Participant characteristics

Cohort 1

At study commencement, 12 of the 14 people undergoing rehabilitation in the SRU were eligible for study inclusion and provided informed consent to participate. Behaviour mapping observational data during the pre-implementation period were recorded for these 12 participants. Behaviour mapping during the post-implementation period was completed for six participants; four patients were discharged. Flow of participants in Cohort 1 is displayed in Figure 1. Demographic data are presented in Table 2.

Cohort 2

Demographic data of Cohort 2 are presented in Table 2. Seventeen SRU clinicians met the inclusion criteria and a total of 16 clinicians returned at least one complete survey (Figure 2).

Behaviour mapping data - Cohort 1

Participant observation occurred across 22 hr in total, pre- and post-implementation. Behaviour mapping data are presented in Table 3. Post-implementation, participants were observed to be active in a greater proportion of observed occasions. Participants performed more independent practice and spent significantly less time lying in bed. Nursing team members were observed with participants on fewer occasions post-implementation ($p < 0.001$). Trends toward reduced time spent sedentary ($d = -0.797$, 95% CI [-1.811, 0.217]), increased independent ADL practice ($d = 0.861$, 95% CI [-0.159, 1.88]), and lower limb active practice were noted post-implementation ($d = 0.778$, 95% CI [-0.234, 1.791]).

Survey data - Cohort 2

Barriers and enablers to activity, diary use, and implementation

Following thematic analysis of the pre- and post-implementation survey data, five main themes were identified. These related to SRU clinician-perceived barriers and enablers to the implementation of activity diaries and adherence to activity level stroke rehabilitation guidelines:

1. Activity diaries improved participant engagement.
2. Competing priorities and resource demands.
3. Implementation process requires more consultation.
4. Participant/stroke-related barriers to activity.
5. Clinician knowledge and engagement.

Theme 1: Activity diaries improved participant engagement

Most participants perceived that activity diaries increased activity engagement among people undergoing stroke rehabilitation. Greater family involvement in rehabilitation was also noted to be related to diary implementation. Almost all participants reported that activity diaries improved activity engagement. Clinicians reported that the diaries served as a prompt for them to guide and develop therapy programmes that could be performed with visitors. One clinician noted that it "… made me think of other ways in which I could include a patients' family to enable more opportunities for rehabilitation" (allied health professional [AH]7).

Figure 1

Flow of Participants (Cohort 1)

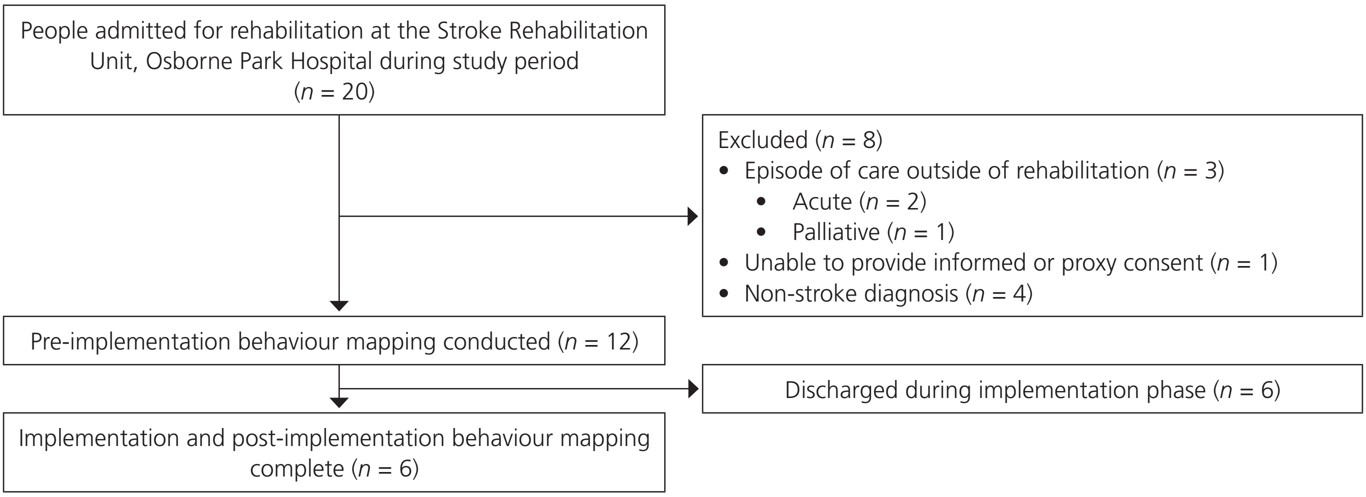
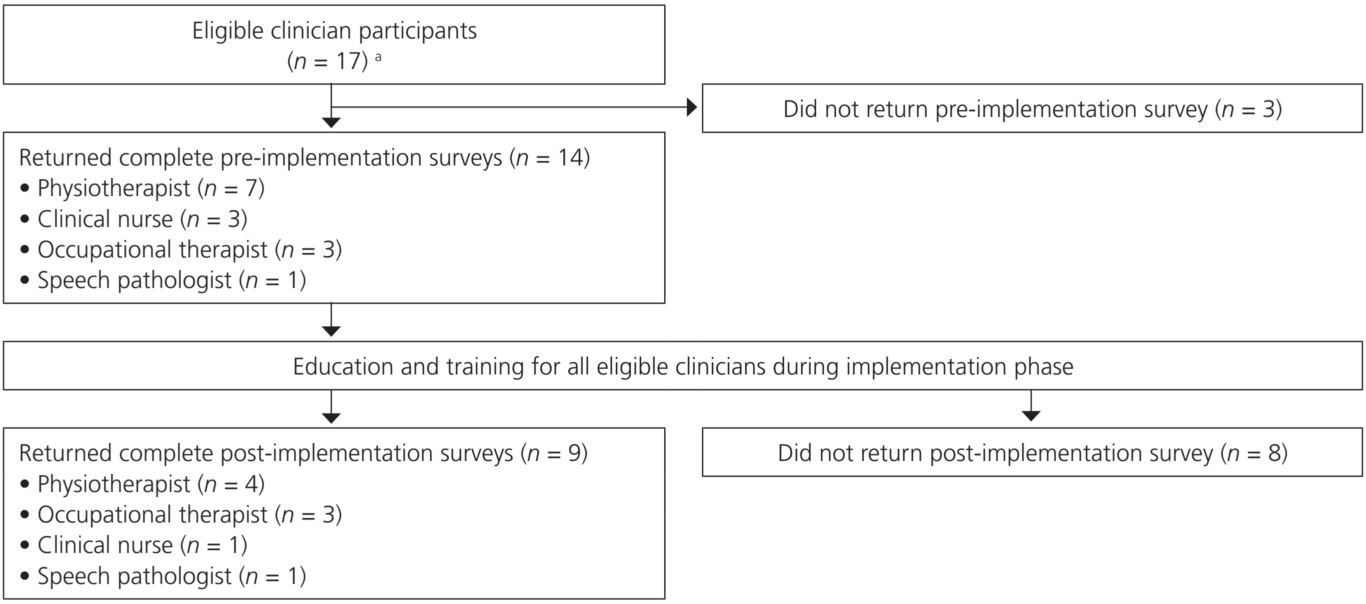


Figure 2

Flow of Participants (Cohort 2)



[a] Seven participants completed both pre- and post-implementation surveys. Seven participants completed the pre-implementation survey only and two completed the post-implementation survey only. A total of 16 participants returned at least one complete survey.

The majority of clinicians perceived that the diaries prompted people in stroke rehabilitation to engage in activity outside of scheduled therapy. Most clinician participants found the diary layout useful. A commonly reported benefit was the role of the diaries as a shared document between disciplines, enhancing interdisciplinary teamwork.

Theme 2: Competing priorities and resource demands

Competing priorities between activity and other demands was noted among clinicians. Clinician caseload demands, prioritisation of medical appointments, and discharge planning were identified as barriers to activity levels. As described by two participants: “Discharge planning taking priority over implementing independent practice” (AH5) and “Varying caseload demands within time available” (AH3).

Almost all clinician participants perceived team-related factors as facilitators of independent practice. The majority of participants perceived that clear, meaningful goals and team communication would foster increased activity engagement by people in stroke rehabilitation. A small number of allied health participants suggested increased education of patients and family would increase patient/carer responsibility for independent rehabilitation, thereby reducing caseload and time burdens of the SRU team.

Insufficient staffing was consistently identified as a barrier to activity level guideline adherence, while half of allied health participants perceived communication and involvement of the whole multidisciplinary team as an enabler to activity level guideline adherence.

Pre-implementation, some SRU clinicians suggested the introduction of resources to educate and enable independent practice, such as re-introduction of group training (group sessions had been ceased with COVID-19 restrictions), more frequent therapy sessions, volunteer engagement, and after-hours nursing team to facilitate independent practice. Post-implementation, some SRU team clinicians reported that the diaries created additional time burdens due to the recording and development of individualised, independent programmes.

Theme 3: Implementation process required more consultation

Almost all clinicians reported the implementation process required improvement, to promote sustained use. Participants reported that greater consultation with people with stroke and their families, and the whole multidisciplinary team would improve the process. A quarter of participants suggested that the diaries should be provided on arrival to the SRU in family meetings and supported by an instruction video on its use. A small number of allied health participants stated that the completion of the diaries relied too heavily on therapists.

Theme 4: Participant / stroke-related barriers

In the pre- and post-implementation surveys, clinicians reported a number of stroke-related factors as barriers to activity. The most frequently identified stroke-related barriers were stroke survivors’ cognitive function and memory. Approximately half of the clinician participants reported that the diary was less helpful for people who had cognitive impairments, meaning they were unable to use the diary or undertake practice independently. For example, “Patients often are not able to practise unsupervised or even without physical support” (AH8).

Most participants reflected that family engagement and support facilitated increased engagement in activity.

Theme 5: Clinician knowledge and engagement

Half of clinicians incorrectly answered the survey question

Table 3

Behaviour Mapping Data (Percentage of Observed Occasions)

	Variable	Pre-implementation (*n* = 12)		Post-implementation (*n* = 6)		Effect size		Between-group differences [a]	
		M	*SD*	*M*	*SD*	*d*	95% CI	Test statistic	*p*
Location	Amenities	4.3	2.1	4.4	1.8	0.063	[–0.917, 1.043]	–0.409	0.699
	Bedroom	70.4	25.3	80.6	13.4	0.455	[–0.536, 1.446]	0.493	0.643
	Corridor	1.7	2.1	3.0	3.1	0.541	[–0.455, 1.537]	–1.837	0.126
	Therapy room	5.2	5.2	5.6	6.1	0.074	[–0.907, 1.054]	0.413	0.697
	Dining room	8.8	19.7	0	0	–0.539	[–1.534, 0.457]		
	Off ward (medical)	2.4	3.2	1.8	3.1	–0.184	[–1.165, 0.798]	0.027	0.980
	Outside	4.9	5.3	3.5	5.3	–0.266	[–1.25, 0.718]	0.123	0.907
	Other	2.3	4.7	1.2	2.9	–0.270	[–1.254, 0.714]	–0.255	0.809
Practice	Active practice	14.4	9.8	19.3	8.7	0.521	[–0.474, 1.515]	–2.748	0.040*
	Sedentary	81.1	12.1	68.4	22.2	–0.797**	[–1.811, 0.217]	1.924	0.112
Personnel present	Physiotherapist	7.2	5.5	6.1	6.1	-0.197	[–1.179, 0.785]	1.383	0.225
	Occupational therapist	6.1	5.8	3.5	5.1	–0.455	[–1.446, 0.536]	0.473	0.656
	Speech pathologist	2.6	4.7	1.8	2.2	–0.211	[–1.194, 0.771]	0.567	0.595
	Nurse	10.5	7.8	4.5	6.5	–0.794**	[–1.808, 0.22]	7.500	< 0.001*
	Medical doctor	1.5	1.7	1.0	1.2	-0.295	[–1.28, 0.689]	0.562	0.598
	Physiotherapy student	4.8	6.4	6.9	9.8	0.273	[–0.711, 1.257]	0.260	0.805
	Occupational therapy assistant	1.2	2.1	1.0	1.8	–0.072	[–1.052, 0.909]	0.668	0.533
	Visitor	37.2	27.1	23.4	29.0	–0.500	[–1.494, 0.493]	1.027	0.352
	Another patient	2.4	3.5	2.3	5.6	–0.046	[–1.026, 0.934]	0.174	0.869
	Alone	32.8	22.3	45.8	21.6	0.588	[–0.411, 1.586]	–1.258	0.264
	Other	1.0	2.0	2.1	1.9	0.536	[–0.459, 1.532]	–0.335	0.751

Activity	Formal individual	14.8	8.3	14.2	8.9	–0.066	[–1.046, 0.915]	0.321	0.761
	Formal group	1.4	3.4	0	0	–0.512	[–1.507, 0.482]	0	0.180
	Walking	0.9	1.2	0.8	1.3	–0.109	[–1.09, 0.871]	3.000	0.157
	Independent speech	0.1	0.4	0	0	–0.348	[–1.334, 0.639]		
	Independent activities of daily living practice	0.5	1.8	2.3	2.7	0.861**	[–0.159, 1.88]	–2.090	0.091
	Independent cognition/ occupational therapy	1.0	2.8	1.8	3.1	0.249	[–0.734, 1.232]	3.000	0.180
	Independent physical activity	0.5	1.8	1.6	2.4	0.529	[–0.466, 1.524]	2.000	0.655
	Socialisation	25.9	13.3	15.9	14.8	–0.722	[–1.73, 0.286]	0.697	0.517
	Sleeping	9.7	9.7	11.9	11.7	0.209	[–0.774, 1.191]	–0.287	0.785
	Watching television	6.3	8.5	11.4	13.3	0.498	[–0.495, 1.492]	–2.132	0.086
	Reading	7.6	10.7	6.9	11.0	–0.065	[–1.045, 0.915]	11.000	0.917
	Medical/nurse intervention	5.1	7.3	2.8	1.8	–0.386	[–1.374, 0.602]	2.000	0.273
	ADL shower/dressing	4.2	2.8	2.9	2.2	–0.502	[–1.496, 0.492]	0.134	0.899
	Meal	7.4	4.8	7.6	2.8	0.061	[–0.919, 1.041]	10.000	0.916
	Phone (talking)	1.5	2.8	1.3	3.1	–0.087	[–1.067, 0.894]	0	0.317
	Phone (typing/looking)	6.5	9.5	8.3	7.0	0.202	[–0.78, 1.185]	0.084	0.936
	Other	0.1	0.4	0.3	0.6	0.254	[–0.73, 1.237]	1.000	0.317
Active limb	Upper limb	7.4	6.1	7.5	3.4	0.029	[–0.951, 1.009]	–0.877	0.421
	Lower limb	3.9	3.6	8.7	9.5	0.778**	[–0.234, 1.791]	–2.000	0.102
Position	Sitting	60.4	27.1	57.0	22.4	–0.135	[–1.116, 0.846]	–1.607	0.169
	Lying in bed	26.0	26.0	23.8	25.2	–0.086	[–1.066, 0.894]	3.955	0.011*
	Standing	3.4	3.2	2.8	3.2	–0.197	[–1.18, 0.785]	–0.109	0.917
	Other	0.5	1.8	0	0	–0.348	[–1.335, 0.639]	0	0.317
	COVID isolation	0	0	0	0				
	Independent practice [b]	0.5	1.7	1.4	2.1	0.477	[–0.516, 1.469]	–2.646	0.0046*

[a] Between-group differences were computed on paired data only ($n = 6$).
[b] Independent practice = independent speech, cognitive, physical, or activity of daily living practice.

* $p < 0.05$.
** Large effect size (> 0.8).

examining knowledge of current rehabilitation guideline recommendations. The majority of participants who answered incorrectly underestimated the guideline-recommended amount of daily activity for people in stroke rehabilitation.

Post-implementation, participants reported challenges in remembering to use the diary and prescribing activities that could be performed independently. Some SRU team participants reported that they lacked the support and time to facilitate and prompt daily diary use. Half of the allied health participants reported that activity champions and reminders from colleagues aided diary implementation. One clinician reported that "[the diaries] prompted more written instruction. I would always provide things for patients to do but wouldn't always write it down or be as prescriptive" (AH10).

DISCUSSION

This study aimed to evaluate the usefulness of diaries to increase activity of people in stroke rehabilitation and explore staff-perceived barriers and enablers to inpatient engagement in activity. Engagement in activity was greater among people undergoing stroke rehabilitation after implementation of the diaries.

The present study found that people in stroke rehabilitation spent less time lying in bed, post-diary implementation. Previous studies have illustrated increased activity levels when nursing staff facilitated personal care task-practice as rehabilitation activity (Rosbergen et al., 2019; van de Port et al., 2012). Clinician participants identified that with diary implementation, visitors and family facilitated higher levels of independent stroke rehabilitation practice. Existing literature (Alsop et al., 2023) also encouraged implementation of patient and family-friendly resources such as an activity diary. Pre-diary implementation surveys raised the barrier of competing priorities, in line with existing literature (Alsop et al., 2023; Lynch et al., 2017; Stewart et al., 2020). Post-implementation, participants were with nurses on fewer occasions than pre-implementation. We hypothesise that this may reflect that diaries empowered participants to perform tasks independently, although this finding and hypothesis should be interpreted with caution due to low participant numbers and the difference could also be explained by participant functional improvement or variation in work practices among nursing staff. Medical appointments and discharge planning, staff shortages, and caseload demands were identified as barriers to rehabilitation activity engagement in the present study, which is consistent with findings of previous studies (Alsop et al., 2023; Burton et al., 2013; Lynch et al., 2017).

The perception among clinician participants that interdisciplinary team communication and goal setting were promoted by the diaries supports existing implementation theory for behaviour change (Atkins et al., 2017; Cane et al., 2012; French et al., 2012; Jobber et al., 2021; Lynch et al., 2017). It is hypothesised that the staff behaviour change was a facilitator of behaviour change among people undergoing rehabilitation.

Cognitive function and memory among people in stroke rehabilitation were identified by clinician participants as barriers to engagement in activity, similar to findings from previous studies (Preston et al., 2017; Stewart et al., 2020). Clinician participants perceived the diaries were of little use for people in stroke rehabilitation with poor cognitive function and memory, especially those lacking familial support. Further work is needed to explore appropriate strategies to promote activity among people with impaired cognition, which affects more than half of stroke survivors and is associated with reduced independence (El Husseini et al., 2023). Clinician participants noted inability to complete the tasks without supervision among some stroke survivor participants to be a barrier to diary use. Further exploration is needed into whether the diary model was unsuitable for some participants, or whether the tasks set in the diaries were unsuitable for the individual stroke survivors. Further clinician training and experience may promote increased prescription of suitable tasks for individual stroke survivors.

Clinician participants suggested improving diary implementation by providing diaries on admission to the SRU in family meetings and conducting regular diary reviews. This is predicted to facilitate early activity-related goal setting and expectation setting for people undergoing stroke rehabilitation and their families. It is recommended that the implementation process is tailored to the individual rehabilitation setting, considering processes and team culture, in future studies exploring activity diaries in stroke rehabilitation.

A strength of the present study was the mixed-methods approach, which enabled investigation of amount of activity performed before and after diary implementation, as well as factors that facilitated and hindered both participation in activity during stroke rehabilitation and implementation of the activity diaries. Findings may inform future implementation projects.

Limitations and future research

Limitations of this study should be considered, when interpreting findings. The study was conducted at a single site, over a limited time period (conducted as an undergraduate physiotherapy honours project; consequently the project was restricted to the allocated honours timeframe). This meant that data represented a small number of stroke survivor participants. The limited time period for the study meant that data regarding long-term behaviour change were not collected, so sustainability of change related to the diaries remains unknown. Time for clinician familiarisation and for piloting of the diary before implementation were also restricted and the process may have improved with more time to prepare for implementation. Future research with larger cohort sizes over a longer time period, with multi-site implementation, is required to investigate the sustainability and generalisability of the findings to other stroke rehabilitation sites. The activity diaries lacked co-design by people with lived experience of stroke, and people with lived experience of stroke were not included in the stakeholder meetings. Perceptions of stroke survivors using the diaries should also be explored and future iterations of the diary should be co-designed by people with lived experience of stroke and should incorporate feedback from stroke survivors undergoing rehabilitation. The present study also did not investigate the association between functional recovery and engagement in activity among people in stroke rehabilitation, which may have confounded results. It is recommended that future studies control for functional recovery when measuring activity levels pre- and post-intervention.

CONCLUSION

Activity diary implementation was associated with increased engagement in activity and decreased time spent lying in bed among people undergoing inpatient stroke rehabilitation. Implementation of activity diaries for people in stroke rehabilitation may present a potential strategy to improve adherence to activity level guideline recommendations. Clinician interdisciplinary teamwork, appointment of activity champions, and family engagement facilitated stroke survivor participation in activity, while limited clinician time and patient-related factors were identified as barriers to participation in activity. Future studies to determine usefulness of activity diaries in promoting activity among larger cohorts of participants at multiple sites, as well as implementation studies to guide and inform implementation processes are recommended.

KEY POINTS

1. Clinician interdisciplinary teamwork, appointment of activity champions, and family engagement were identified as facilitators of participation in activity during inpatient stroke rehabilitation.
2. Limited clinician time and patient-related factors were identified as barriers to engagement in activity during inpatient stroke rehabilitation.
3. Implementation of activity diaries for people admitted to stroke rehabilitation may present a potential strategy to enhance engagement in inpatient rehabilitation for people with stroke.

DISCLOSURES

There are no conflicts of interest that may be perceived to interfere with or bias this study. No funding was obtained for this study. JN held a Raine Foundation / Department of Health Clinician Research Fellowship (CRF04-R9) during the time in which the study was conducted.

PERMISSIONS

This project was approved by Osborne Park Hospital (QI44008) and by the University of Notre Dame Australia Human Research Ethics Committee (2022-162F).

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CONTRIBUTIONS OF AUTHORS

All authors contributed to conceptualisation and design of the study. Data collection, GM, EG, and JN; data analysis, GM, PC, and JN; interpretation of findings, GM, PC, and JN; writing-original draft preparation, GM; all authors contributed to editing for publication.

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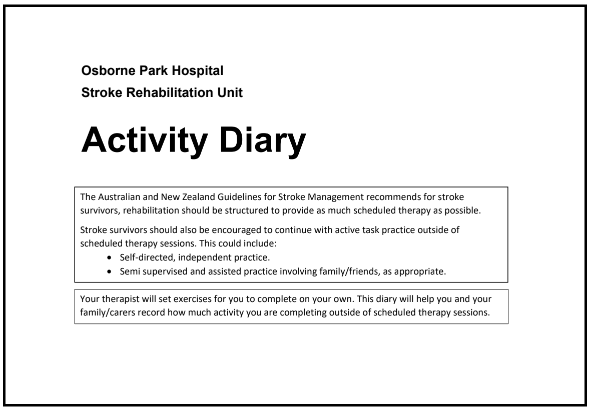
APPENDIX A



Osborne Park Hospital
Stroke Rehabilitation Unit

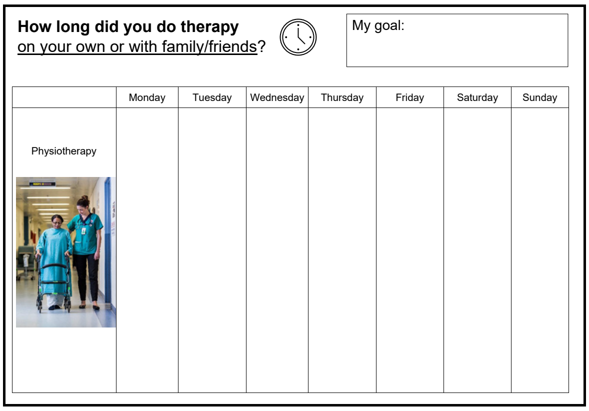
Activity Diary

The Australian and New Zealand Guidelines for Stroke Management recommends for stroke survivors, rehabilitation should be structured to provide as much scheduled therapy as possible.

Stroke survivors should also be encouraged to continue with active task practice outside of scheduled therapy sessions. This could include:

- Self-directed, independent practice.
- Semi supervised and assisted practice involving family/friends, as appropriate.

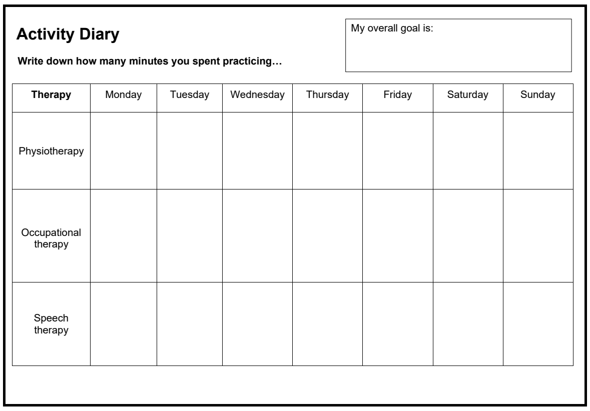
Your therapist will set exercises for you to complete on your own. This diary will help you and your family/carers record how much activity you are completing outside of scheduled therapy sessions.



How long did you do therapy
<u>on your own or with family/friends</u>?

My goal:

	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Physiotherapy							

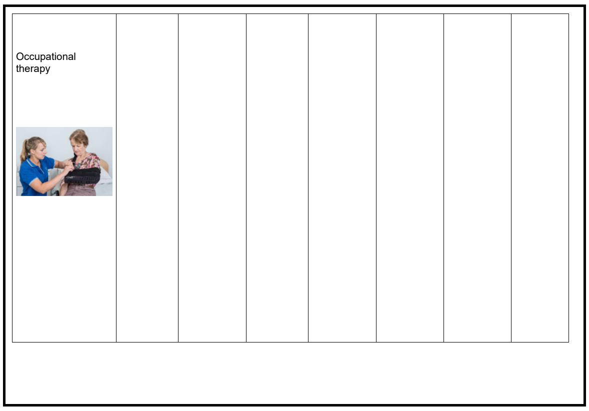


Activity Diary

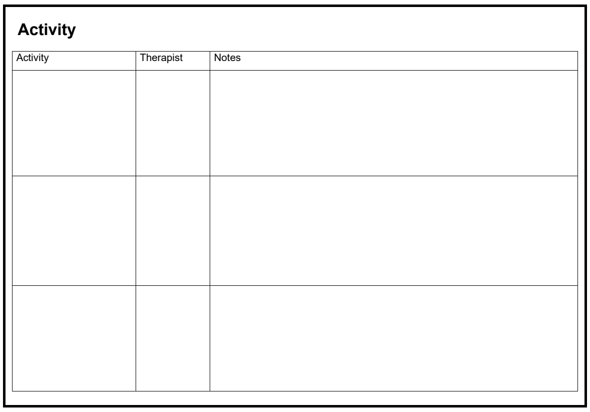
Write down how many minutes you spent practicing…

My overall goal is:

Therapy	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Physiotherapy							
Occupational therapy							
Speech therapy							

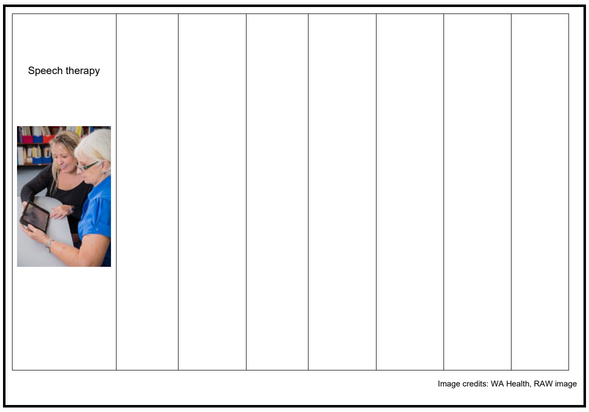


Occupational therapy							



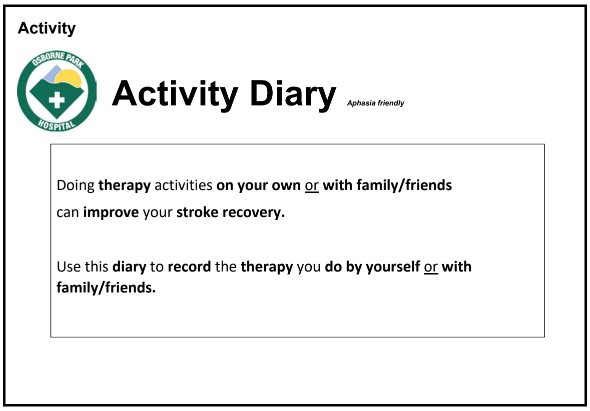
Activity

Activity	Therapist	Notes



Speech therapy							

Image credits: WA Health, RAW image



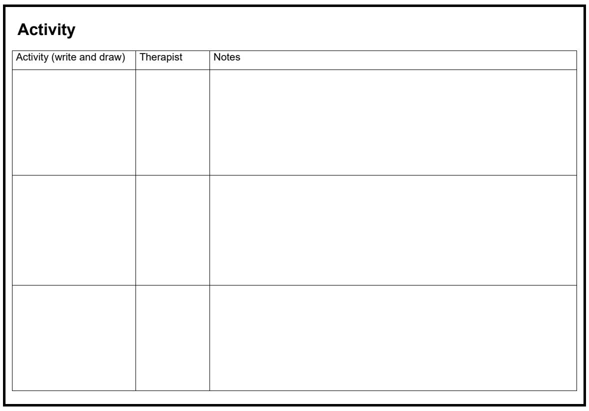
Activity

Activity Diary

Aphasia friendly

Doing **therapy** activities **on your own** <u>or</u> **with family/friends** can **improve** your **stroke recovery.**

Use this **diary** to **record** the **therapy** you **do by yourself** <u>or</u> **with family/friends.**



Activity

Activity (write and draw)	Therapist	Notes

APPENDIX B

BEHAVIOUR MAPPING

Time	Location								Active practice		Personnel Present											Activity																	Active Limb							Comments
	Amenities	Bedroom	Corridor	Therapy room	Dining room	Off ward (Medical)	Outside	Other	Yes	No	PT	OT	SP	Nurse	Medical Doctor	PT Student	OTA	Visitor	Other patient	Alone	Other	Formal Individual	Formal group	Walking	Indep Speech	Indep ADL practice	Indep cog/OT	Indep physical activity	Socialisation	Sleeping	Watching tv	Reading	Med/nurse intervention	ADLs shower/dressing	Meal	Phone (Talking)	Phone (typing/looking)	Other	UL	LL	Sitting	Lying in bed	Standing	Other	Covid Isolation	
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DAY 3

APPENDIX C

SURVEY QUESTIONS

Pre-implementation survey questions

1. What is your health employment number?
2. What your profession?
   - Clinical or coordinating nurse
   - Occupational therapist
   - Physiotherapist
   - Speech pathologist
   - Other
3. For how long have you worked in stroke rehabilitation?
   - < 1 year
   - 1–5 years
   - 5–10 years
   - > 10 years
4. For how long have you worked on the stroke rehabilitation unit at OPH?
   - < 1 year
   - 1-5 years
   - 5–10 years
   - > 10 years
5. What is your age?
   - < 25 years
   - 25–35 years
   - 35–45 years
   - > 45 years
6. What is your gender?
   - Female
   - Male
   - Non-binary
   - Other/prefer not to say
7. How many hours of independent task practice are recommended per day during stroke rehabilitation, according to the Stroke Foundation?
8. What are some barriers to meeting the independent practice guidelines?
9. What are some things that might help meet the independent practice guidelines?

Post-implementation survey questions

Questions 1–6, as per the pre-implementation survey

7. Has the implementation of the activity diary increased your knowledge about care of patients with stroke?
   - Yes. If yes, how has the diary increased your knowledge?
   - No
8. Has the implementation of the activity diary changed care of patients with stroke survivors and their families?
   - Yes. If yes, how has the diary changed care?
   - No
9. What was helpful about the diary?
10. What was less helpful about the diary?
11. What were the barriers to implementing the diary?
12. What were some facilitators to implementing the diary?
13. What needs to be improved to make the diary more useful?
14. If the diary was not used, what should be used instead?
15. What needs to be done differently regarding the process of implementing the diary?
16. On a scale of 1–10, how active have you been in the implementation process?
17. On a scale of 1–10, how useful has the diary been (i.e., do you consider the diary to have improved care for this patient group)?

The Effect of Menstrual Cycle Phase-based Rehabilitation for Females Following Anterior Cruciate Ligament Reconstruction: A Randomised Controlled Trial

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ABSTRACT

Recent research reports that follicular phase-based resistance training, where females predominantly perform resistance training in the first half of their menstrual cycle (MC), appears to result in better responses than regular training. The objective of this study was to compare the effects of MC phase-based rehabilitation (MCPBR) versus usual care (UC), following anterior cruciate ligament reconstruction (ACLR). Forty-three females participated in a 12-week intervention commencing six weeks post-ACLR. The primary outcome was knee extension strength limb symmetry index (LSI), and the secondary outcome was self-reported function (measured using the Knee Injury and Osteoarthritis Outcome Score, International Knee Documentation Committee Questionnaire, and Knee Self Efficacy Scale), measured at baseline and endpoint. Participants were randomly assigned to MCPBR ($n = 21$) or UC ($n = 22$). Participants' MCs were monitored using calendar tracking, basal body temperature tracking, and urinary ovulation testing. Thirty-six females provided data for the final analysis. The *M (SD)* knee extension LSI for participants following MCPBR was 81.2% (13.2%), compared to 73.5% (21.8%) for those following UC ($p = 0.17$). The *M (SD)* one repetition maximum knee extension of the injured leg was 38.8 kg (14.1 kg) following MCPBR and 30.4 kg (11.7 kg) following UC ($p = 0.06$). Self-reported function was similar between groups. The findings of this study show that MCPBR and UC result in similar knee extension LSI and function and therefore do not support the recommendation of MCPBR for ACL rehabilitation in a New Zealand context. Future research should investigate females' experience of MCPBR following ACLR.

O'Loughlin, M., Reid, D., Sims, S., & Larsen, P. (2024). The effect of menstrual cycle phase-based rehabilitation for females following anterior cruciate ligament reconstruction: A randomised controlled trial. *New Zealand Journal of Physiotherapy, 52*(3), 219–235. https://doi.org/10.15619/nzjp.v52i3.456

Key Words: Anterior Cruciate Ligament, Female Athlete, Menstrual Cycle, Rehabilitation, Resistance Training

INTRODUCTION

Rates of female anterior cruciate ligament (ACL) injuries have increased in recent years, with the likelihood of sustaining an ACL injury three to six times greater for females than for males (Herzog et al., 2018; Sutherland et al., 2019; Zbrojkiewicz et al., 2018). This may be due to a combination of anatomical, biomechanical, physiological, and gender-related environmental factors (Hewett et al., 2006; Parsons et al., 2021). Post-ACL reconstruction (ACLR) females have reduced quadriceps strength recovery, worse self-reported knee-related function, and are less likely to return to sport compared to males (Devana et al., 2022; Kuenze et al., 2019). Reduced quadriceps strength may put athletes with ACLR at a higher risk of further subsequent ACL injuries (Grindem et al., 2016) and early onset post-traumatic osteoarthritis (Tourville et al., 2014). Females are under-represented in ACLR research and, subsequently, there are no female-specific guidelines to specifically approach their rehabilitation (Culvenor et al., 2022; Filbay & Grindem, 2019; Mok et al., 2022; Van Melick et al., 2016).

Restoring lower limb strength is a key focus of rehabilitation following ACLR, with particular emphasis on the quadriceps (Kuenze et al., 2014). Subsequently, research recommends resistance training as part of post-ACLR rehabilitation (Culvenor et al., 2022). The response to resistance training depends on nutrition, sleep, and hormonal responses (Douglas et al., 2016; Hawley et al., 2011). Specifically for females, the hormone oestrogen is known to have an anabolic effect on skeletal muscle (Lowe et al., 2010). In contrast, progesterone has anti-oestrogenic effects and is considered catabolic (Kriengsinyos et al., 2004). Recent reviews have recommended that non-injured, naturally cycling females, where possible, concentrate their resistance training in the follicular phase of their menstrual cycle (MC) to benefit from rising levels of oestrogen and low levels of progesterone (Oosthuyse & Bosch, 2010; Thompson et al., 2020).

MC phase-based resistance training has not been investigated in females post-ACLR. Therefore, the primary objective of this study was to investigate if menstrual cycle phase-based rehabilitation (MCPBR), where females post-ACLR periodise resistance training to the follicular phase of the menstrual cycle (MC), results in improved quadriceps strength symmetry following ACLR, compared to usual physiotherapy rehabilitation. The secondary objective was to investigate if MCPBR resulted in improved self-reported functional outcomes and self-efficacy in females following ACLR compared to usual physiotherapy care (UC).

METHODS

Study design

This randomised, single-blind, two-arm study was registered with the Australian and New Zealand Clinical Trials Registry (Trial registration number: ACTRN12621000517875). The study is reported in line with the Checklist for Statistical Assessment of Medical Papers statement (Mansournia et al., 2021).

Participants

Females residing in New Zealand, aged 16 years or older, post-ACLR with a regular MC were eligible for the trial. Females using a copper or progestin-only intrauterine device were eligible for inclusion (Ortiz & Croxatto, 2007). For the first year after insertion, the progestin-only intrauterine device causes anovulatory cycles, with ovulatory cycles resuming thereafter (Apter et al., 2014). Exclusion criteria included using the oral contraceptive pill, those who were under 16 years old, more than six weeks post-operation, had an allograft surgery, or revision surgery (Janse de Jonge et al., 2019). Surgeons and physiotherapists identified potential participants in their clinics between August 2021 and November 2022 and gave them a study advert. The research team advertised the study in the media and online. All interested participants contacted the primary researcher (EOL). All participants completed screening questions via an online Google Forms questionnaire, received trial information, and provided written consent pre-operatively.

Randomisation and blinding

The primary researcher (EOL) generated a randomisation list online (www.random.org) and randomly allocated participants to one of two groups. The study used block randomisation to obtain equal groups of 10 control and intervention participants throughout the study. After randomisation, the primary researcher informed the physiotherapist of the participant's group assignment. Participants were informed about the nature of the study, including that the study investigated the effects of certain exercises at certain parts of the menstrual cycle, but were not told whether they were in the control or intervention group. The participants were blind to their group assignment.

Changes to trial protocol

The trial protocol originally excluded females with meniscal repairs and greater than grade two cartilage damage. However, in focus groups conducted prior to trial commencement, physiotherapists identified that these patients would be able to engage in rehabilitation without limitation (O'Loughlin et al., 2023). Therefore, these participants were included in the trial. Secondly, physiotherapists were to measure participants' one repetition maximum (1RM) leg extension strength of both lower limbs at the start and end of the trial. However, physiotherapists noted that post-operative pain on the injured side would limit the initial test. Therefore, only non-injured limb strength was measured at the start of the trial (Figure 1, Table 1).

Location

Twenty-eight private physiotherapy clinics across New Zealand participated in the trial. All physiotherapists had experience treating ACL injuries. All clinics had access to either a leg extension machine or handheld dynamometer to measure leg strength. The research team educated physiotherapists regarding the study protocols and the MC, provided a written instruction booklet (Appendix A), and created an online resource to ensure methods were standardised across clinics and physiotherapists. Physiotherapists only treated control or intervention participants, not both.

Outcomes

The primary and secondary outcomes are outlined in Table 1.

Interventions

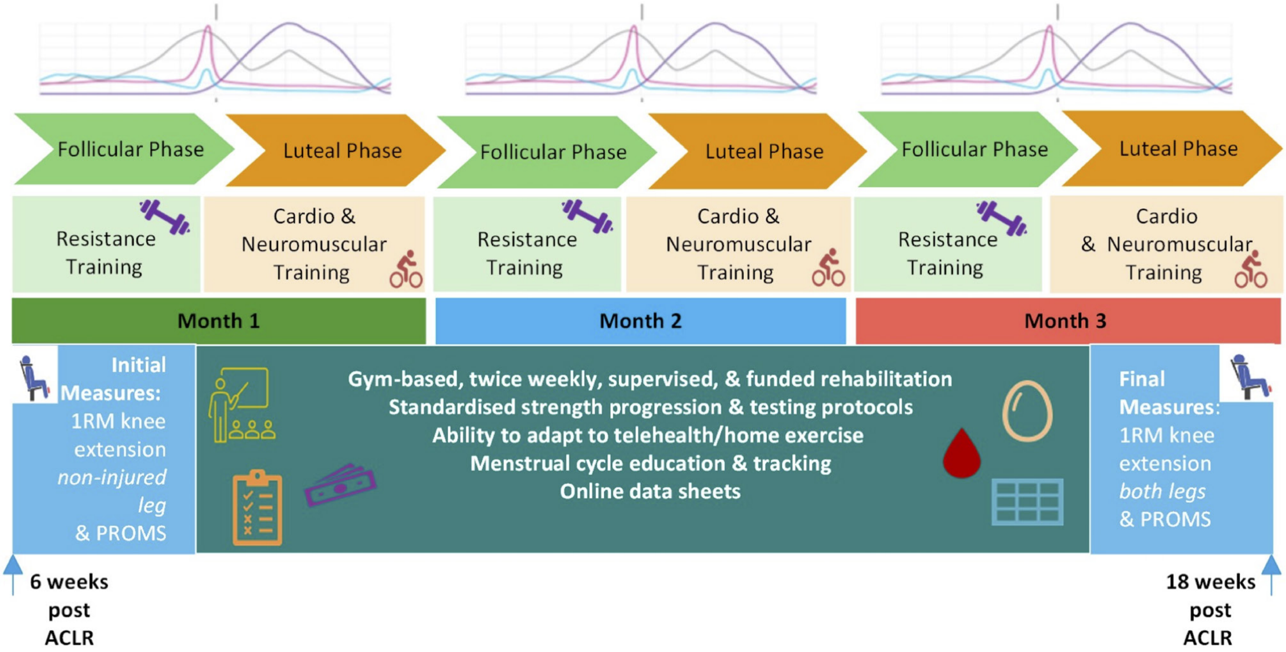
The research team sent all participants an education pack, which included education and testing kits to verify their MCs (Appendix B). These testing kits included a basal body thermometer, a urinary cup, and 20 ovulation strip tests. Each participant had an individual online datasheet where they entered this MC information, which the primary researcher and physiotherapist could also access. The primary researcher assisted with queries regarding MC tracking.

All participants attended twice-weekly, supervised, fully funded, individual 30 min gym-based physiotherapy appointments for 12 weeks, commencing at 6 weeks post-ACLR. Non-injured lower limb knee extension strength was measured at the start of the trial, and knee extension of both lower limbs was measured at the end of the trial, at 18 weeks postoperatively (Figure 1, Table 1). Several patient reported outcomes were measured at the start and end of the trial (Figure 1, Table 1). The American College of Sports Medicine guidelines recommend that people undertake resistance training 2–3 times per week. (Ratamess et al., 2009). While there is no established optimal amount of strength training post-ACLR (Nichols et al., 2021), for the general population, evidence shows greater gains from additional training frequency (Grgic et al., 2018). However, these additional gains can be negated if the overall training volume per week is the same (Grgic et al., 2018). Focus group participants recommended scheduling twice-weekly sessions to complete all their exercises during supervised physiotherapy sessions (O'Loughlin et al., 2023). Twice weekly frequency was chosen to focus on quality sessions with substantial exercise volume to elicit muscle strength gains while balancing study constraints. The study commenced at 6 weeks post-operatively as focus group physiotherapists recommended this timeframe as being when post-operative swelling and pain decreases to a point where a loading programme can be commenced without restriction (O'Loughlin et al., 2023).

Physiotherapists offered participants telehealth and home exercise sessions if they were unable to attend the in-person sessions during the programme. Participants could not perform lower limb resistance training outside their rehabilitation sessions. However, participants could complete cardiovascular,

Figure 1

Menstrual Cycle Phase-based Rehabilitation Programme



Note. Visual representation of the menstrual cycle (MC) phase-based quadriceps resistance training programme. Training commenced at six weeks post-surgery and continued until 18 weeks post-surgery. Participants attended twice weekly to a gym-based setting for supervised rehabilitation. These sessions were adapted if needed, i.e., telehealth. The researcher, physiotherapist, and participants entered all data into an online datasheet. Females received MC education and inputted information into their datasheet to establish their MC phase. Participants engaged in resistance training in the follicular phase sessions and cardiovascular and neuromuscular exercises in the luteal phase sessions. Physiotherapists used standardised strength testing to measure outcomes and standardised progression protocols to prescribe strength exercises. Funding was available for females to attend sessions. Image used with permission (O'Loughlin et al., 2023). PROMS = patient reported outcome measures.

neuromuscular, trunk exercises and upper limb resistance training outside their rehabilitation sessions. Participants recorded the frequency, content, and duration of exercise outside physiotherapy in their online datasheet. Physiotherapists also recorded each participant's rehabilitation attendance and session content in their online datasheet.

Tailoring to the menstrual cycle

Participants were randomised into two groups – either MCPBR or UC. The details of their twice-weekly supervised, fully funded, gym-based physiotherapy sessions depended on the group assignment.

MCPBR

Participants completed resistance training during the follicular phase of their MC. Participants were considered in their follicular phase from day one of menses, as noted on their individual datasheet. Squat, leg press, and knee extension exercises were compulsory in each follicular phase rehabilitation session (Figure 1). The luteal phase-based training commenced once a positive urinary ovulation test and/or a consistent rise in basal body temperature was recorded on their datasheet. Physiotherapists prescribed neuromuscular and cardiovascular exercises for the luteal phase at low to moderate intensity, as measured by the Borg Rate of Perceived Exertion scale (Figure 1). The research protocol did not define these exercises; however, the research team provided a guide (Appendix A).

UC

Participants completed their twice-weekly supervised, fully funded, gym-based physiotherapy rehabilitation as guided by their physiotherapist, most often in keeping with referring surgeons' post-operative protocols. The research team provided a general guide for ACL rehabilitation based on recent consensus statements (Appendix A) (Van Melick et al., 2016).

MC verification and synchronisation

Participants used a three-step method, which included calendar tracking, basal body temperature checking, and urinary ovulation testing, to confirm their MC phases. Participants commenced tracking their MC from study enrolment, usually at their ACLR surgery date, to provide 6 weeks of initial MC data before the programme commenced. This enabled the research team and physiotherapist to understand each participant's individual usual MC timeframe and ovulation dates. Participants were excluded from post hoc analysis if there was more than one month where their temperature and urinalysis did not verify ovulation. In addition, participants were excluded if their cycles differed by greater than seven days outside their norm for more than two cycles.

Sample size estimation

Based on previous studies, the research team estimated that with an alpha level of 0.05 and 90% power, a sample size of 27 in each group would enable an 80% probability of detecting

Table 1

Trial Outcome Measurement and Interpretation

Construct and measure	Assessment method and interpretation
LSI (%) of 1RM, injured versus non-injured leg	Physiotherapists experienced with collecting strength measurements post-ACL injury carried out a 1RM knee extension strength test, using a knee extension machine or handheld dynamometer (see Appendix A): Percentage difference between limbs = 1RM strength of the affected limb divided by the 1RM unaffected limb, multiplied by 100. Recent research defines 90% LSI as the standard target for max quadriceps strength of the injured versus non-injured leg following ACLR (Urhausen et al., 2022). Recent research recommends 1RM testing on a knee extension machine following ACL due to sufficient construct and criterion validity (Urhausen et al., 2022). Future trials are needed to establish the reliability of 1RM strength testing on knee extension machines following ACLR (Roos et al., 1998). In contrast, isometric extensor strength tests using handheld dynamometry offer sufficient intra-rater reliability (Urhausen et al., 2022).
Self-reported knee function: KOOS (Roos et al., 1998)	Addresses participants' pain, symptoms, activities of daily living, sport and recreation function, and knee-related quality of life (Roos et al., 1998). The score is a percentage score from 0–100, with 0 representing extreme problems and 100 representing no problems. The KOOS is valid and reliable for patients undergoing ACLR (Roos et al., 1998).
Self-reported knee function: IKDC (Collins et al., 2011)	The IKDC includes seven questions on knee symptoms – pain, swelling, locking, and giving way, as well as questions on knee function and activity (Collins et al., 2011). Scores range from 0 points (indicating the lowest level of function or the highest level of symptoms) to 100 points (indicating the highest level of function and the lowest level of symptoms). The IKDC is considered valid and reliable for use in a broad patient population, including following ACLR (Higgins et al., 2007).
Self-efficacy regarding knee injury: K-SES (Ezzat et al., 2020)	The K-SES consists of 22 items subdivided into four categories: daily activities, sports and leisure activities, physical activities, and future knee function (Ezzat et al., 2020). Participants respond to each item on an 11-point Likert scale from 0–10, where 0 indicates poor self-efficacy and 10 indicates strong self-efficacy. The English K-SES is considered a valid and reliable measure for knee-specific self-efficacy in individuals following a sport-related intra-articular knee injury in the previous 5 years (Ezzat et al., 2020).

Note. All measurements were obtained at 6 and 18 weeks post-ACLR, with the exception of 1RM knee extension strength of the leg, which was assessed at 18 weeks post-ACLR only. ACL = anterior cruciate ligament; ACLR = anterior cruciate ligament reconstruction; LSI = limb symmetry index; 1RM = one repetition maximum; KOOS = the Knee Injury and Osteoarthritis Outcome Score; IKDC = the International Knee Documentation Committee Questionnaire; K-SES = Knee Self-Efficacy Scale.

a 20% knee extension strength limb symmetry difference between the two groups (Harput et al., 2019; Reis et al., 1995). As this study used handheld dynamometers and knee extension machines to measure strength, which may be less reliable than isokinetic dynamometry as used in previous studies, numbers were boosted by 10% to 30 per group (Urhausen et al., 2022).

Statistical analysis

The distribution of continuous variables was assessed using the Spiro-Wilk test. Variables that were normally distributed are expressed as *M* (*SD*). Variables that were not normally distributed were expressed as *Mdn* (interquartile range). Categorical variables were expressed as count (%). Categorical variables were compared between groups using the Chi-squared test, and continuous variables using either unpaired t-test (normally distributed) or Mann-Whitney U test (not normally distributed). The primary endpoint, limb symmetry index (LSI) and 1RM injured were compared between groups using the Mann-Whitney U test. The secondary endpoints of 1RM non-injured, Knee Injury and Osteoarthritis Outcome Score (KOOS), International Knee Documentation Committee (IKDC), and Knee Self Efficacy Scale (K-SES) scores, as outlined in Table 1, were examined over time and between groups using repeated measures ANOVA. In all cases, $p < 0.05$ indicated statistical significance.

Ethics, diversity, and inclusion statement

The researchers discussed the project with the Mātauranga Māori Committee at the Auckland University of Technology. The research team sought advice from Māori regarding the wording of the trial forms and translated the trial name and the participant information sheet into te reo Māori. The study provided fully funded physiotherapy sessions to ensure participants of different socioeconomic statuses could participate. Furthermore, the research team was gender balanced and included junior and senior researchers.

RESULTS

Participants

The trial included 43 females from 75 potential participants recruited between July 2021 and November 2022 (Figure 2). The trial was stopped due to constraints in the availability of key personnel. Participant characteristics are reported in Table 2. Participants' surgical graft type and concomitant injuries were noted from their surgical notes. There were no significant differences in baseline outcomes between groups (Appendix C, Table C1). Participants in the MCPBR group attended a *M* (*SD*) of 19.9 (3.6) appointments, while participants in the UC group attended 17.9 (5.4) appointments over the course of the trial ($p = 0.18$, Appendix C, Table C2).

Primary outcome

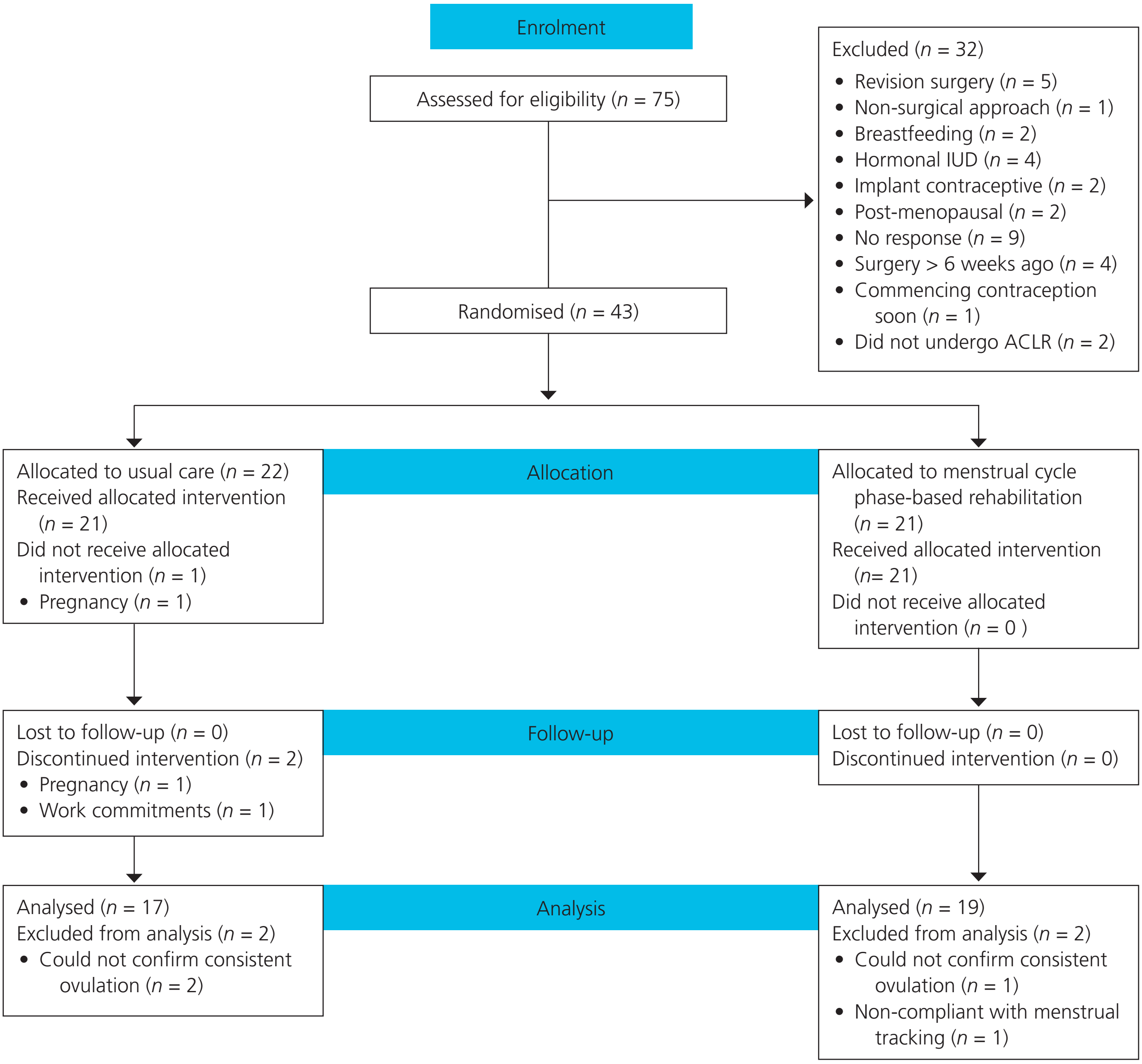
All outcomes are presented as *M* (*SD*). There were no statistically significant between-group differences in knee extension LSI at 18 weeks post-ACLR ($p = 0.17$, Table 3, Figure 3). The mean LSI was 81.2% (13.2%) following MCPBR compared to 73.5% (21.8%) following UC (Table 3, Figure 3). The mean knee extension 1RM for the injured leg was 38.8 kg (13.4 kg) following MCPBR and 30.4 kg (11.7 kg) following UC, resulting in a mean difference of 8.4 kg (95% CI [–0.3, 17.1], $p = 0.06$), as detailed in Table 3 and Figure 3. The mean knee extension 1RM for the non-injured leg increased from 41.0 kg (10.8 kg) to 47.3 kg (12.4 kg) following MCPBR, and from 38.1 kg (7.9 kg) to 40.7 kg (9.5 kg) following UC, demonstrating a significant time effect ($p = 0.01$). However, there was no significant treatment effect, with a mean difference of 5.7 kg (95% CI [–1.8, 13.2], $p = 0.18$), as detailed in Table 3 and Figure 3.

Secondary outcomes

Total and sub-scale KOOS and IKDC scores improved significantly for both groups throughout the trial from baseline to endpoint (Table 3, Figure 3). There was no between group treatment effect (Table 3). Similarly, total K-SES scores improved significantly for both groups, but there were no between-group effects (Table 3).

Figure 2

Flow of Participants Through the Study



Note. ACLR = anterior cruciate ligament repair; IUD = intrauterine device.

Table 2

Participant Characteristics

Characteristic	Usual care group (*n* = 22)		MCPBR group (*n* = 21)		*p*
	n [a]	% [a]	*n* [a]	% [a]	
Age, *M* (*SD*)	30.4 (7.6)		32.8 (8.4)		0.33
Ethnicity					
New Zealand European	11	50	13	62	0.65
Māori	4	18	2	9	
Samoan	1	5	1	5	
Chinese	2	10	1	5	
Indian	0	0	2	9	
Other European	3	14	1	5	
Other Asian	1	5	1	5	
Menstrual cycle status					
Natural	17	77	20	95	0.22
Copper IUD	1	5	0	0	
Hormonal IUD	4	18	1	5	
Contralateral injury					
No	18	82	19	90	0.96
Yes	3	14	3	10	
Resistance training status					
Untrained	9	41	9	43	0.25
Moderate	8	36	3	14	
Well trained	5	23	7	33	
Graft type					
Hamstring	15	68	17	81	0.34
Bone-patella-bone	7	32	4	19	
Cartilage damage					
None	15	68	17	81	0.62
Grade 1	2	10	2	9.5	
Grade 2	4	18	2	9.5	
Grade > 2	1	5	0		
Meniscal treatment					
No	14	64	10	47	0.56
Meniscectomy	4	18	5	24	
Meniscal repair	4	18	6	29	
Associated ligamentous injury					
None	18	82	18	86	0.53
MCL	2	10	3	14	
LCL	1	5	0	0	
Multiple (LCL and MCL)	1	5	0	0	
Delay to surgery (days), *Mdn* (IQR)	178	(97–299)	128	(78–392)	0.98

Note. IUD = intrauterine device; IQR = interquartile range; LCL = lateral collateral ligament; MCL = medial collateral ligament; MCPBR = menstrual cycle phase-based rehabilitation.

[a] Except where indicated.

DISCUSSION

Primary outcome

The main finding of this study was that the MCPBR and UC groups had similar knee extension LSI at the end of the study. Females had a *M* (*SD*) LSI of 81.2% (13.2%) following MCPBR and 73.5% (21.8%) following UC. While these were not statistically different, even small differences in LSI can be clinically important for females after ACLR, as there is a 3% reduction in re-injury rate for every 1% point increase in strength symmetry post-ACLR (Grindem et al., 2016). Recent studies recommend 90% LSI as the standard target for 1RM extension strength symmetry following ACLR (Lynch et al., 2015). Thirty-three percent of females in the MCPBR group and 25% in the UC group met the 90% LSI goal. These LSI cut-offs are pertinent as criterion-based rehabilitation has surpassed

Table 3

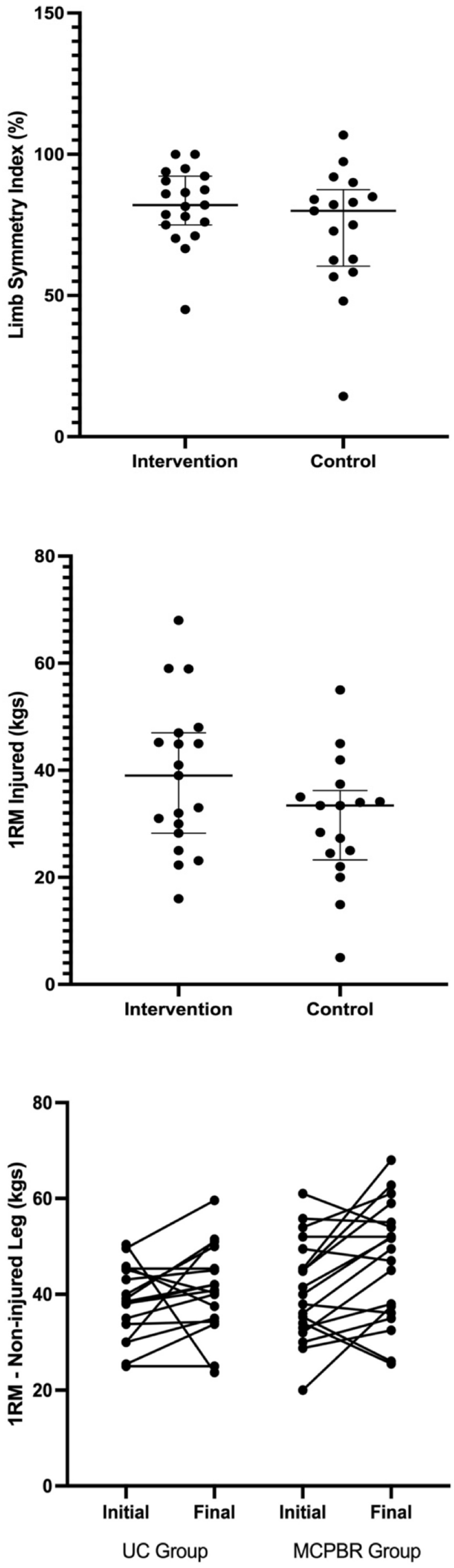
Summary of Participant Primary and Secondary Outcomes

Outcome	Usual care group (*n* = 17)				MCPBR (*n* = 19)				Difference between groups				*p*	
	Baseline		Final		Baseline		Final		Baseline		Final			
	M	*SD*	*M*	*SD*	*M*	*SD*	*M*	*SD*	*M* difference	95% CI	*M* difference	95% CI		
Quadriceps strength LSI (%)	–		73.5	21.8	–		81.8	13.2	–		8.3	[–3.7–20.4]	0.17	
1RM injured (kg)	–		30.4	11.7	–		38.8	14.1	–		8.4	[–0.3–17.1]	0.06	
													Time effect	Rx effect
1RM non-injured (kg)	38.1	7.9	40.7	9.5	41.0	10.8	47.3	12.4	4.3	[1.0–7.6]	5.7	[–1.8–13.2]	0.01	0.18
KOOS (%)														
Total	59.8	15.1	73.2	14.9	65.0	13.0	73.2	11.9	10.6	[5.8–15.4]	-0.02	[–9.1–9.1]	< 0.001	0.28
Pain	56.4	18.8	81.0	11.1	53.3	13.4	82.3	9.8	26.8	[22.3-31.4]	1.3	[–5.8–8.3]	< 0.001	0.81
Symptoms	50.1	13.4	75.4	20.2	48.2	13.9	74.3	18.5	25.7	[19.9–31.5]	–1.1	[–14.2–11.9]	< 0.001	0.76
ADL	70.9	18.7	89.1	12.2	71.4	17.2	93.4	6.7	20.2	[14.9–25.3]	4.3	[–2.2–10.8]	< 0.001	0.56
Sports	25.6	19.4	63.8	19.0	31.3	27.8	64.5	18.8	35.5	[29.1–41.9]	0.7	[–12.1–13.5]	< 0.001	0.63
QoL	31.0	16.4	56.6	20.6	22.4	15.6	52.5	14.8	27.7	[21.0–34.5]	–4.1	[–16.2–7.9]	< 0.001	0.23
IKDC (%)	39.6	11.6	68.6	13.3	37.4	13.7	64.1	11.9	27.7	[23.5–31.9]	–4.6	[–13.1–3.9]	< 0.001	0.36
K-SES														
Total (max 180)	61.1	33.3	127.4	31.7	50.6	35.1	129.1	39.7	72.7	[60.9–84.5]	1.7	[–22.7–26.2]	< 0.001	0.67
Movement (max 80)	19.6	14.2	56.0	18.1	17.9	17.4	59.6	21.5	39.2	[33.2–45.2]	3.6	[–9.9–17.2]	< 0.001	0.85
Leisure (max 80)	29.1	18.2	57.1	15.3	21.8	16.5	57.6	14.0	32.1	[26.4–37.7]	0.5	[–9.4–10.4]	< 0.001	0.47
Future (max 20)	12.5	6.0	14.2	3.6	10.8	5.1	12.8	5.5	1.9	[0.05–3.8]	–1.5	[–4.6–1.7]	0.001	0.28

Note. Quadriceps limb symmetry index (LSI) and one repetition maximum (1RM) injured were compared between groups using the Mann-Whitney U test. The secondary endpoints of 1RM non-injured, KOOS, IKDC, and K-SES scores were examined over time and between groups using repeated measures ANOVA. ADL = activities of daily living; CI = confidence interval; KOOS = the Knee Injury and Osteoarthritis Outcome Score; IKDC = the International Knee Documentation Committee Questionnaire; K-SES = Knee Self-Efficacy Scale; MCPBR = menstrual cycle phase-based rehabilitation; QoL = quality of life; Rx = treatment.

Figure 3

Strength Outcomes Following MCPBR and Usual Care



Note. UC = usual care; MCPBR = menstrual cycle phase-based rehabilitation; 1RM = one repetition maximum.

time-based rehabilitation (Culvenor et al., 2022). Only 32.5% of ACLR patients achieve an average 90% LSI 1RM knee extension at six months post-ACLR (Cristiani et al., 2019). Therefore, both study groups in this trial had comparatively high levels of LSI at this early time point compared to these previously reported figures. The relatively high mean LSI following UC, in addition to the relatively high pre-determined estimated mean difference (20% difference between groups) in the sample size calculation, may also have affected the ability of MCPBR to demonstrate a substantive improvement over the UC group. The effect size in this study was smaller than initially estimated (approximately 10%). Future studies, using a primary outcome of limb symmetry index, would require a sample size of 200 participants to demonstrate a 10% difference between groups (90% power and $\alpha = 0.05$).

There was no significant difference in the maximum strength of the injured leg between the MCPBR and the UC group. Although no baseline measures were available, the estimated strength differences at the final measurement suggest that the MCBPR group may have been stronger than the UC group. However, the small sample size limits the ability to draw firm conclusions. Similarly, while there was a significant change in the strength of participants' non-injured leg over the course of the trial, there was no significant difference between the MCPBR and UC groups. However, the estimated strength gain differences suggest greater improvement in the MCPBR group. If the MCPBR group participants' non-injured leg became stronger alongside their injured leg, this could have affected the final limb symmetry index score, making it less reflective of the strength changes over the course of the trial.

Previous research describes superior strength gains following MC phase-based resistance training in non-injured populations (Sung et al., 2014; Wikström-Frisén et al., 2017). In these two studies, participants engaged in a higher volume of resistance training (five sessions per week) during the follicular phase. In contrast, in the current study, MCPBR participants attended biweekly rehabilitation across all MC phases, but resistance training was restricted to the follicular phase only. No training limitations were placed on the UC group, and physiotherapists prescribed quadriceps exercises more frequently to the UC group than to the MCPBR group. Consequently, the MCPBR group engaged in less quadriceps loading as compared to UC, which may have negatively affected responses. Future studies should ensure a similar level of resistance training between groups.

Secondary outcomes

All KOOS subscales improved throughout the study for both MCPBR and UC groups. There was no significant difference between groups for KOOS change or absolute values at the start or finish. Previous literature has identified a patient acceptable symptom score (PASS score) for KOOS (Muller et al., 2016). In this study, 61% of participants in both MCPBR and UC groups met the six-month KOOS ADL subscale PASS criteria at only 18 weeks post-ACLR. This compares favourably to previous research, where 55% of patients from the Norwegian Knee Registry considered their symptoms acceptable at their six-month follow-up (Ingelsrud et al., 2015). Similarly, IKDC scores and present knee self-efficacy improved for all participants, and there were no between-group differences.

Clinical implications

Based on the results of this study, MCPBR is not currently recommended in a New Zealand context for ACL rehabilitation. However, patients and physiotherapists may consider undertaking such rehabilitation if that is their preference, as there is no evidence yet that such a programme may lead to poorer outcomes than usual care.

Strengths

This study was a novel design explicitly aimed at improving outcomes for females by benefitting from female hormone fluctuations and female-specific preferences for ACLR rehabilitation. This study was the first to adapt previous MC phase-based training designs and apply them to a rehabilitation context. Second, this study was designed utilising recommendations given by females. Because the programme was tailored to meet the preferences of females, this could explain why the attrition rate was lower than anticipated based on the sample size estimation. Similarly, adherence to MCPBR was positive, with participants attending most scheduled appointments, and only one participant was excluded due to non-compliance with MC verification methods. Finally, the research team excluded a further three females post priori due to being unable to verify regular ovulation, which ensures that the results reflect the truth in the population studied rather than methodological error and ensures a high level of internal validity (Patino & Ferreira, 2018).

Limitations

This study did not meet the numbers required for statistical power, limiting its ability to detect a true effect if it existed. Therefore, this study may not have identified real differences between MCPBR and UC when there may have been some. Difficulty recruiting the targeted sample size may reflect the timing of the trial during ongoing COVID-19 lockdowns in New Zealand, and the small proportion of eligible ACL injuries: females with a eumenorrheic MC. This small sample size may also have meant there was a risk of sampling bias and an increased variability of outcomes, both of which may increase the chance of Type I and Type II errors. Additionally, subgroup analyses were unable to be conducted due to the small sample size, which may have provided extra insight into how results may have varied across different subpopulations, such as those who carried out more or less quadriceps strengthening.

Participants carried out twice weekly strengthening in their physiotherapy sessions; however, they were not allowed extra resistance training outside of this prescribed training environment. This may have limited some participants – particularly trained individuals – from reaching their maximum ability of strength gain over the 12-week period. Furthermore, participants did not have an initial strength test of their injured leg, which could have meant baseline differences were erroneously interpreted as treatment effects or, concurrently, Type II errors may have occurred if true baseline differences were not accounted for and masked**.** Although physiotherapists were provided with protocols and training to standardise measurements, the number of different physiotherapists may have led to variability in the strength measurements. Similarly, both knee extension machines and handheld dynamometry were used to collect strength measures, depending on what was available in the treating physiotherapy clinic, which also may have led to variability in the strength measurements. No long-term data were collected, including return to function or re-injury rates. Finally, this study did not discuss females' experiences of engaging with MCPBR.

CONCLUSION

Results from this study demonstrate that participating in MCPBR and UC resulted in similar LSI and self-reported function for females at 18 weeks post-ACLR. However, the study was underpowered to detect a difference in the primary outcome, which limits the ability to draw definitive conclusions. This study does not support the premise that MCPBR needs to be recommended for ACL rehabilitation in a New Zealand context. Conversely, patients and physiotherapists may consider undertaking this rehabilitation if this is a patient's preference, as there is no evidence yet that such a programme may lead to poorer outcomes than usual care. Future research should investigate a larger cohort of females, including strength measures of both legs over a longer period. Similarly, it would be pertinent to understand females' acceptability of engaging with MCPBR.

KEY POINTS

1. This rehabilitation programme synchronised ACLR rehabilitation to females' MCs.
2. Participants had similar limb symmetry following MCPBR versus UC. Therefore, this study does not support that MCPBR needs to be recommended for ACL rehabilitation in a New Zealand context.
3. Patients and physiotherapists may consider undertaking such rehabilitation if that may be their preference, as there is no evidence yet that such a programme may lead to poorer outcomes than usual care.

DISCLOSURES

The primary author (EOL) received a scholarship from the New Zealand Manipulative Physiotherapists Association (NZMPA) in 2020 and at the time of the study was an employee of the Accident Compensation Corporation (ACC). ACC provided funding for her PhD fees as part of her continuing professional development allowance. In addition, DR had a research fund that provided funding for the trial. No conflicts of interest exist that may be perceived to interfere with or bias this study.

PERMISSIONS

This study was approved by the New Zealand Health and Disability Ethics Committee 21/CEN/92 and the Auckland University of Technology Ethics Committee application 20/224. Permission has been granted by the *New Zealand Journal of Sports Medicine* to republish Figure 1 in the *New Zealand Journal of Physiotherapy*.

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CONTRIBUTIONS OF AUTHORS

EOL, DR, and SS designed the study and created the study protocol; PL conducted statistical analysis; all authors contributed to writing and editing the manuscript.

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APPENDIX A

MENSTRUAL CYCLE PHASE BASED ACLR REHABILITATION GUIDE FOR PHYSIOTHERAPISTS

Part A: Guide for Intervention Group

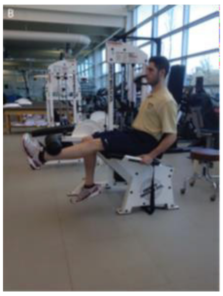
This includes:

- Instructions for first and last appointments.
- Instructions on how to measure quadriceps strength.
- Instructions for verifying menstrual cycle phase with participant.
- Instructions for periodisation of rehabilitation.
- Instructions regarding which strengthening exercises to complete with participant, and a guideline for the progression of these.
- Examples of exercises appropriate for the luteal phase rehabilitation sessions.

Initial appointment – 6 weeks post-operation

1. Screen operation notes and notify researcher if client does not meet inclusion criteria.
2. Check Google Sheets to ensure calendar tracking, basal body temperature and ovulation prediction results have been entered by participant.
3. Establish participant's menstrual cycle (MC) phase and enter result into Google Sheet.
4. Client to complete KOOS 12 form and enter result into Google Sheet.
5. Client to complete IKDC subjective knee evaluation form and enter result into Google Sheet.
6. Client to complete K-SES form and enter result into Google Sheet.
7. Ensure appointments booked x 2/week for 12 weeks and enter dates into Google Sheet.
8. Obtain 1RM knee extension strength of the uninjured leg and enter into Google Sheet.

How to assess 1RM (Sinacore et al., 2017)



- Requires a knee extension machine.
- All 1RM testing should begin with the uninvolved limb and alternated between limbs.
- The tester will instruct the patient to extend the knee against the resistance of the machine in a slow and controlled fashion.
- Trials are deemed successful when the patient has achieved the targeted angle of knee extension and maintained it for 2 s.
- Resistance is increased after a successful trial on each limb by 2 to 14 kg, at the tester's discretion, depending on the difficulty of the previous repetition.
- Failure is defined as three unsuccessful attempts to lift the weight to the targeted angle, with a rest interval of up to 60 s given between attempts.
- The final 1RM values for the involved and uninvolved legs are to be recorded.
- Testing can be done at 90–0° knee extension or 90–45° knee extension. As time progresses, clearly the resistance of the test needs to increase.

Periodisation of rehabilitation programme

How to establish if the participant is in follicular phase:

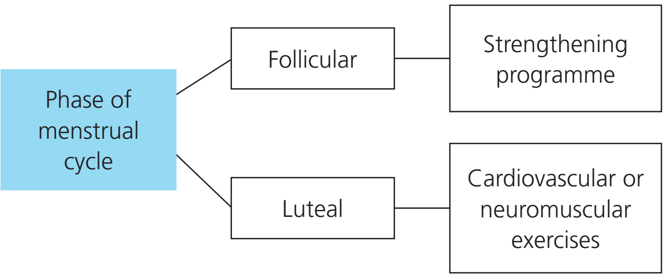
1. They have logged their recent menses into their calendar.
2. They have not yet logged a positive urinary ovulation predictor kit result.

How to establish if the participant is in luteal phase:

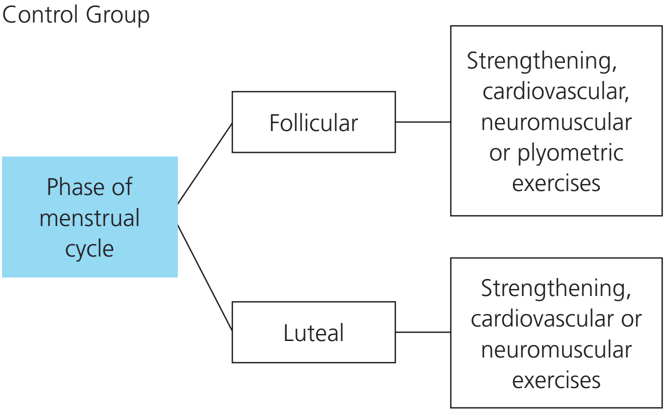
1. Their calendar indicates that ovulation should have occurred.
2. They have entered several raised basal body thermometer reading.
3. They have entered in a positive urinary kit result.

Periodisation

Intervention Group



Control Group



Follicular phase guide

Please complete these three exercises per session in the follicular phase.

Olympic leg press – Closed kinetic chain

Squat – Closed kinetic chain

Seated knee extension – Open kinetic chain

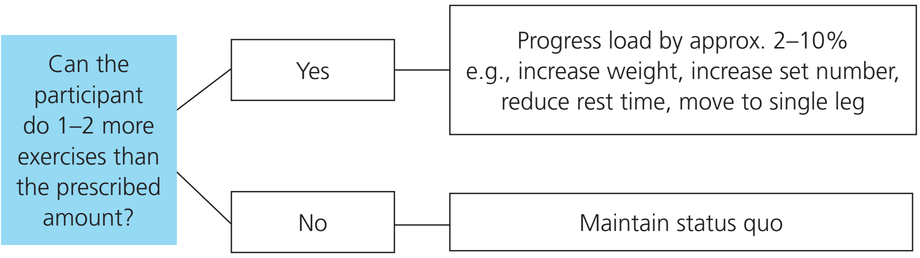
*Open chain exercises should be incorporated as per surgeons' instructions. Open chain should start at 90-45°, then full arc 90-0° but without resistance. Strong isometric quadriceps holds are to be encouraged at the end of the full arc.

*From 8–12 weeks (week 4 of research study) onwards you can introduce resistance and graduate this over the next 4–6 weeks.

Progression Guide

Week 6–10	Week 11–14	Week 15–18
Double leg leg press and double leg squat 60% of 1RM 8–12reps 2–3 sets	Double leg press and double leg squat 70–80% of 1RM 6–8 reps 2–3 reps Progress to single leg	Single leg press and single leg squat 70–80% of 1RM 4–6 reps 2–3 sets
Leg extension 90-45°, then 90-0° Strong isometric holds Start to add resistance approx. week 8	Double leg knee extension 60% of 1RM 8–12 reps 2–3 sets	Single leg knee extension 70–80% of 1RM 6–8 reps 2–3 sets

Do I progress the client?



Remember! Any increase in pain and swelling following exercise sessions indicates the exercises were too hard – drop back to previous week until the knee settles.

*Strength exercises should be done at the start of each session (before neuromuscular control or mobility exercises).

*Multi-joint exercises (leg press and squat) should be done before single joint (leg extension) exercises.

Luteal phase guide

All exercises stated below are examples of exercises that are suitable (depending on the participant's ability) to complete within the luteal phase sessions.

Cardiovascular exercises
Walking
Ergo machine
Rowing
Cycling

Neuromuscular exercises
Toe stand Toe/heel walk
Bosu/wobble board stand/single leg stand/mini squat/step ups
Step up/downs
Lateral step up/downs
Single leg stand/balance – Star exercise, balance and reach
Grapevine
Medicine ball core exercise
Graduated agility exercises with good movement form
Consider controlled vertical hopping (on the spot) when movement patterns are appropriate

Final appointment – 18 weeks post–operation

1. Check Google Sheets to ensure calendar tracking, basal body temperature, ovulation prediction, outcome measures and exercise records are entered.
2. Client to complete KOOS 12 form and enter result into Google Sheet.
3. Client to complete IKDC subjective knee evaluation form and enter result into Google Sheet.
4. Client to complete K-SES form, enter result into Google Sheet.
5. Obtain isometric quadriceps strength measures with handheld dynamometer on bilateral lower limbs and enter result into Google Sheet.
6. Obtain 1RM knee extension strength of bilateral lower limbs and enter result into Google Sheet.
7. Email researcher to acknowledge end of protocol with patient.

Part B: Guide for Control Group

- It is expected the control group will also receive an evidence based, phased, and criterion based progressive ACLR rehabilitation programme.
- Below is an adapted postoperative rehabilitation guide from Van Melick et al. (2016) and Adams et al. (2012) which can be used as a guide for best practice post op ACLR rehabilitation for the control group.

Phase 2. Range of motion/strength/muscle reactivation/ balance (2–12 weeks)

Goals

- Build knee strength
- Restore normal range of motion
- Restore balance and walking confidence

Intermediate postoperative phase (weeks 3–5) milestones

- Knee flexion ROM to within 10° of uninvolved side
- Quadriceps strength greater than 60% of uninvolved side

Treatment

- Tibiofemoral mobilisations with rotation for ROM if joint mobility is limited
- Progress bike duration (10 min minimum)
- Begin graduated balance and proprioceptive activities

Late post-operative phase (Weeks 6–8) milestones

- Quadriceps strength greater than 80% of uninvolved side
- Normal gait pattern
- Full knee ROM (compared to uninvolved side)
- Knee effusion of trace or less

Treatment

- Progress exercises in intensity and duration
- Continue exercise programme at fitness facility (if all milestones are met)
- Maintain or gain quadriceps strength (greater than 80% of uninvolved side)
- Sports-specific activities – graduate from easy to more challenging over time

Phase 3. Function: In a controlled environment and with good movement patterns – running, jumping, hopping, landing (3–6 months)

Goals

- Restore strength to 80% of uninvolved limb
- Restore functional movements – running, jumping, landing, hopping, landing

Follow-up functional testing (4 months, 5 months, 6 months, 1 year post-operative)

- Milestones functional phase (3–6 months)
- Maintain gains in strength (greater than or equal to 90% to 100%)
- Consider controlled vertical hopping (on the spot) when movement patterns are appropriate
- Return-to-sport criteria (see below)
- Recommend changes in rehabilitation as needed. Progression may emphasise single-leg activities in gym, explosive types of activities (cutting, jumping, plyometrics, landing training)

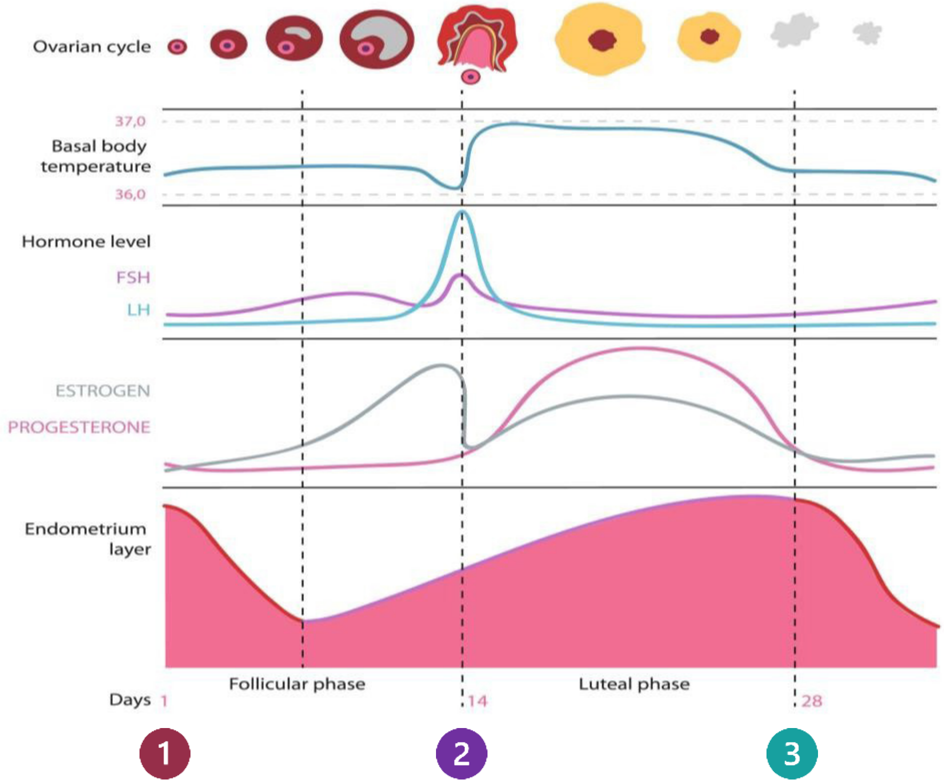
APPENDIX B

PARTICIPANT EDUCATION PACK

Thank you for your interest in taking part in ‘A Female Specific Menstrual Cycle Phased Anterior Cruciate Ligament Rehab Programme’.

The research team will track your menstrual cycle as part of the programme. This education pack aims to educate you about your menstrual cycle, and the processes involved to track your menstrual cycle.

The Menstrual Cycle



① When you get your period, this is the first day of the follicular phase.
Ovulation occurs on approximately day 14. This is when your ovary releases an egg.

② Once ovulation occurs, you are in the luteal phase.
Your basal body temperature and luteinising hormone (LH) levels rise around ovulation.
The luteal phase lasts about two weeks.

③ When you get your period again, you have finished the luteal phase.
You will now start a new menstrual cycle.

Tracking Your Menstrual Cycle

The research team will send you a link to your own online logbook (a Google Sheet), and will post you a basal body thermometer and an ovulation predictor kit to help track your menstrual cycle.

Tracking your menstrual cycle is a **3 step process**.

1 Record your period in your online logbook. When? Daily when you have your period.

- The length of the menstrual cycle is the duration from your first menstrual bleeding day to the day before the next bleeding begins.

2 Measure your basal body temperature.

When? Daily.

- The process for basal body temperature tracking is simple, but it does require a small commitment.
- Every morning before getting out of bed, take your temperature and note it in your logbook.
- The thermometer needs to be placed under the tongue and left there until it beeps.
- Take your temperature as close to the same time every day as you can.
- You should have a minimum of five hours of sleep before measuring.

3 Use an ovulation prediction kit

When? Daily, starting 10 days from the start of your period, until a positive result is recorded.

- If you have a short cycle, you should start using an ovulation test kit 4 day prior to your cycle's midpoint. *(The research team can help you with this)*.
- Your ovulation kit instructions can be found here: https://www.pregmate.com/pages/ovulation-test-strips-instructions-for-use
- In short:
  1. Dip the strip into the urine for 3-5 seconds.
  2. Lay the strip flat.
  3. Read results in 5 minutes.

  Positive: If two colour lines are visible and the test line is equal to or darker than the control line.

  Negative: Only one line appears in the control area or the test line is lighter than the control line.
- Record the results in your logbook.
- **How long should I continue to perform the test?** At least 5 days or until the LH surge has been detected.

Any questions? Contact the research team at ccq8275@autuni.co.nz or 0221723949

The research team is here to help you understand this information and is available via email or phone at any time, to answer any questions you may have.

APPENDIX C

Table C1

Initial Outcome Scores

Outcome	Usual care group (*n* = 17)		MCPBR group (*n* = 19)		*p*
	M	*SD*	*M*	*SD*	
1RM non-injured (kg)	38.4	7.7	40.8	10.5	0.37
KOOS					
Total (%)	59.8	15.1	65.0	13.0	0.14
Pain (%)	56.4	18.8	53.3	13.4	0.28
Symptoms (%)	50.1	13.4	48.2	13.9	0.68
ADL (%)	70.9	18.7	71.4	17.2	0.94
Sports and recreation (%)	25.6	19.4	31.3	27.8	0.48
Quality of life (%)	31.0	16.4	22.4	15.6	0.21
IKDC (%)	39.6	11.6	37.4	13.7	0.61
K-SES					
Total	61.1	33.3	50.6	35.1	0.21
Self-efficacy movements	19.6	14.2	17.9	17.4	0.76
Self-efficacy leisure	29.1	18.2	21.8	16.5	0.22
Future self-efficacy	12.5	6.0	10.8	5.1	0.51

Note. ADL = activities of daily living; KOOS = Knee Osteoarthritis Outcome Score; IKDC = the International Knee Documentation Committee Questionnaire; K-SES = Knee Self-Efficacy Scale; MCPBR = menstrual cycle phase-based rehabilitation; 1RM = one repetition maximum.

Table C2

Programme Engagement and Adherence

Variable	Usual care group (*n* = 16)		MCPBR group (*n* = 18)		*p*
	M [a]	*SD* [a]	*M* [a]	*SD* [a]	
Total physiotherapy sessions attended	18.0	5.5	19.7	3.7	0.27
Total physiotherapy sessions attended in follicular phase	8.5	3.5	9.3	1.9	0.35
Total physiotherapy sessions attended in luteal phase, *Mdn* (IQR)	11 [6–12]		11 [7–12]		0.44
Total home exercise physiotherapy sessions completed, *Mdn* (IQR)	0 [0–4]		0 [0–2]		0.70
Total telehealth physiotherapy sessions completed, *Mdn* (IQR)	0 [0–0]		0 [0–0]		0.28
Total physiotherapy sessions which included quadriceps strengthening exercises	17.4	6.1	9.6	2.2	< 0.0001
Total physiotherapy sessions which included knee extension exercises	9.3	7.3	8.9	3.2	0.85
Total days active outside physiotherapy	45.3	18.5	40.2	23.2	0.45
Total days no exercise outside physiotherapy	22.0	13.9	21.3	18.2	0.89
Measurement equipment used for strength tests, *n* (%)					
Knee extension machine	10	(63)	14	(78)	0.33
Handheld dynamometer	6	(37)	4	(22)	

Note. IQR = interquartile range; MCPBR = menstrual cycle phase-based rehabilitation.

[a] Except where indicated.

Development of an Entrustable Professional Activities Framework for Physiotherapists Working in Orthopaedic Triage and Assessment Roles in New Zealand

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ABSTRACT

In New Zealand, an increasing number of physiotherapists have been engaged in orthopaedic triage and assessment (OTA) roles within elective orthopaedic departments to help optimise surgeon clinic time and improve timely access to diagnostic assessment and treatment planning for people with musculoskeletal conditions. To date no framework has been available to guide physiotherapists and surgeons in developing these roles. This commentary describes the development of an Entrustable Professional Activity (EPA) framework for physiotherapists in OTA roles in which five key clinical activities were identified. The framework defines the context, limitations, knowledge, skills, attributes, and behaviours needed for each activity. The EPAs were mapped to existing New Zealand physiotherapy competencies and key competencies identified that are needed for safe and effective practice with minimal or no supervision. This EPA framework is intended for use in elective orthopaedic departments, to support the development of physiotherapists working in orthopaedic triage and assessment roles in clinical subspecialty areas.

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Keywords: Musculoskeletal Disorders, Orthopaedics, Physiotherapy Specialty, Triage

INTRODUCTION

Musculoskeletal complaints are a major health concern, affecting approximately 1.71 billion individuals worldwide and a leading contributor to disability globally, with an enormous impact on quality of life and work productivity, and an increasing burden on healthcare systems (World Health Organization, 2022). In New Zealand, musculoskeletal conditions represent approximately 12% of all non-communicable diseases (Ministry of Health, 2020) and account for 23% of the annual health expenditure (Arthritis New Zealand, 2018). Low back pain, osteoarthritis, and shoulder pain are among the most prevalent musculoskeletal conditions and represent a substantial portion of primary care and specialist consultations (Liu et al., 2022).

"Musculoskeletal" is defined as "of, relating to, or involving both musculature and skeleton" (Mirriam-Webster, n.d.a). "Orthopaedics" is defined as "the branch of surgery concerned with disorders of the spine and joints and the repair of deformities of these parts" (Mirriam-Webster, n.d.b). Effective management of musculoskeletal conditions requires timely access to the appropriate surgical (orthopaedic) or non-surgical treatment pathway for the individual (Speerin et al., 2020). The demand for both non-surgical and surgical management pathways for musculoskeletal conditions is likely to increase in coming years due to an increasing ageing population (Fayaz et al., 2016; World Health Organization, 2022).

In New Zealand, there continues to be a lack of primary care funding for the non-surgical management of chronic musculoskeletal conditions, including community-based physiotherapy and interventional procedures (Speerin et al., 2020). Data collected from the New Zealand regional health services between 2019 and 2022 show the number of people waiting more than 12 months for a First Specialist Assessment (FSA) across all elective specialty services, including orthopaedics, increased from 253 to 4,255, and the number waiting more than four months increased from 12,894 to 35,264 (Te Whatu Ora, 2022). It is clear the healthcare system in New Zealand is facing significant challenges to meet its demands and deliver equitable and timely care for people with musculoskeletal conditions (Ministry of Health, 2020; Naik et al., 2023).

Advanced practice physiotherapy models

Many countries have been exploring alternative models to improve access to timely care from appropriately qualified professionals for people with musculoskeletal and orthopaedic conditions in both primary and secondary care (Bicker et al., 2024; Goodwin et al., 2021; Goodwin & Hendrick, 2016; Samsson et al., 2016). These models aim to direct patients to the appropriate management pathway, facilitate timely access to care (minimise waiting times), and optimise consultant clinic time. Several models are described, which include physiotherapists being utilised in orthopaedic departments for pre-operative screening and optimisation, post-operative follow-up, and orthopaedic triage and assessment roles (OTA) with data supporting the utilisation of physiotherapists in these roles to improve timely access to appropriate care (Marks et al., 2017; Trøstrup et al., 2020; Vedanayagam et al., 2021; Williams et al., 2019).

Orthopaedic triage and assessment

OTA roles are based within clinical subspecialty services in elective orthopaedic outpatient departments where physiotherapists assist surgeons with triage of referrals, and carry out clinical assessment and treatment planning services (Downie et al., 2019; Goodwin et al., 2021; Jones, 2018). The aim of OTA roles is to optimise surgeon clinic time by taking on referral management responsibilities (triage) and to provide a comprehensive clinical assessment to evaluate the management needs of patients with musculoskeletal conditions and to facilitate access to appropriate elective surgical and non-surgical clinical pathways. Although there is no universally agreed definition of orthopaedic triage, it is generally understood to be the process by which a team (most often a physiotherapist and surgeon team) reviews a paper or electronic referral from a general practitioner and allocates the patient to an appropriate clinical pathway as a precursor to a clinic-based assessment for more detailed treatment planning (Morris et al., 2015). Most commonly, triage is used as a waiting list management strategy to prioritise patients for surgery according to urgency, and to screen and streamline care through assessment, diagnosis, and appropriate treatment planning for patients referred to a specialty service (Morris et al., 2015).

Implementation of OTA roles has been shown to increase department capacity to accept referrals for people whose referrals would otherwise likely be declined and therefore to reduce the unmet need (Marks et al., 2017). Other benefits of OTA services in orthopaedic departments include reduced wait times for orthopaedic FSA, releasing surgeon time for higher priority surgical cases, completion of diagnostic work-up prior to FSA, and completion of non-surgical management pathways helping to improve surgical conversion rates (Marks et al., 2017). High levels of agreement between the surgeon and physiotherapist with regard to diagnosis and treatment plans are reported and patient satisfaction with OTA services is high (Desmeules et al., 2012; Desmeules et al., 2013; Lyons et al., 2022; Madsen et al., 2021; Napier et al., 2013; Trøstrup et al., 2020; Vedanayagam et al., 2021).

Orthopaedic triage and assessment roles in New Zealand

Orthopaedic triage and assessment roles are not new in New Zealand. Physiotherapists have been working within orthopaedic departments in OTA roles in New Zealand since at least 2002 (Hames & Exton, 2010; Naik, 2021). In 2014 a regional Canterbury initiative was implemented in response to the government's focus on improving access to "better, sooner and more convenient" care for musculoskeletal conditions (Ministry of Health, 2011). This initiative consisted of a physiotherapy-led orthopaedic triage and assessment service in the elective orthopaedic department (shoulder service) and allocation of public funding for community-based physiotherapy treatment. Additionally, it established a network of general practitioners with training in providing peripheral corticosteroid injections (McGonigle & McGeoch, 2020). This was one of the first integrated primary and secondary care models. This model recognised the need to provide additional resource for delivery of community-based non-surgical treatments including physiotherapy and injections, for patients referred from the new non-surgical assessment pathway in secondary care.

Based on the Canterbury Initiative experience, a role description and training framework for orthopaedic physiotherapy practitioner (OPP) roles was developed in collaboration with the New Zealand Orthopaedic Association (NZOA) (Cadogan, 2018). This initial document outlined the definition and scope of OTA roles, detailed the administrative and resource requirements, and provided an overview of clinical governance including suggested training models to guide surgeons in setting up OTA roles in their departments.

Since then, OTA roles have become established in many elective orthopaedic departments across New Zealand. These roles have been developed on an ad-hoc basis, being adapted to the specific needs of the local service with provision of on-the-job training and supervision from orthopaedic consultants (Naik, 2021). However, funding for these roles has been difficult to secure, with most roles being funded through secondment of funding from existing salaried physiotherapy budgets within public hospitals, thus limiting widespread uptake of these roles (Naik, 2021).

The evolving health system

In 2022, the New Zealand Planned Care Taskforce was created to again review and improve access to elective services. The taskforce developed a "Reset and Restore Plan" with recommendations to enhance the current health system, which included the utilisation of highly trained allied health professionals to complete first assessments for musculoskeletal conditions to increase access to care and reduce waitlists (Te Whatu Ora, 2022).

OTA roles often involve the assessment of complex clinical presentations with physiotherapists regularly encountering situations that border, or fall outside, the scope of physiotherapy practice. However, no competency or capability frameworks are currently available that are specific to the New Zealand setting to help guide the safe and effective practice in OTA roles (Naik, 2021). As physiotherapist-led roles in various orthopaedic subspecialties continue to expand in New Zealand, and with stakeholders exploring nationwide development and funding of similar roles, a detailed competency framework is needed to ensure consistent standards of practice for the whole profession to ensure safe, effective patient management across primary, public, and private sectors.

To address this need, a group of physiotherapists with experience working in OTA roles formed a working group to develop a competency framework. The intended purpose was to identify key competencies required for OTA roles and develop a pragmatic competency framework that can be used by physiotherapists and orthopaedic surgeons in elective orthopaedic departments to support the development of safe and efficient clinical practice for physiotherapists working in these roles across New Zealand.

DEVELOPMENT OF THE COMPETENCY FRAMEWORK

In 2018, as interest in OTA roles grew, a virtual Zoom meeting was convened with approximately 30 physiotherapists from across New Zealand who were either actively engaged in or interested in OTA roles. The meeting underscored significant issues such as resource duplication, lack of professional support, and the pressing need for a comprehensive capability and training framework to facilitate "on-the-job" training, ultimately enabling physiotherapists to competently and safely perform their specialised duties with minimal supervision (Figure 1).

Following this meeting six physiotherapists, who collectively possessed over 40 years of experience in OTA roles in New Zealand, volunteered to form a working group to further define the role, scope, and associated clinical competencies for these roles (Table 1). The guiding principles of the working group included:

1. the importance of the physiotherapist–surgeon partnership with collaboration and support from the wider orthopaedic community
2. a practical framework that was easy to implement with the ability to train on the job
3. a framework that maps to existing New Zealand physiotherapy competencies (Physiotherapy Board of New Zealand, 2022b).

The working group conducted an informal scoping review of existing local and international competency frameworks related to physiotherapists working within advanced practice roles in the domain of musculoskeletal physiotherapy. Six competency frameworks were identified with existing role descriptions and competencies for physiotherapists operating at advanced levels of practice within the domains of musculoskeletal physiotherapy or orthopaedic triage (Table 2) (Australian Physiotherapy Association, 2019, 2023; Chartered Society of Physiotherapy, 2018; Health Education England, 2017, 2021; International Federation of Orthopaedic Manipulative Physical Therapists (IFOMPT) Inc., 2016; Scottish Government, 2013). All these were based on international models from the United Kingdom, Canada, and Australia. Only one advanced practice competency framework was identified that is specific to the New Zealand setting (Physiotherapy Board of New Zealand, 2022a). However, this is not (nor was it intended to be) specific to the musculoskeletal domain and does not adequately detail

Figure 1

Timeline and Summary of Methods

2017	**2018**	**2019–2023**
Development of role description and training framework for OPP roles	Virtual meeting of approx. 30 physiotherapists working in OTA roles	Development of EPA framework
ANNUAL CONSULTATION WITH NEW ZEALAND ORTHOPAEDIC ASSOCIATION REPRESENTATIVES		
Collaborative project with NZOA. Consultation: Physiotherapy Board of New Zealand. Funding: Physiotherapy New Zealand.	Need for competency framework identified. Volunteer working group established.	Existing professional competency and capability frameworks reviewed. Working group held virtual deliberative and iterative sessions (approx. 6 per year) to identify EPAs. Mapping of clinical activities with New Zealand physiotherapy competencies. Funding: None received.

Note . EPA = entrustable professional activity; NZOA = New Zealand Orthopaedic Association; OPP = orthopaedic physiotherapy practitioner; OTA = orthopaedic triage and assessment.

Table 1

*Description of the Working Group (*N *= 6)*

Description	*n* [a]
Age (years), *M* (range)	45.5 (36–58)
Time working in OTA role (years), *M* (range)	8.1 (6–12)
Clinical setting	
Orthopaedic department (DHB/Health NZ)	5
DHB band level	11–17
Orthopaedic private practice	1
Clinical subspeciality	
Spine	3
Shoulder	3
Location	
Counties-Manukau, Auckland	2
Waitemata, Auckland	1
Canterbury	2
Private practice, Auckland	1
Education	
Bachelor's degree	1
Master's degree	3
PhD/DHSc	2
Registration status	
General scope	4
Specialist	2

Note. DHB = district health board; OTA = orthopaedic triage and assessment.

[a] Except where indicated.

the specific competencies and performance criteria required for OTA roles.

Competency frameworks

In reviewing existing frameworks, the limitations of competency-based frameworks in the context of role-specific, on-the-job training became evident. Competency-based training such as the widely-used CanMeds framework (Royal College of Physicians and Surgeons of Canada, 2024) represents a deconstructed approach that focuses on achievement of specific clinical, professional, and ethical communication, education, and leadership competencies in isolation. However, this method is limited in its capacity to assess the clinician's ability to carry out clinical tasks requiring simultaneous application and integration of overlapping competencies (ten Cate & Young, 2012).

For example, when reviewing the results of radiologic investigations the physiotherapist must simultaneously integrate multiple competencies: 1) clinical competency in reading and interpreting the imaging, 2) communication competency in sensitively discussing the results with the patient or surgeon, 3) professional competency in understanding their limits of scope of practice, 4) self-directed and reflected learner competencies in managing risk in the presence of equivocal results, and 5) clinical competency (advanced clinical reasoning) in determining how the results inform changes to the treatment plan. While each one of these competencies could be assessed separately using existing competency frameworks, they do not provide information about the trainee's ability to perform specific tasks requiring integration of these competencies in specific contexts. For this reason, competency-based assessment has been questioned as an appropriate assessment method to justify decisions to entrust clinicians with specific clinical activities (ten Cate & Young, 2012).

Entrustable professional activities

Entrustable professional activities (EPAs) are an emerging concept used in the implementation of competency-based medical education (Mulder et al., 2010; Royal Australian and New Zealand College of Psychiatrists, 2024; University of Otago, 2024). EPAs are designed to link competency frameworks with actual practice providing a practical framework for training and assessment (ten Cate & Young, 2012).

An EPA is defined as a unit of professional practice that can be entrusted to a trainee when they have demonstrated competency to execute a specific activity without supervision (ten Cate et al., 2015). While competence describes the attribute of the practitioner, EPAs describe the attributes of the task that is then mapped to specific competencies to identify where knowledge, skills, or behaviours need to be developed in order to reach the level of entrustment for specific clinical activities. Although competency-based frameworks have been widely adopted to support similar advanced practice roles internationally (Australian Physiotherapy Association, 2019, 2023; Chartered Society of Physiotherapy, 2018; Health Education England, 2017, 2021; International Federation of Orthopaedic Manipulative Physical Therapists (IFOMPT) Inc, 2016; Scottish Government, 2013), the decision was made to develop an EPA framework that may be more practical for the New Zealand setting. Between 2019 and 2023 the working group participated in several deliberative and iterative rounds of discussion (with interruption during Covid-19 lockdowns) to develop an EPAs framework using the methodology described by ten Cate et al. (2015). In these sessions the working group reviewed and discussed the literature findings, and shared their own experiences to reach consensus on the key clinical activities performed by physiotherapists in these roles that aligned with the OPP role description previously developed collaboratively with the NZOA (Cadogan, 2018). A list of EPAs was compiled and associated knowledge, skill, and attributes/behaviour requirements for each EPA were identified, discussed, and refined.

ENTRUSTABLE PROFESSIONAL ACTIVITY FRAMEWORK FOR OTA ROLES

The working group identified 20 clinical tasks that are performed by physiotherapists working in OTA roles in New Zealand. Using established processes for development of EPAs (ten Cate et al., 2015) these clinical activities were grouped into five key tasks (Table 3).

1. Referral triage and management
2. Clinical assessment
3. Referring for diagnostic investigations
4. Treatment planning and management
5. Referring for interventional procedures

Table 2

List of Competency Documents Reviewed

Licensing body/organisation	Document title and reference
Australian Physiotherapy Association	Physiotherapy competence framework (2023), version 7.1 (Australian Physiotherapy Association, 2023) National advanced musculoskeletal practice (AMP) physiotherapy competency framework (Australian Physiotherapy Association, 2019)
Canadian Physiotherapy Association	Clinical speciality program (Canadian Physiotherapy Association, 2017)
New Zealand Nursing Council	Competencies for the mātanga tapuhi nurse practitioner scope of practice (New Zealand Nursing Council, 2017)
Chartered Society of Physiotherapy	Musculoskeletal core capabilities framework for first point of contact practitioners (Chartered Society of Physiotherapy, 2018) Physiotherapy framework (Chartered Society of Physiotherapy, 2020)
National Health Service/Health Education England	Multiprofessional framework for advanced practice in England (National Health Service, 2018)
Physiotherapy Board of New Zealand	Physiotherapists practising in a defined field standard (Physiotherapy Board of New Zealand, 2021) Physiotherapy specialist competencies (Physiotherapy Board of New Zealand, 2024) APP seven key competencies (Physiotherapy Board of New Zealand, 2022b)
Articles	Advanced practice in physiotherapy: A global survey (Tawiah et al., 2021) Developing a competency profile for international standardization of advanced practice physiotherapy (Tawiah, 2022) Developing a core competency and capability framework for advanced practice physiotherapy: A qualitative study (Tawiah et al., 2023) Developing an international competency and capability framework for advanced practice physiotherapy: A scoping review with narrative synthesis (Tawiah et al., 2024) Competency profile for physiotherapists in Canada (Canadian Alliance of Physiotherapy Regulators and Canadian Council of Physiotherapy Regulators, 2017) Advanced musculoskeletal physiotherapy practice: Informing education curricula (Fennelly et al., 2020)

Each EPA represents an activity that is related to patient care, can be readily observed and assessed, can be executed within a specific timeframe by registered physiotherapists, and is suitable for focused entrustment decisions in this setting (ten Cate & Taylor, 2021). To provide clarity to the role and help manage clinical risk the description of each EPA includes its context and limitations, knowledge requirements (Table 4), skill requirements, attitudes/behaviours (Table 5), and domains of competence (Table 6).

Context and limitations

The context and limitations for EPAs specifies the setting and population to whom the EPA applies, to provide clarity and to minimise clinical risk. All EPAs in this model apply to adult patients (> 16 years old) being assessed by physiotherapists in elective orthopaedic subspecialty clinics including presentations with moderate–high complexity.

Limitations specify what is not covered by the EPAs. In this model, general limitations and exclusions for the EPAs are paediatric patients, acute trauma, and those that fall outside the specific clinical subspecialty area, outside scope of physiotherapy practice, or outside the physiotherapist's area of specific training/expertise.

Physiotherapy competency mapping

The EPAs were then mapped to competency domains aligned with the Physiotherapy Board of New Zealand's (PBNZ) seven key competency areas (physiotherapy practitioner, professional and ethical practitioner, communicator, self-directed and reflective practitioner, collaborator, educator, manager/leader) at the minimum level of advanced practice physiotherapy (Physiotherapy Board of New Zealand, 2022a). Specific competencies domains relating to each EPA activity were identified (document available on request to the corresponding author). Within each competency domain, enabling competencies and performance criteria were developed that relate specifically to OTA roles. An EPA-competency matrix was then developed cross-referencing EPA activities with PBNZ competency domains (Table 6). Some competencies were included that did not meet criteria for an EPA, such as outcome monitoring, clinical audit, and risk analysis, because they are not discrete, observable clinical activities; however, these aligned with the role description for OTA roles.

The PBNZ had been previously consulted and had established that these roles fell within physiotherapy scope of practice (Cadogan, 2018). The NZOA provided feedback and input into the role description, EPAs, and associated competencies.

Table 3

Entrustable Professional Activities

EPA	Specific context and limitations [a]	Tasks
1. Referral triage and management	Triage and management of referrals for adults (> 16 years old) received to the elective orthopaedic service under the clinical oversight of orthopaedic specialist.	1.1. Evaluate patient referrals from GPs (or other referrers) and action a triage decision based on local service eligibility, access criteria, and clinical thresholds. 1.2. Send requests for further information to the referrer when required to reach a triage decision. 1.3. Arrange necessary diagnostic investigations when required in order to reach a triage decision. 1.4. Allocate accepted referrals to appropriate orthopaedic FSA or non-surgical assessment pathways and prioritise according to clinical urgency and service-specific prioritisation tools. 1.5. Escalate urgent/serious pathologies to appropriate clinical pathway. 1.6. Transfer patient referrals to other appropriate services or departments.
2. Clinical assessment of musculoskeletal conditions		2.1 Complete clinical assessments that include review of clinical notes, previous investigations and interventions, patient history, and physical examination. 2.2 Formulate a clinical differential diagnosis. 2.3. Escalate referrals for people with potentially serious pathologies, medical conditions, or complex pain presentations to local management pathways. 2.4 Dictate (or otherwise document) clinical notes for each clinical encounter and sign off/authorise dictated notes and letters prior to distribution.
3. Refer for diagnostic investigations for non-traumatic musculoskeletal conditions	Excludes requests for specific investigations that require medical sign-off where these are not covered under "standing order" or other agreed service/ department authorisations.	3.1 Refer for diagnostic investigations. 3.2 Follow-up, act-on, and communicate investigation results to the patient, liaising with surgeon or supervisor where there are unexpected results. 3.3 Document and communicate the results and updated treatment plan to the referrer and healthcare team.
4. Treatment planning and non-surgical management for non-traumatic musculoskeletal conditions	Excludes requests for specific interventions or other treatments that require medical sign-off where these are not covered under "standing order" or other agreed service/department authorisations.	4.1 Undertake treatment planning that prioritises the person's needs and preferences. 4.2 Refer to orthopaedic FSA, medical, or allied health services as appropriate for treatment of their condition. 4.3 Arrange and undertake follow-up clinical assessment and update the treatment plan according to the person's evolving needs. 4.4 Document and communicate the treatment plan and any updates and changes to the referrer and healthcare team for each clinical encounter. 4.5 Undertake discharge planning in collaboration with the person and healthcare team and complete discharge documentation including hand-over of care.
5. Refer for interventional procedures for non-traumatic musculoskeletal conditions.	Excludes requests for specific interventions that require medical sign-off where these are not covered under "standing order" or other agreed service/ department authorisations.	5.1 Refer for interventional procedures within local service specification and authorisation pathways. 5.2 Complete follow-up (in clinic, telehealth, or other method of follow-up) after interventional procedures and update, document, and communicate the updated management plan to referrer and wider healthcare team.

Note. EPA = entrustable professional activity; FSA = first specialist appointment.

[a] This sets out the conditions under which this EPA operates and its exclusions. All EPAs apply to adult patients (> 16 years old) being assessed by physiotherapists in orthopaedic subspecialty clinics including those with moderate–high complexity. All EPAs exclude paediatric patients, acute trauma, and those that fall outside the specific clinical subspecialty area, outside scope of physiotherapy practice, or outside the physiotherapists' area of training/expertise. The specific context and limitations included here are in addition to the general context and limitations

Table 4

Knowledge Requirements for Orthopaedic Triage and Assessment Roles

Topic	Specific knowledge requirements
Cultural	Te Tiriti o Waitangi. Māori and Pacific action plans. Role and scope of Māori and Pacific Island support teams. How to access and utilise interpreter services.
Serious pathologies	Red flags indicators for potentially serious pathologies including vascular, infection, neoplastic, neurologic, autoimmune/systemic inflammatory, trauma, mental health.
Medical conditions	Features of non-musculoskeletal pain. Clinical features, diagnostic, referral and management pathways for neurovascular claudication, rheumatology (rheumatoid arthritis, gout, spondyloarthritis, polymyalgia rheumatica, osteoporosis), endocrine conditions (diabetes), neurologic conditions, congenital conditions (connective tissue diseases), psychological conditions (clinical depression), oncological conditions. Implications of specific medical conditions and their relevance to surgical and anaesthetic, imaging, and interventional procedure risk.
Pain classifications	Mechanisms, features, objective clinical tests, and management pathways for specific pain classifications: nociceptive pain (including inflammatory pain), neuropathic pain, nociplastic pain.
Pharmacology	Therapeutic use and dosage, indications, contraindications, interactions, side effects and clinical relevance of common pain, anticoagulant, hypertensive, anti-inflammatory (steroidal and non-steroidal), antidepressant, rheumatologic, epilepsy, diabetes medications, and cancer therapies. Implications of specific medications for selection of surgical and non-surgical treatment interventions.
Specific musculoskeletal conditions	In-depth knowledge of specific traumatic, non-traumatic, and congenital musculoskeletal conditions in the sub-specialty area including prevalence, pathoaetiology, differential diagnosis, diagnostic criteria for (clinical and imaging criteria), natural history, prognosis, evidence-informed clinical pathways (continuum from non-surgical to surgical management), evidence-informed treatment, and outcomes.
Diagnostic investigations	Utility and utilisation, indications, contraindications, safety, limitations, procedure details, specific sequences and views, risks, adverse effects and complications of radiologic imaging (x-ray and ultrasound), high-tech imaging (MRI, CT, and bone scan), laboratory tests, diagnostic blocks, nerve conduction studies. Range of normal and abnormal test results and prevalence of population-specific abnormal findings.
Interprofessional practice	Knowledge of the indications, access criteria, referral pathways, and estimated wait times for orthopaedic FSA, medical specialty referral, physiotherapy (including specialist physiotherapy services), occupational therapy, pain service.
Prognostic factors	Knowledge of prognostic factors that may influence selection of diagnostic or treatment interventions and treatment outcome including how these are screened, identified, measured, and interpreted including biologic, cognitive, psychologic, social factors, and other health determinants.
Differential diagnosis	Pain mechanisms: criteria, screening tools and clinical features of nociceptive, neuropathic, nociplastic pain, complex regional pain syndrome. Diagnostic accuracy of clinical tests for specific pathoanatomic conditions and how accuracy is influenced by prevalence in specific populations and other factors. Clinical and imaging diagnostic criteria for specific conditions.
Non-surgical management	Evidence-informed and/or locally agreed clinical pathways for specific musculoskeletal conditions including indications, contraindications, benefits, risks, treatment techniques, adverse effects, timeframe and expected outcomes for medications, physiotherapy, interventional procedures (see below). Understand when all non-surgical management options have been completed and onward referral for orthopaedic assessment is indicated.

Topic	Specific knowledge requirements
Interventional procedures	Evidence and therapeutic use of interventions for specific conditions including indications, contraindications, procedure details, risks, benefits, adverse effects, complications, expected effects and timeframes, prognostic factors and outcomes for injectables, hydrodilatation, nerve blocks, radiofrequency ablation, fenestration/barbotage, aspiration.
Surgical management	Understand the role and timing of surgery within the continuum of care for specific musculoskeletal conditions and list indications for orthopaedic referral for specific musculoskeletal conditions within the sub-specialty area. Broadly describe common surgical techniques including surgical procedure, risks, adverse effects, and possible complications. Describe post-operative precautions, specific limitations, rehabilitation requirements, milestones, and timeframes. Describe prognostic factors, expected outcomes, and timeframes for common surgical procedures. Describe pre-optimisation requirements for common surgical procedures in the sub-specialty area.

Note. CT = computerised tomography; FSA, first specialist assessment; MRI, magnetic resonance imaging; NSAIDs = non-steroidal anti-inflammatory drugs.

Table 5

Attitudes and Behaviours that Enable Trust

Quality	Description
Agency	Proactive towards work, team, safety, and personal development. Takes positive action when appropriate within boundaries of scope and local service authorisations. This must be balanced with overconfidence.
Capability	Task-specific knowledge, skills, and experience. Situational awareness.
Conscientiousness	Thoroughness and consistency of actions with attention to detail. Takes a serious approach to managing risk.
Responsibility	Takes responsibility and accountability for decisions and actions. Ensures continuity of patient care in their absence. Identifies and acknowledges errors and lapses by self and others and initiates action. Acts upon urgent needs of care if others are not available
Reliability	Predictable and consistent behaviour. Takes responsibility and accountability for decisions and actions. Dependable. Punctual.
Integrity	Honest, providing accurate descriptions of observations or encounters including what they did and why and what they should have done/not done. Benevolent. Patient centred.
Humility	Recognises limits (personal and professional). Willing to ask for help when needed. Receptive to constructive feedback.
Collegial and respectful interprofessional relationships	Ability to develop collegial and effective working relationships with other medical and health professionals. Respects the expertise of other health professionals and communicates in a collegial manner.
Organisation and time management	Organised with a systematic approach to delivering and monitoring care. Able to prioritise tasks. Completes tasks including clinical assessment, documentation, and referrals within acceptable time-frames.

Table 6

Entrustable Professional Activities Competency Matrix

Competencies	EPA 1	EPA 2	EPA 3	EPA 4	EPA 5
	Referral triage and management	Clinical assessment	Refer for diagnostic investigations	Treatment planning and management	Refer for interventional procedures
Physiotherapy practitioner	1.1, 1.2	1.1, 1.2	1.1	1.1, 1.2,1.3, 1.4	1.2, 1.3
Professional and ethical practitioner	2.1	2.1	2.1	2.1	2.1
Communication	3.2	3.2	3.1, 3.2	3.1, 3.2	3.1, 3.2
Reflective practice and self-directed learner	4.5	4.5	4.4, 4.5	4.5	4.4, 4.5
Collaborator			5.2	5.1, 5.2	5.2
Educator				6.1	
Manager/leader		7.1		7.1	

Note. These are the physiotherapy competencies that should be achieved in order to reach entrustment Level 4. A full description of these competencies can be provided on request to the corresponding author.

Assessment

The responsibility for EPA assessment may be shared or delegated according to availability of appropriately qualified personnel and according to local time and personnel resources. Initially, while there is a small number of physiotherapists in these roles, the majority of this responsibility will likely fall to the senior medical officer (SMO) responsible for the subspecialty service. As the roles become more established with a greater number of physiotherapists achieving the required level of training and competency, assessment responsibilities may be delegated accordingly.

Assessment of the EPAs is typically framed in the context of supervision. EPA-based assessment tracks the progression of competence for each EPA resulting in summative entrustment decisions to act according to a specified level of supervision. The level of mastery of an EPA is reflected by five stages of decreasing supervision requirements (Mulder et al., 2010; ten Cate & Scheele, 2007).

- Level 1 – no task execution (trainee observes only).
- Level 2 – task execution under direct supervision on site (direct supervision).
- Level 3 – task execution with supervision quickly available on call (indirect supervision).
- Level 4 – unsupervised practice (distant supervision with post-hoc or virtual checking available).
- Level 5 – provide supervision to junior trainees.

Entrustment decisions regarding the level of supervision required are based upon the following questions (ten Cate et al., 2015):

- Do I need to assist this trainee?
- Can I leave the room/department to come back later?
- Will I trust the information in the electronic patient record to be adequate and sufficient when I see it tomorrow?

EPAs are entrusted when the supervisor is confident the physiotherapist:

1. demonstrates the knowledge, skills, and attitudes required of the task
2. knows when to ask for help and
3. can be trusted to seek assistance in a timely manner.

By the end of the "training" period the physiotherapist should be able to perform each EPA with minimal/distant supervision (Level 4). The EPA competency matrix provides an overview of essential competencies that should be present before trainees may be trusted to act unsupervised or with only indirect supervision (Table 6).

Mandated assessment procedures were not included in the development of this framework as it is likely that local time and personnel resources will vary. However, progress can be assessed using a range of formative and summative assessment methods. Such methods include, but are not limited to, completion of mandatory departmental training (e.g., radiology, health and safety, cultural), minimum of weekly direct observation, weekly case-presentations and case-based discussion, quarterly clinical audits of medical notes and referrals, and diagnostic and management audits against supervisor decisions. The number of observations or encounters required to constitute the basis for entrustment for a specific EPA is at the discretion of the supervising clinician or training team and dependent on progress of the individual.

Supervision

Until these roles become more established, with enough physiotherapists practising at Level 4 or 5 with the required expertise to supervise others, it is likely the majority of supervision will fall to the SMO. The experience of our working group is that this does not place a significant additional burden on the SMO as they are frequently training registrars and junior doctors, which is viewed as a similar process by many of the surgeons.

As more physiotherapists take on these roles and progress to reach higher levels of entrustment, supervision and training may be shared among the wider team. This may include other physiotherapists, or other allied health professionals who are working in OTA roles who have, themselves, demonstrated the required level of expertise to enable supervision of other practitioners. Supervision requirements for individual practitioners will depend upon the entry level of individual physiotherapists and may be high initially, but will likely reduce as competency and confidence increase.

Training period

The amount of time required for physiotherapists to reach entrustment may vary significantly due to the diverse professional profiles and non-linear progression of practitioners. The physiotherapists' entry-level knowledge, clinical skills, and experience; the number of hours allocated to the role; the availability of supervisors; and opportunities for feedback and development also influence the rate of progression. Those with lesser entry-level experience working in part-time roles are likely to take longer to achieve entrustment than those with more advanced clinical skills who are working full time.

It is the experience of the group that, based on a role with a full-time equivalent of 0.2 (approx. 1 day per week) where the SMO is available for direct and indirect supervision and feedback at every clinic, a physiotherapist with a minimum of 4–5 years of experience in musculoskeletal physiotherapy may take a minimum of 2 years to reach Level 4 entrustment. This also assumes a component of self-directed learning and professional development.

IMPLICATIONS

The Orthopaedic Physiotherapy Practitioner (OPP) roles, first officially described in 2018 (Cadogan, 2018) have evolved in response to individual organisational needs (Naik, 2021). Stakeholders are now exploring the possibilities of developing these roles nationwide as a solution to the country's musculoskeletal healthcare needs. OTA represents one role physiotherapists can fulfil to help improve timely access to musculoskeletal care.

The EPA framework is the first step in providing physiotherapists and orthopaedic consultants with clarity on the activities and associated competencies required for these roles. This will help to guide the professional development of physiotherapists within elective orthopaedic departments towards the capability to act safely and independently with limited supervision within the assigned clinical subspecialty areas (e.g., spine, shoulder, hip/knee service). In this section we discuss some of the implications, considerations, and perspectives related to the use of the EPA framework in OTA roles in New Zealand.

Definition of triage

As OTA roles expand in New Zealand, a clear and consistent definition of triage is needed to provide clarity for funders, employers, clinicians, regulators, and educators. In elective settings, the triage, or referrals without patient contact, requires a different skillset from the "triage" of patients during a clinical assessment. Paper-based triage of referrals often involves identifying and managing serious pathologies, organising appropriate investigations, and urgency of escalation and referral. In contrast, in-person clinical assessment and "triage" for hip and knee osteoarthritis typically focuses on evaluating the severity of symptoms and determining the need for surgical intervention. These differences highlight the need for clear operational definitions for "triage" in different contexts including the source of referrals, specific conditions, scope of practice and competency of the triaging clinician, location of triage (within orthopaedic outpatients or the community setting), and purpose and outcome of triage (e.g., for diagnostic assessment or treatment or surgical prioritisation).

Relationship to other New Zealand competency frameworks

The level of competence required for OTA roles is aligned at the level of the PBNZ Advanced Practice Physiotherapist (Physiotherapy Board of New Zealand, 2022a). Physiotherapists working at this level are expected to manage and lead episodes of care, acting independently in complex situations within scope of practice, demonstrating advanced clinical reasoning, influencing health service delivery with involvement in mentoring, supervision, teaching, and research (Physiotherapy Board of New Zealand, 2024). However, registration under the advanced practice physiotherapy scope of practice or even specialist scope of practice with the PBNZ does not equate to nor imply competence in OTA roles and vice versa. In addition, national agencies such as Health New Zealand Te Whatu Ora may define specific roles for physiotherapists under titles such as advanced clinical practitioner/advanced practitioner or consultant physiotherapist. However, assignment of these titles and designated roles does not equate to nor imply competence in OTA roles.

Operational perspectives

The intended use for the EPA framework is to provide support for rapid implementation of "on-the-job' training of physiotherapists in OTA roles. This framework includes much detail by necessity, but for the SMOs working in busy clinics, often responsible for junior doctors, registrars, fellows, as well as training OTA practitioners and their own caseload, simplified documentation is likely to be required to streamline the supervision process and assessment of entrustment level. A summary document of key knowledge, skills, and behaviours in specific clinical subspecialty areas may assist SMOs in identifying gaps and focusing learning opportunities for individual physiotherapists.

Physiotherapy education

Physiotherapists are well suited to working in OTA roles. Physiotherapy scope of practice includes the ability to practise autonomously including diagnostic decision-making and patient management (Marks et al., 2017). Physiotherapy undergraduate training typically includes a strong musculoskeletal focus and many who are working in OTA roles also have postgraduate musculoskeletal qualifications including master's degrees. However, currently no comprehensive clinical programmes exist that combine the knowledge, skill, and clinical supervision requirements needed by physiotherapists specifically for these roles. In addition, some clinical activities including triage, diagnostic investigations, and patient management that present a higher level of clinical risk, sit within the PBNZs "defined field" of practice requiring additional training and supervision to ensure safety.

At present, the majority of physiotherapists working in these OTA roles rely on a combination of on-the-job training under the guidance of orthopaedic surgeons, the availability of relevant online and practical courses, and self-directed learning to acquire this expertise. Advanced practice musculoskeletal training programmes have been developed with success in other countries (Stevenson et al., 2020), with key elements of success including the bespoke and flexible nature of the programme, and mentoring (Stevenson et al., 2020). At present no structured training programmes exist in New Zealand. In the absence of a role-specific training programme, the EPA framework clearly sets out the knowledge and skill requirements enabling individual clinicians and their supervisors to identify knowledge and skill gaps from which individualised learning plans can be developed.

In addition to developing clinical skills, entrustment decisions integrate assessment of the trainee's understanding of autonomy, clinical risk management, awareness of boundaries, when to seek assistance, and escalation points that are essential in trusting trainees with specific clinical tasks. The EPA framework thus integrates multiple competencies under specified conditions, identifying specific knowledge, skills, and attributes, and provides suggestions for assessment methods while allowing flexibility for training processes and timeframes. Entrustable professional activities represent building blocks for the trainee, and they provide clear assessment goals for the trainer.

Reported benefits of EPA models include providing an integrated learning approach and enabling fundamental knowledge and skills to be learned at the same time as trainees are introduced to patient care (University of Otago, 2024). The ability to learn "on the job" thus allows immediate practical application of new knowledge, repeated opportunities for skill acquisition, and immediate feedback. It also 1) provides exposure to interprofessional practice and supervision; 2) is cost-effective for both trainee and the department by not requiring extended periods of study leave outside the department; 3) fosters a culture of continuous learning; 4) provides a flexible learning environment; and 5) meets governance requirements for practising in a defined field of interest. The EPA framework thus represents an initial step to facilitate the safe and efficient upskilling of suitable trainees at a time of rapid implementation of these roles.

Clinical governance

The working group's goal was primarily to identify key activities and associated competencies to establish a clear set of EPAs for use by SMOs and physiotherapists working in OTA roles. There are additional and important training, clinical governance, and pastoral care requirements in OTA roles for safety, efficacy, and performance monitoring purposes. These requirements include evaluating patient experience, clinical audits, risk management, adverse reaction register, clinical outcome monitoring, staff development, mentoring and pastoral care, IT management, and research and development. It was beyond the working group's scope to establish operational guidelines for these aspects of the OTA role. As these roles expand over coming years, further guidance on these areas will be required. The EPAs and associated competencies presented here are intended to provide a possible foundation from which this can evolve.

Conceptual development

The EPA framework presented here is designed specifically for physiotherapists engaged in OTA roles within elective orthopaedic departments within clinical subspecialty areas. As these roles continue to evolve, the framework could be expanded and adapted to integrate additional orthopaedic departmental activities that can be performed by suitably trained physiotherapists, including postoperative reviews and administering injection procedures. At present, this EPA framework does not include any activities that currently fall outside the physiotherapy scope of practice in New Zealand, such as prescribing medications or performing injections. A small number of physiotherapists in New Zealand are administering injections under the defined field of interest scope of practice, and these activities are routinely being performed by physiotherapists in other countries to further ease the burden on surgeon and interventional resources. In time, EPAs could be developed specifically for these activities supported by standing orders within the department and added to this EPA framework.

Other uses and applications of this framework extend to physiotherapists working in other advanced practice musculoskeletal settings, such as first contact roles, other musculoskeletal triage roles, and emergency departments. Many of the EPAs in the orthopaedic framework are readily transferable to these settings, where they can be adopted or modified, and other EPAs added to develop specific EPA frameworks for each clinical role and healthcare setting. This framework may also be adapted for physiotherapists working in advanced practice roles across other clinical specialties including women's health, paediatrics, cardiorespiratory, and rheumatology. By identifying knowledge and skill requirements, the EPAs may also serve to inform development of educational curricula for advanced practice roles in New Zealand.

Limitations

Care should be taken not to extrapolate and apply this EPA framework beyond its intended scope, setting, context, and inherent limitations. The EPA framework does not include milestones that are typically included in EPA frameworks. This was a deliberate decision, recognising the diverse professional profiles of these practitioners, suggesting that the progression towards entrustment in different tasks and domains may be non-linear, necessitating a flexible approach within the framework. This framework, in its initial form, is grounded in the collective expertise of the working group and insights from the New Zealand orthopaedic community. Its application has not yet been widespread and external validation is needed. The document does not intend to impose mandates on the clinical governance aspects of implementation such as supervision and assessment requirements and timeframes. While this may require further work, flexibility must be retained to serve the time and personnel resources in local departments. Post-implementation, it is imperative to periodically review and update the framework to accommodate refinements based on user feedback and the evolving nature of these roles.

CONCLUSION

The EPA framework, developed in collaboration with the New Zealand Orthopaedic Association provides New Zealand physiotherapists and their supervising clinicians with a tool to guide the implementation, training, and capability development of physiotherapists working in OTA roles within elective orthopaedic departments in specific clinical subspecialty areas in New Zealand. The EPA framework may be expanded to include other clinical activities performed by physiotherapists in orthopaedic departments and may serve as a template for physiotherapists engaged in similar advanced practice roles in other areas of healthcare.

KEY POINTS

1. The EPA framework: Is specifically designed for physiotherapists working in orthopaedic triage and assessment roles within sub-specialty services in elective orthopaedic departments in New Zealand.
2. Clinical capability: This provides a practical framework for the development of capability and entrustment for specific clinical activities with minimal/no supervision.
3. Adaptability of the framework: The framework allows for flexibility and adaptability in training and skill development and provides scope for the addition of important or high-risk tasks, and may have transferable use across other advanced practice physiotherapy roles.
4. Continual evaluation and update: The framework anticipates regular updates and revisions based on practical application and feedback, ensuring it remains relevant and effective in evolving clinical settings.

DISCLOSURES

No funding was obtained for this project. There are no conflicts of interest that may be perceived to interfere with or bias this study.

PERMISSIONS

This project did not require ethical approval as per institutional and national guidelines. The research did not involve any experimental research on humans or animals. This study exclusively involved the theoretical development of a professional framework and associated competencies. No proprietary or confidential information was utilised in this process.

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Conceptualisation and project administration, AC; validation, LN; methodology and formal analysis, AC, LN, MB, MZ, PT, and KC; writing – original draft preparation, AC, LN, MB, MZ, PT, and KC; writing – review and editing, AC and LN.

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What Are Possible Reasons for the Different Choices of Low Back Pain Healthcare Between European, Māori, and Pasifika for Services Funded by the Accident Compensation Corporation?

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ABSTRACT

Aotearoa New Zealand has a unique funding model in the Accident Compensation Corporation (ACC), for those who have an injury. The ACC funds a range of healthcare practitioners to treat low back pain from accidental causes and the costs continue to rise. However, there are clear ethnic differences in the services accessed. Data were obtained from ACC and analysed to observe trends in the number of claims and the cost per claim over an 11-year period. The three key findings were: (a) Māori and Pasifika have a lower number of claims than their European counterparts, proportional to population; (b) Māori have fewer claims, but a higher cost per claim than other ethnic groups; and (c) Māori and Pasifika use GP services most frequently, whereas Europeans use physiotherapy. Several factors are potential drivers of these differences, including cost of services leading to delay in seeking help, lack of culturally appropriate information about services, lack of culturally appropriate services, and disproportionately low numbers of Māori and Pasifika in the healthcare workforce. Possible solutions include earlier referral for physiotherapy, building connections with patients, and embracing principles of health models, Te Whare Tapa Whā (Māori) and Fonofale (Pasifika) (which describe the essential elements for health: spiritual, physical, mental and emotional, family, and social).

Saywell, N. L., Gordon, J., Adams, T., Niazi, I., & Hill, J. (2024). What are possible reasons for the different choices of low back pain healthcare between European, Māori, and Pasifika for services funded by the Accident Compensation Corporation? *New Zealand Journal of Physiotherapy, 52*(3), 250–256. https://doi.org/10.15619/nzjp.v52i3.458

Key Words: Accident Compensation Corporation, Healthcare, Low Back Pain, Māori, Pasifika

INTRODUCTION

Most New Zealanders (87%) will experience low back pain (LBP) at least once in their lifetime (Darlow et al., 2014) from disease, accident, or injury. Recent annual figures show there were over 304,000 Accident Compensation Corporation (ACC) claims for LBP from accidental causes in 2020 (Hill et al., 2023). ACC offers a range of services via approved providers for people with LBP seeking primary healthcare, offering a wide choice for claimants (Accident Compensation Corporation, 2024).

Aotearoa New Zealand is an ethnically diverse country. At the last census, 68% of the population were European, 18% Māori, 9% Pasifika, 17% Asian, and 2% Middle Eastern, Latin American, or African (people can identify as more than one ethnicity, so the total is more than 100%) (Stats NZ, 2023). Māori and Pasifika are particularly poorly served by the health system and ethnicity-based inequity in healthcare has been well documented, so the focus of this paper is on differences between European, Māori, and Pasifika use of services for LBP (Health Quality and Safety Commission, 2019).

To achieve an inclusive healthcare system for all New Zealanders, it is important to understand individual healthcare needs, including recognising ethnic differences in health priorities and values, such as the attributes, competencies, and skills people value in health practitioners and that engender trust. This impacts who people choose as their healthcare provider. Our initial step was to analyse the choice of healthcare provider by ACC claimants with LBP. While data were collected for all ACC claims, the focus of this paper is on Māori and Pasifika healthcare. The discussion focuses on findings from a paper by Hill et al. (2023).

The aim of this paper is to present a scholarly opinion on the differences between European, Māori, and Pasifika healthcare use and costs for ACC services for people with low back pain, found in a recent study (Hill et al., 2023). In collaboration with a Māori physiotherapist (JG), tribal affiliation Ngāti Raukawa and Ngāti Maniapoto, we suggest reasons for this and present possible solutions to promote equity.

METHODS

We extracted ethnicity data from a larger retrospective audit and descriptive analysis of ACC-funded, healthcare service for people with LBP (Hill et al., 2023).

The data sets used are as follows:

1. Claims and costs of healthcare, by ethnicity as a proportion of the population.
2. The number of claims, and the cost, by ethnicity as a proportion of ACC funding for LBP claims.
3. The trends in healthcare usage by ethnicity between 2009 and 2020.

We collected and analysed data from ACC-recorded claims and costs of LBP healthcare services between 2009 and 2020. All data were de-identified, so participant consent and ethical approval were not required.

Data management

Every person who seeks healthcare funded by ACC is asked to identify their ethnicity on an ACC45 claim lodgement form. The choices offered by ACC of ethnic groups are Māori, Pasifika, Asian, European, or other. Those who identify as Māori, even if they identified with several ethnicities, were recorded as Māori. Data on ethnicity, and where people accessed their healthcare, were charted.

Data analysis

Descriptive analysis of the healthcare services was completed. The "other" category was excluded in this analysis as it was a heterogeneous group with no ability to categorise ethnicity. Trends were considered from 2009 to 2020 and an analysis of the most recent full year of data (2020) was undertaken. Graphs were plotted in R (The R Foundation for Statistical Computing, 4.1.0) (CoreTeam, 2021) using package ggplot2 (version 3.3.3) (Wickham et al., n.d.).

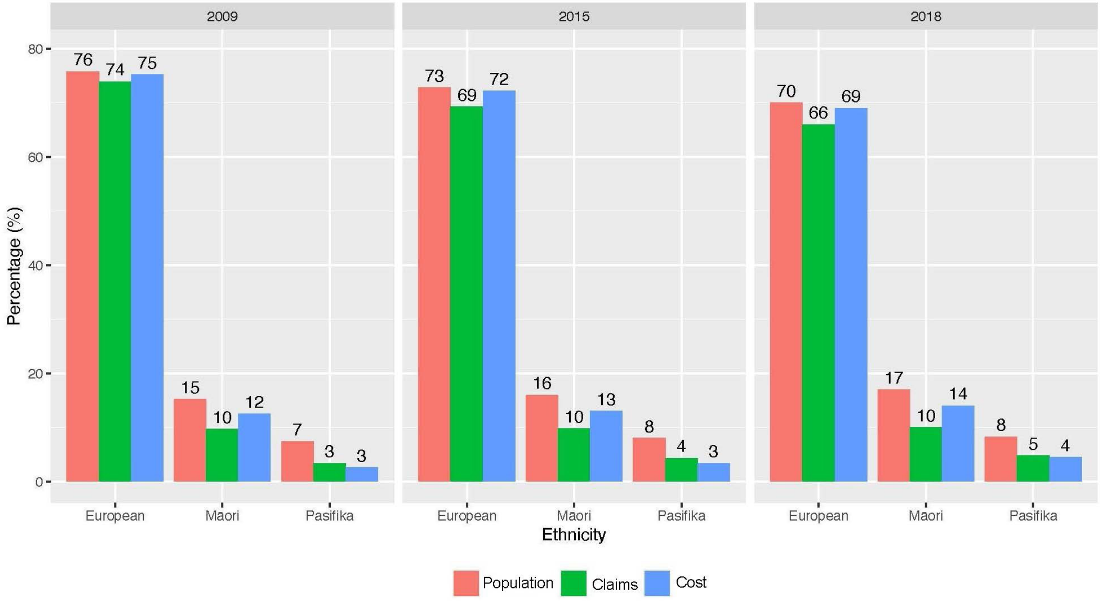
RESULTS

The results present differences in healthcare use by ethnicity. It was established using the Chi-square test of independence that selection of service type and ethnicity are dependent. This means the choice of service type is significantly associated with ethnicity across all years examined. The three data sets are shown below.

Figure 1 shows the proportion of total claims and the cost of claims relative to the proportion of each ethnicity in Aotearoa New Zealand. Europeans represented most claims, and their claims and costs were commensurate with their percentage of the population. Pasifika people had the lowest number of claims and the lowest healthcare costs, which were well below their percentage of the population. Claims by Māori were lower relative to their percentage of the population, but their relative healthcare costs were higher (closer to their percentage of the population).

Figure 1

ACC Claims and Costs by Ethnicity During the Study Period



Note. The proportion of each ethnicity changed over time.

Figure 2 shows the number of claims and their cost, as a percentage of total ACC LBP claims. Europeans claimed at a level commensurate with their proportion of the population; however, both their number of claims and costs decreased over the period in review. Claims by Māori and Pasifika increased at a very slow pace < 2% over the 11 years in review; however, for Māori claimants the cost per claim was higher than any other ethnic group.

Figure 3 presents the data for the healthcare provider selected by individuals (presented by ethnicity), which shows that for Europeans physiotherapy is consistently the most used service, with the GP second. For Māori and Pasifika, GP services are used more frequently than physiotherapy

DISCUSSION

The aim of this paper was to hypothesise reasons for the differences between European, Māori, and Pasifika healthcare use and costs, for ACC services for people with low back pain, and to present possible solutions to promote equitable access to healthcare.

Māori and Pasifika used GP services more than any other healthcare service for LBP, compared to their European counterparts, who used physiotherapy services most frequently. There was a low number of claims for Māori and Pasifika, who had fewer claims than Europeans, proportional to their population. Although Māori had a lower percentage of claims, they had higher costs per claim. There is considerable overlap of potential drivers of the key study findings. Reasons for each key finding are hypothesised and represented with possible solutions, in Figure 4.

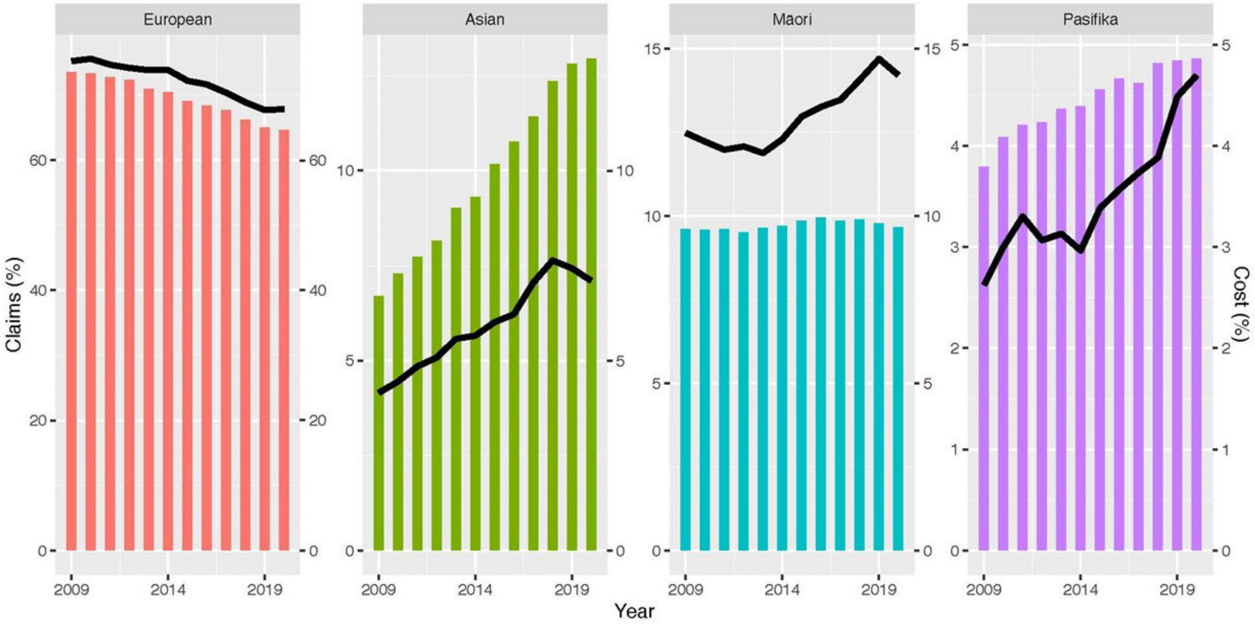
Why do Māori and Pasifika have a lower number of claims than Europeans proportional to population?

The lower claim lodgement could be explained by a lower injury rate for Māori and Pasifika. However, as both groups are highly represented in manual work and contact sport (Ministry of Social Development, 2016), the more likely explanation is more complex and includes the cost of accessing appropriate healthcare and the availability of culturally appropriate services. Jeffreys et al. (2023) investigated cost barriers to accessing healthcare in Aotearoa New Zealand and found that 22% of Māori, compared to 13% of non-Māori, encountered cost barriers to seeing a GP. In their study Māori represented only 10% of total LBP claims, despite making up 18% of the Aotearoa New Zealand population (Stats NZ, 2015). There is a burgeoning body of literature exploring Pasifika peoples' access to healthcare and the multiple barriers Pacific people face in a system where cultural support is often "overloaded and under resourced", and a Ministry of Health report (Ministry of Health, 2023; Ryan, 2019) found Pasifika people also experienced significant cost barriers to accessing healthcare services.

A biomedical approach, focused on physical symptoms, may disregard culturally relevant methods of managing health, thus reducing equity of care (Dixon et al., 2021; Graham & Masters-Awatere, 2020). A scoping review by Harfield et al. (2018) investigated characteristics of successful healthcare services for Indigenous populations and found that cultural consideration was the most prominent characteristic that underpinned all other identified characteristics. At the heart of culturally appropriate services are a skilled workforce, community participation, and self-determination and empowerment (Harfield et al., 2018).

Figure 2

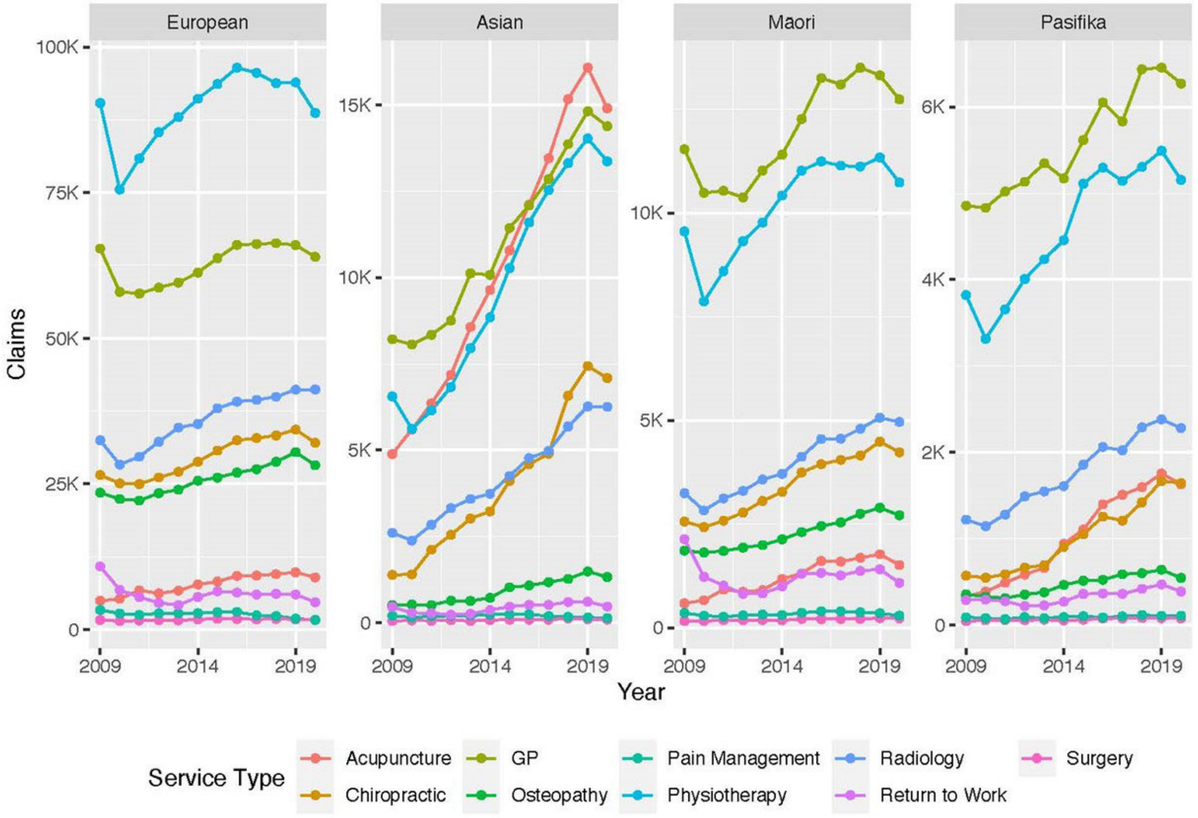
Percentage of Total ACC-funded LBP Claims and Costs by Ethnicity



Note. Claims = coloured columns; costs = black line. Note the floating Y axis that shows trends more clearly.

Figure 3

Percentage Distribution of Total LBP Claims by Service Type for Each Ethnicity, 2010–2020



Note. This figure provides a proportional view of service utilisation, highlighting how each service type contributes to the total claims for each ethnic group.

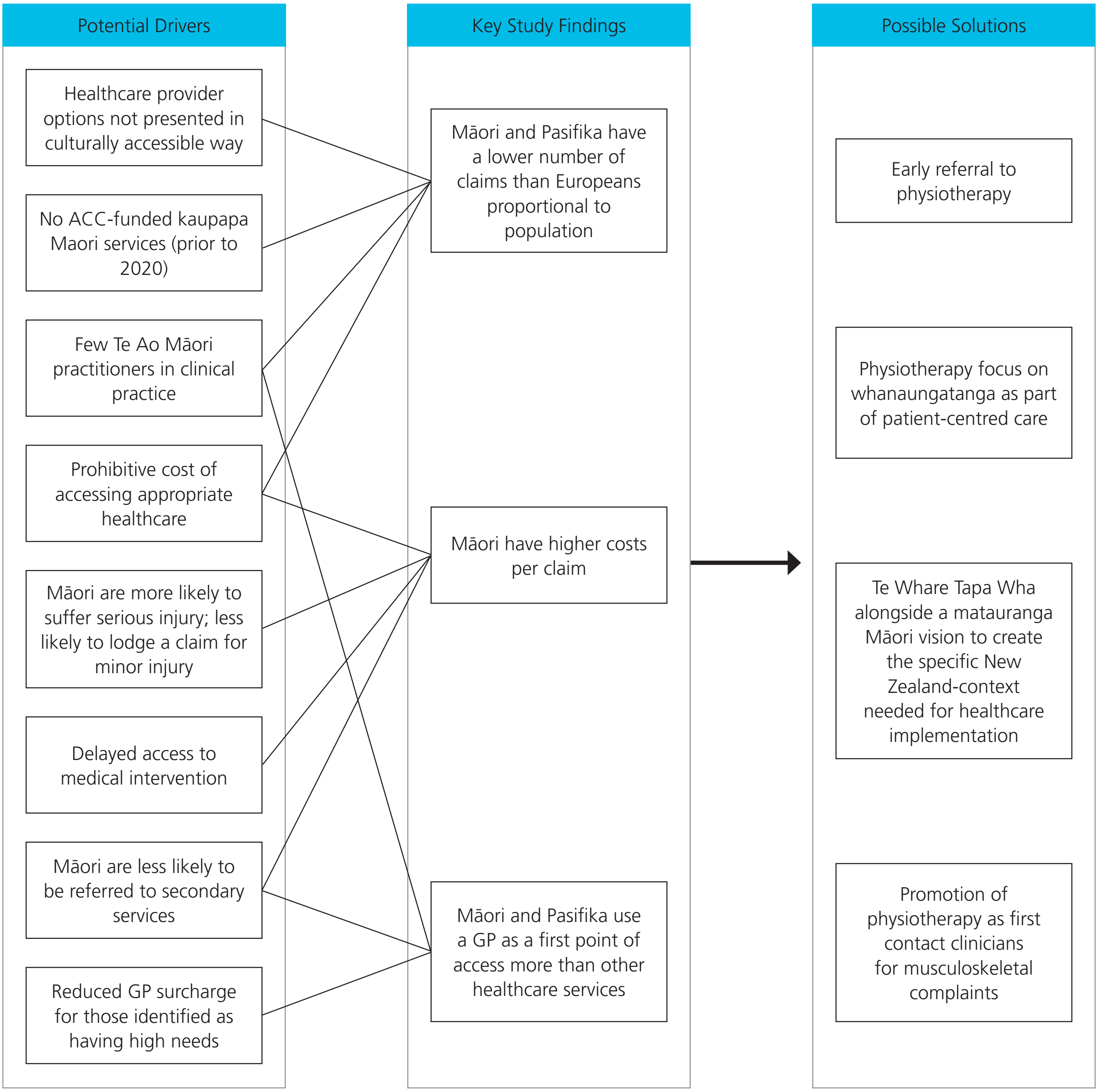
The Physiotherapy Board of New Zealand annual report (Physiotherapy Board of New Zealand, 2024), reported the percentage of physiotherapists in Aotearoa New Zealand as 4% Māori and 2% Pasifika. This shows significant under-representation in the workforce considering 18% of the population of Aotearoa New Zealand are Māori and 9% Pasifika. This potentially reduces the inclusion of Māori-specific beliefs or practices in mainstream Western-oriented public healthcare. There have been no kaupapa Māori services funded by ACC for LBP. However, in 2020 for the first time the use of rongoā Māori (traditional healing processes) was supported by ACC, reversing the longstanding omission of culturally relevant services, to improve access to and experience of ACC services for Māori. Graham and Masters-Awatere (2020), in a systematic review of qualitative research over two decades, state that Māori health practitioners who provide "warm, holistic, culturally appropriate" (p. 198) healthcare improve engagement with Māori patients. Adopting Māori models of healthcare such as Te Whare Tapa Whā (Durie, 1994), alongside a mātauranga Māori vision (using Indigenous knowledge) and Pasifika models of health such as Fonofale (Pulotu-Endemann & Tu'itahi, 2009), will create the specific Aotearoa New Zealand context needed for healthcare implementation, helping to remove barriers for Māori and Pasifika to access appropriate LBP services.

Why do Māori have higher costs per claim?

Ministry of Health data show that disability related to injury is higher for Māori than for non-Māori (Ministry of Health, 2016). The reasons for this are outlined in this section. The findings from the current study show that people with LBP have the choice of consulting a wide range of healthcare practitioners. Bise et al. (2023) in a study in the USA, suggest that patients who chose physiotherapy and chiropractic early during their care had the shortest median length of LBP episode, which lowered costs and decreased the likelihood of developing a chronic condition. Other studies support this finding, that patients who receive physical therapy or chiropractic treatment early in their LBP episode require less expensive and less invasive procedures compared to those who select GP care (Fritz et al., 2016). Māori access these rehabilitation services less frequently and often present later after the onset of their LBP than their European counterparts; ACC data show that Māori and Pasifika are less likely to be referred to services like physiotherapy, and Māori experience longer waiting times and are less likely to receive best-practice interventions for their health conditions (Accident Compensation Corporation, 2021; Health Quality and Safety Commission, 2019). These factors increase the likelihood of developing a chronic condition, leading to higher costs per claim for Māori.

Figure 4

Potential Drivers of the Key Study Findings and Possible Solutions



There is a need to change patient perception that the GP is the "only rational choice for … management of a musculoskeletal complaint" (Moffatt et al., 2018, p. 128). General practice services for those with a community services card are heavily subsidised by ACC, which may account for them being the most frequently accessed by Māori and Pasifika, and for the reduced appeal of other healthcare services such as physiotherapy or chiropractic, which are not included in this scheme (Accident Compensation Corporation, 2021; Health Quality and Safety Commission, 2019). Electing to visit the GP is the lowest cost option for patients but the highest cost option for ACC (Hill et al., 2023). Access to physiotherapy treatment without a surcharge to the patient is available via Health New Zealand Te Whatu Ora with a GP referral. However, this entails long waiting times, so if a patient wishes to access physiotherapy via this route, the delay may increase the chance their LBP will become chronic, disabling, and more costly (Wyeth et al., 2013). One further cause of higher cost per claim is that Māori are more likely to suffer a serious injury and less likely to lodge a claim for a minor injury (increasing the average cost per claim) (Accident Compensation Corporation, 2022).

Why do Māori and Pasifika use a GP more than other healthcare services?

The relationship with the GP is often established over many years; however, similar relationships with physiotherapists are less common. Dixon et al. (2021) state the need to incorporate te ao Māori into clinical practice, encouraging physiotherapists to focus on whanaungatanga, creating relationships with patients prior to treatment.

The range of healthcare provider options have not always been presented in a culturally accessible way. ACC have begun to address this with “Kia Mahea Kia Puawai” (making it clear so we can flourish), which is a “by Māori for Māori” campaign to increase awareness of ACC services and support. The result of this campaign has been an increase in digital engagement by Māori seeking ACC support services (Accident Compensation Corporation, 2022). Our study only collected data up to the end of 2020, so will not have captured any resultant change in healthcare use.

In an attempt to improve access to healthcare, an initiative known as “The Very Low-Cost Access scheme” was introduced in 2006. This scheme reduced GP service charge for those identified as having high needs. The high-needs population identified represents around 50% of the enrolled GP population, of which Māori, Pasifika were over-represented (National Hauora Coalition, 2016). While this initiative helped increase access to GP services for Māori and Pasifika, there is still a disparity in access to healthcare services (Accident Compensation Corporation, 2021). Māori also have a higher proportion of the population living in rural areas where treatment providers such as physiotherapy and GP services are less accessible.

CONCLUSION

There are differences between ethnic groups in their choice of healthcare provider and use of health services for LBP. There is still an unmet need for a range of visible, accessible, affordable, and evidence-based healthcare services, which may influence where Māori and Pasifika seek help. Appropriate services need to encompass more than just physical health and must address cultural needs as an equally important part of recovery. While healthcare practices are adapting and changing in response to the needs of Māori and Pasifika, the initiatives led by those with cultural knowledge have the best chance of improving equity in healthcare.

KEY POINTS

1. The choice of healthcare provider for low back pain after injury differs between ethnicities.
2. Europeans are most likely to consult a physiotherapist; Māori and Pasifika are most likely to consult a GP for low back pain after injury.
3. Māori have higher cost per claim, as they are less likely to claim for minor low back pain after injury and more likely to delay seeking treatment.
4. Service information, service provision, and service providers that meet cultural needs may improve access to physiotherapy.

DISCLOSURES

No funding was obtained for this study. There are no conflicts of interest that may be perceived to interfere with or bias this study.

PERMISSIONS

No permissions were required for this publication. De-identified data were used so neither consent nor ethical approval was required.

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CONTRIBUTIONS OF AUTHORS

The clinical perspective is from a previous study; design, conceptualisation and methodology, JH and NS; clinical perspectives, TA; cultural perspectives, JG. The formal analysis was undertaken by IN; validation and design, TA; writing–original draft preparation, JG, NS, JH, IN and TA; writing–review and editing, NS, JH, TA, IN and JG.

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Collaborative Goal Setting for Disabled Children Within Education: A Scoping Review

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ABSTRACT

Successful collaborative goal setting for disabled children is an essential part of family-centred practice (FCP). There is a paucity of research that collates concepts or approaches to collaborative goal setting. This scoping review aimed to explore key features and the application of collaborative goal setting frameworks and approaches used in an educational context for disabled children and their families. Ten databases were systematically searched using the keywords and synonyms of collaboration, goal setting, children, and disability from 2000 to January 2023. Data were collated and analysed thematically. Twenty-four studies were included for review and four key elements were identified as supporting collaborative FCP: (a) adopting a child-centred approach to enhance the child's strengths and dreams; (b) using goal-setting tools to identify the child's current ability; (c) applying structured processes to achieve collaborative family-centred practice; and (d) accessing external support during collaborative goal setting. A new working model was developed from the findings, which describes collaborative constructs and practical strategies for child-centred goal setting. Exploration and use of this model may support professionals to enhance collaborative family-centred goal-setting practice.

Robinson, L., Calder, A., & Carrington, L. (2024). Collaborative goal setting for disabled children within education: A scoping review. *New Zealand Journal of Physiotherapy, 52*(3), 257–272. https://doi.org/10.15619/nzjp.v52i3.459

Key Words: Children, Collaboration, Disability, Education, Goal Setting

INTRODUCTION

Collaborative goal setting in education is imperative for disabled children. Research has illustrated ways in which disabled students are missing out, including being unable to attend school or participate in education, with little change seen over the last 16 years (Clark & MacArthur, 2008). In the educational context, independent educational plans (IEPs) are one example of a formal approach to collaborative goal setting that is used for disabled children. In different countries IEPs are either a legislature requirement or considered good practice for disabled students (de Bruin, 2019). In New Zealand, it is mandatory to complete an IEP every six months for any student who receives Ministry of Education Ongoing Resource Scheme Funding (ORS) (Ministry of Education, 2017).

Family-centred practice (FCP), also referred to as family-centred care, is considered the gold standard philosophy and best-practice approach to rehabilitation service delivery for disabled children (King et al., 2004). The core principles of FCP include parental involvement in care and co-decision making (Carmen et al., 2008; Kuo, 2012), respectful family–professional partnership (Arango, 2011), and collaboration (Jolley & Shields, 2009; Kuo, 2012).

Co-decision making, self-determination, and autonomy for disabled persons and their families is supported by the United Nations Convention on the Rights of Persons with Disabilities (Andersen & Dolva, 2015; Curryer et al., 2015; Marshall & Goodall, 2015; O'Connor et al., 2021; United Nations, 2006). In addition, national governing bodies advocate for independence, community inclusion, and supported decision making within health and education (Education Review Office, 2022; New Zealand Government, 2016, 2019; Zhang et al., 2019).

Within education, IEPs should emulate FCP and provide an opportunity to build family–professional relationships that support family empowerment and improved outcomes for the child (Casagrande & Ingersoll, 2017; Ministry of Education, 2011). Families should feel they are in a collaborative partnership with professionals and seen as the experts of their child (Edwards et al., 2018). Instead, families often feel stressed, disempowered, and not adequately prepared to engage in IEPs (Hodge & Runswick-Cole, 2008; Jessop, 2018). Families can feel overwhelmed and confused by the IEP process (Jessop, 2018) or perceive their role as passive, which reduces collaboration (Childre & Chambers, 2005b), especially when their concerns and priorities are not heard or reproduced into goals (Kurth et al., 2019). In particular, families from Indigenous cultures can disengage due to feeling fear, insecurity, frustration, and intimidation in the school setting (Sheehey, 2006).

The International Classification of Functioning Disability and Health (ICF) and the child adaptation version for children and youth (ICF-CY) are examples of biopsychosocial models used to guide collaboration in the rehabilitation setting (Martinuzzi et al., 2015), with more recent publications in education (CanChild, 2024b). CanChild (an organisation dedicated to research for children and youth with disabilities and their families) developed a child- and family-friendly ICF-based tool called the F-words (Rosenbaum & Gorter, 2012), which consider the overall function and wellbeing of the child in every setting (Vargus-Adams & Majnemer, 2014). The F-words (i.e., fitness, function, friends, family, fun, future) replace the traditional ICF model terminology: health condition, body structure and function, activities, participation, environmental factors, and personal factors (CanChild, 2024a). They both provide a common language (Nguyen et al., 2021) to support holistic assessment, evaluation, and planning (Andrade et al., 2012; Mweshi, 2016) and focus on meaningful collaborative goal setting (Angeli et al., 2021).

Throughout this paper we have adopted disability-first language more recently recommended by disabled persons, including Autism New Zealand with their guide to language and terminology (Andrews et al., 2022; Botha et al., 2023; Monk, 2022). We acknowledge this is a shift from the traditional philosophy of seeing people first and then their disability (Gernsbacher, 2017), as advocated by the American Psychological Association (APA) referencing style (Pickren & Rutherford, 2018).

Working with disabled children in education and rehabilitation has exposed the primary author (LR) to a variety of ways in which therapists and educators assist children and families through goal setting. As such, LR has observed challenges with IEPs as the main form of collaborative goal setting, including confused families, families who do not come back to the next IEP, and professionals who struggle to find a process to support the families. There is limited research in the field of collaborative goal setting for disabled children and their families. A systematic review conducted by Goldman and Burke (2017) showed only five studies supporting parents of disabled students and their involvement at school. Families surveyed reported limited improvement in collaboration (Blietz, 1988; Brinckerhoff & Vincent, 1986; Hirsch, 2004; Mueller & Vick, 2019; Plunge, 1998). While a scoping review by Pritchard-Wiart and Phelan (2018) reviewed 62 papers and found family-centred care well represented with some descriptions of goal-setting theoretical frameworks, they concluded there were significant gaps in the literature around goal-setting theory and processes.

The purpose of this scoping review was to collate and summarise literature relating to collaborative goal setting to better understand the available framework(s) and/or approach(es) to enhance collaborative, family-centred goal setting for disabled children and to provide recommendations for education practice. The research questions were:

1. What are the key features of collaborative, family-centred goal setting frameworks/approaches?
2. What are the impacts of using these frameworks/approaches with disabled children and their family in an education context?

METHODS

This scoping review was conducted using the five-stage methodological framework as described by Arksey and O'Malley (2005): (a) identify the research question; (b) identify relevant studies; (c) study selection; (d) charting data; and (e) collating, summarising, and reporting the results by constructing themes to present a narrative account of the existing literature. The PRISMA extension checklist for scoping reviews (Tricco et al., 2018) was also applied.

Identifying relevant studies

Following consultation with a University librarian, we searched the databases of Medline, CINAHL, Web of Science, Scopus, Cochrane, Education Research Complete, Education Database (ProQuest), ERIC (ProQuest), NZCER Journals Online, and Psych INFO in July 2020 and updated the search in January 2023. Searches used the key concepts and synonyms of collaboration, goal setting, children, and disability (see Appendix A) specifically tailored to each database. An example of the search strategy from one database (Medline) is included in Appendix B.

Study selection

Following duplicate removal, articles were screened in three stages against the inclusion and exclusion criteria by LR (see Table 1): (a) title review; (b) abstract review (in the absence of an abstract, the full text was reviewed); and (c) full text review.

Table 1

Inclusion, Exclusion Criteria and Associated Definitions

Inclusion criteria
Participant
Relates to children with disability aged up to 21 years
Families, whānau, caregivers, and professionals working with disabled children
Concept
Frameworks or approaches for parent collaboration as the primary focus of the study or family-centred processes for goal setting or a framework for goal setting for disabled children
Context
Published between January 1 2000 and January 30 2023
Published in English
Within education
Within paediatric rehabilitation
Exclusion criteria
Full text not available
Publications in a language other than English
Definitions
Disability: for the purposes of this study, disability will include only physical impairments and autism spectrum disorder lasting or expected to last six months or more and not eliminated by assistive devices
Family and caregivers – for the purposes of this study, whoever the child lives with on a full-time basis

Two researchers (AC and LC) independently reviewed a selection of studies randomly chosen by LR to cross-check the eligibility process. In the case of eligibility uncertainty, studies were reviewed by AC and LC and continued to the next stage of screening if unanimous agreement was not reached. LR also reviewed and checked all cited references of the included studies to determine eligibility, resulting in the addition of one reference. EndNote 20 software (Clarivate, 2021) was used to store, de-duplicate, and reference.

Data charting, collation, and summarising

The data were charted in Microsoft Word (by LR), using the headings author, date, country, study design, participant, frameworks/approaches, and outcomes. Charted data were analysed narratively by constructing themes using a five-step process: (a) compiling: synthesising information from included papers into a table; (b) disassembling: mind mapping ideas from papers; (c) reassembling: grouping like ideas and concepts together; (d) interpreting: making sense of the links between concepts, and (e) concluding: summarising into a model (Castleberry & Nolen, 2018). The research team met regularly throughout the data charting, collation, and summary stages to discuss and refine the themes until consensus was reached.

RESULTS

The initial search yielded 1026 studies, which were screened following the PRISMA process, resulting in 23 relevant studies for inclusion (see Figure 1).

Characteristics of included studies

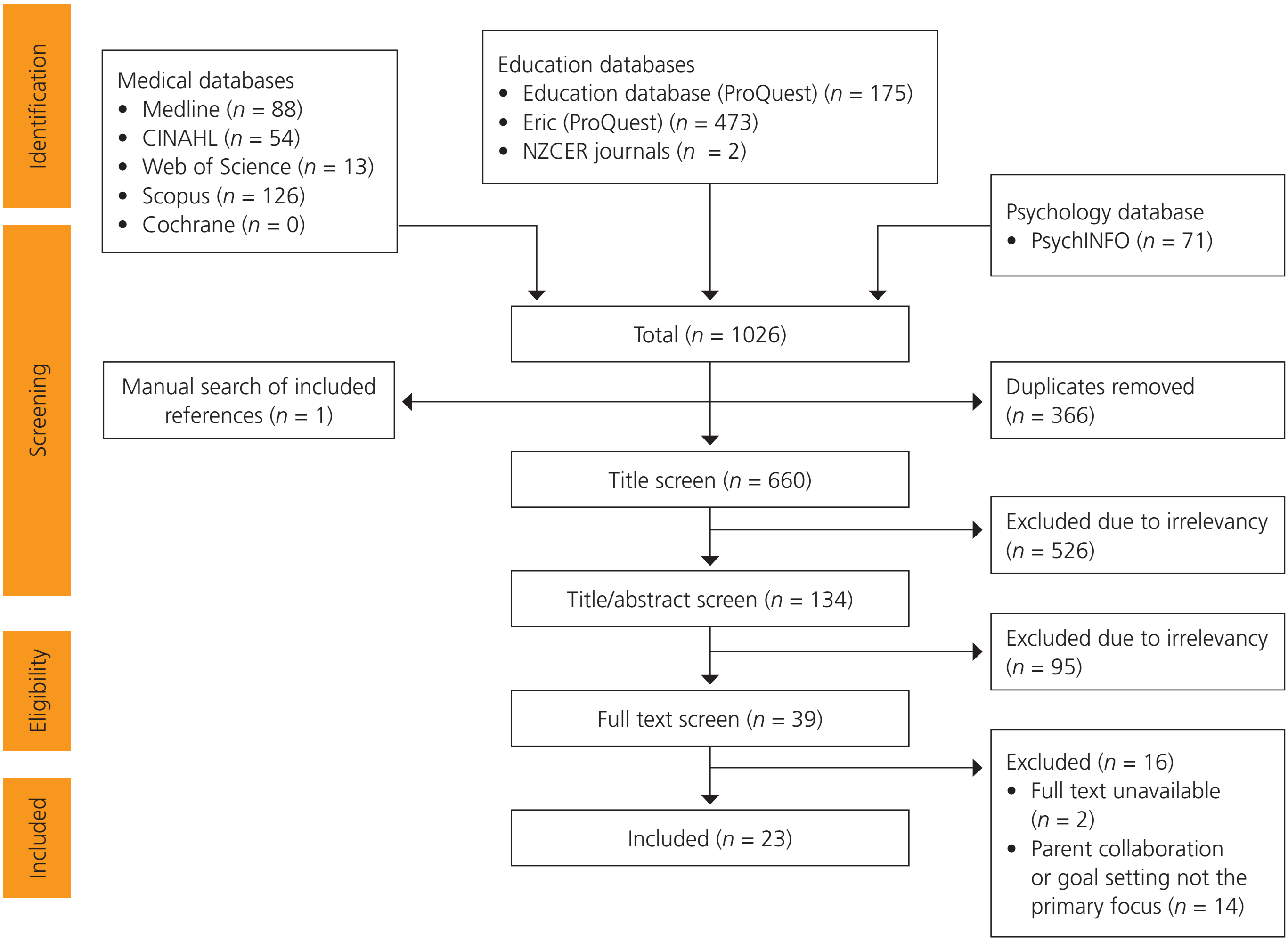
The study designs of the included studies were, expert opinion (*n* = 8), qualitative studies (*n* = 8), training programmes (*n* = 2), theses (*n* = 2), cohort studies (*n* = 2), and a randomised control trial (*n* = 1). The countries of study origin included the USA (*n* = 11), Australia (*n* = 4), Canada (*n* = 3), South Korea (*n* = 2), Israel (*n* = 1), Norway (*n* = 1), and Portugal (*n* = 1). Studies were located in early childhood centres (*n* = 10), schools (*n* = 8), and rehabilitation centres (*n* = 6) with the reported age ranges of participants varying between 0–5 years (*n* = 12), 4–13 years (*n* = 4), 5–21 years (*n* = 3), 0–21 years (*n* = 1), and 15–40 years (*n* = 1). Two-thirds of the studies encompassed professionals from the wider education team including health professionals, teachers, school leaders, and service managers along with two studies that included solely physiotherapists. The remaining six studies included a multi-disciplinary healthcare team (Table 2).

Key elements of collaborative goal setting for disabled children

Data synthesis of the included studies revealed four key elements for collaborative, family-centred goal setting for disabled children in educational settings: (a) adopting a child-

Figure 1

PRISMA Flow Chart of Study Inclusion and Exclusion Process



Note. CINAHL = Cumulated Index in Nursing and Allied Health Literature; NZCER = New Zealand Council for Educational Research.

Table 2

Characteristics of Included Studies

Author(s), date, country, evidence level	Participants (*N*) children (age), disability type, families (*n*), professionals (*n*), context	Collaborative family-centred goal-setting frameworks or approaches [a]	Outcomes for disabled children and families
An et al. (2016) South Korea Expert opinion with case examples	1 male (10 years), 1 female (8 years) Physical disability Families (2) Physiotherapists (2) Outpatient rehabilitation	Four-step model of family professional collaboration: – Mutually agreed-upon goals using the client-centred interview process of the COPM. – Shared planning using visualising, scaling, routine, and activity matrix. – Shared implementation with shared reflection. – Shared evaluation using the COPM modified measure.	– The COPM was easy for families to answer questions. – Families found it more difficult to reflect on scaling questions about progress to goals and a preferred future. – Shows the feasibility of specific strategies to support collaboration.
An et al. (2019a) South Korea Randomised control trial	13 male, 5 female (4–12 years) Physical disability Families (18) Physiotherapists (16) Rehabilitation at hospital/clinic or family's homes	This 4-step model was evaluated by looking at how much professional and family collaboration occurred. Evaluation including referencing seeking, giving, positive behaviour, neutral behaviour, negative behaviour, giving direction, child-related behaviour, no interaction.	– Parents and therapists interact more frequently in goal setting. – Parents were more actively engaged during goal setting and planning.
Boavida et al. (2014) Portugal Training programme review	*n* unknown (0–21 years) Mixed disabilities Early childhood teachers (21), special education teachers (17), regular teachers (23), therapists (8) General disabilities Early intervention team (38), private non-profit (14), school groups (24), community service (1)	Training programme for professionals completing IEPs: five face-to-face sessions plus one email to learn a full process for IEP or IFSP interview: – Concept and philosophy. – Ecomap of the family and supports and routines-based interview. – Writing of a functional profile with increased knowledge on the use of International Classification of Function.	– Goals and objectives improved. – Use of routines-based interview developed a positive relationship with the family. – Improved information about routines at home.
Byington and Whitby (2011) USA Expert opinion with case examples	1 male (3 years) Physical disability Family (1) Professionals (*n* unknown) Early childhood centres	Family centred strategies as a framework for increased collaboration in IEPs: – Preparation prior to meeting, setting an agenda with families, bring advocate, start with a blank IEP, review current IEP prior. – IEP process – welcome, parking info, role expectations clear, neutral facilitator, name badges, agenda, guidelines for conduct. – Parent as the expert model. Personalising the meeting – child first, disability second. By doing a personalised presentation.	– Parents need to be empowered to be active members in early intervention. – Preparation pre meetings, increased family's confidence to be the advocate and the expert for their child. – Development of a visual portfolio so the focus is the child not the disability.

Author(s), date, country, evidence level	Participants (*N*) children (age), disability type, families (*n*), professionals (*n*), context	Collaborative family-centred goal-setting frameworks or approaches [a]	Outcomes for disabled children and families
Chambers and Childre (2005b) USA Expert opinion with case examples	1 male (6 years) Autism Family (1) Professionals (*n* unknown) Primary school	Person-centred planning model "true direction" to provide student centred IEP planning: – Family forms prior to meeting. – Student forms prior to meeting. – Team forms at the meeting.	– A process for collaborative decision making that allows families to feel like they are in true partnership with professionals.
Darrah et al. (2001) Canada Cohort study	5 male, 7 female (18 months–5 years) Cerebral palsy Families (12) Multidisciplinary therapists (*n* unknown) Outpatient therapy rehabilitation	Family-centred functional therapy as a framework. – Functional goals identified through the COPM by families in a 1:1 meeting. – Observation by the therapist. – Then together family and therapists identify constraints within the child, task, or environment preventing performance.	– Improved achievement of goals. – Families and professionals working on the same aspects.
Darrah et al. (2010) Canada Qualitative study	59 children (0–18 months) Cerebral palsy Parents: mothers (32), fathers (5) Managers (37), occupational therapists (23), physiotherapists (31) All services servicing children with cerebral palsy in rehabilitation and education	Therapists followed the concepts of family-centred service, functional therapy goal setting and co-ordination between programmes. This was reviewed to see if a standardised family-centred approach as a framework across services was required for collaboration.	– Standardised processes are required to achieve family-centred care and collaborative goal setting. – Checklists were recommended.
Debelak (2020) USA Thesis – mixed methods	*n* unknown (5–21 years) Mixed disabilities Parents (98) General teachers (88), special education teachers (35), psychologists (4), managers (14), service providers (13) All school systems: Home, day student, or special education	Looked at shared patterns and behaviours to obtain facilitators and barriers to shared decision making in IEP to guide school frameworks to include parents as shared decision makers.	– Mutual respect. – Parent advocates: to assist families through the process. – Communication: honest and open. – Stress and anxiety from parents. – Need for honesty: to move beyond participation to equal partners is decision making. Understand the daily schedule, progress, behaviour. – More informal, collegial relationships with IEP teammates – more frequent and information conversation will allow for a richer understanding of the child's needs.

Author(s), date, country, evidence level	Participants (*N*) children (age), disability type, families (*n*), professionals (*n*), context	Collaborative family-centred goal-setting frameworks or approaches [a]	Outcomes for disabled children and families
Gregg et al. (2011) USA Expert opinion with case example	1 female (5 years) Autism Extended family School professionals (*n* unknown) Transition from kindergarten to school	Strength-based family-created portfolio "Take a look at me". To be used for person-centred planning and goal setting in a family-centred framework.	– Development of the portfolio gave the parent confidence at the IEP meeting to be a key participant. – Family empowerment. – The family filling out the portfolio engaged family and educators in a dialogue about the child that is about the holistic child, not just school activities.
Hanscom (2015) USA Thesis – multiple single case design	3 male (2, 3, 5 years) Mixed disabilities Family members (1 or 2 per child) Teachers, speech and language therapists, occupational therapists, psychologists, principals (*n* varied) Early childhood	Development of themes and strategies to increase collaboration for IEPs. Provision of strategies and techniques as a framework to support collective and collaborative education planning.	– Strategies for promoting effective collaboration. – Preparation: giving parents information about what to expect at an IEP. Giving info before they arrive at the IEP, not surprising them while there. – Communication: clear, less jargon so it is understood. – Clarity of roles in the meeting so everyone understands. – Collaboration: really depends on the perception of collaboration so this needs to be defined.
Hebel and Persitz (2014) Israeli Qualitative research	20 children (3–21 months) Severe motor or cognitive disabilities Parents (1 or 2 per child) Teachers (9) Education non-profit organisations	Development of themes and patterns for barriers for parental involvement and collaboration for IEPs supporting a family-centred process.	– Provide families with training to increase understanding of special education issues and clarify expectations. – Workshops to support parents to communication and collaborate with teachers: strategies for equal partnerships. – Written information about IEPs. – Leaders/teachers: increase opportunity to communicate with families. – IEP case manager: to support with the paperwork load. – IEP forms in language that is understandable to families.
Jones et al. (2019) Australia Qualitative research	9 children (3–6 years) ASD Mothers (9) Teachers (5), speech and language therapists (3), occupational therapists (2), family support worker (1) Early childhood centres	Family goal setting tool: Autism Spectrum Disorder version as a framework for goal setting.	– A comprehensive approach. – Supported family/professional collaboration. – Assisted with goal prioritisation. – Supported a reduction in stress associated with goal setting. – Practitioners described that the tool empowered families and enabled family-centred practice.

Author(s), date, country, evidence level	Participants (*N*) children (age), disability type, families (*n*), professionals (*n*), context	Collaborative family-centred goal-setting frameworks or approaches [a]	Outcomes for disabled children and families
Kaczmarek et al. (2004) USA Qualitative research	44 children (unknown ages) Families (44) Early intervention teachers (38), related service providers (16), para professionals (8), early childhood teachers (6) Preschool centre "head start" classrooms	Family consultant model as a family-centred framework. Family consultants act as a liaison between families and professional staff and the broader community.	– Model changed over time to be one of parent support for IEPs particularly to support them to fill in pre-IEP forms. – Issues with funding to continue the project.
McDougall and Wright (2009) Canada Expert opinion	*n* unknown (unknown ages) Mixed disabilities Families (unknown) Professionals (unknown) Paediatric rehabilitation	International Classification of Function, Child, and Youth (CF-CY) and Goal Attainment Scale (GAS) to set collaborative goals with families.	– Identifies the specific aspects of individual functioning and the environmental factors that a client's goals should target for change. – The ICF-CY formed the collaborative approach to determining needs. – The GAS provided the format for goal setting. – Both together allowed understanding how goals are meaningful and interrelated within the overall context of the client's life and long-term development.
Meadan et al. (2010) USA Expert opinion with case examples	1 male (13 years), 1 female (6 years) Down Syndrome (1) Learning disabilities (1) Family Professionals Education	Person-centred planning for students and families. A team approach to problem solving by developing a holistic long-term vision. This is a destination for 3–5 years serving as a map for other goals. Described five approaches to person-centred planning and long-term goal setting: – Circle of friends. – Choosing outcomes and accommodations for children. – Group action planning. – Making action plans. – Planning alternative tomorrow with hope.	– Gave insight into family dynamics. – A better understanding of family expectations and where they were headed as a team. – Long-term vision gave them directions for appropriate and needed goals and objectives for the IEP. – Vision statement changes the overall tone of the meetings to be more positive and constructive. – Parents felt empowered because they believe their voices are heard and their values are reflected in the IEP. – "It allowed the parents to feel more a member of the team, feel respected by the team, and feel prepared."
Mueller and Vick (2019) USA Qualitative research	n unknown (15–40 years) Mixed disabilities Families (7) Administrators (8), facilitators (6), parent advocates (4), educators/facilitators (5), administrators/facilitators (2) Education and community homes	Facilitated IEP process as a framework for goal setting. Used a neutral facilitator and meaningful procedures intended to encourage family and professional IEP team members to collaboratively develop a meaningful educational program for students with disabilities.	– Beneficial for conflict prevention and resolution between families and educators; encouraged active parent participation through consensus building.

Author(s), date, country, evidence level	Participants (*N*) children (age), disability type, families (*n*), professionals (*n*), context	Collaborative family-centred goal-setting frameworks or approaches [a]	Outcomes for disabled children and families
Øien et al. (2009) Norway Qualitative research	9 male (23–50 months), 4 female Cerebral palsy Families (13) Service providers (13) Paediatric rehabilitation	COPM and GAS to structure a collaborative goal-setting process.	– COPM supported the collaborative assessment. – GAS supported the joint process of goal writing and attainment. – Parents perceived themselves as drivers of the process and incorporated the child's perspectives in goal setting. – Parental perspectives were expressed and made into concrete goals. – Professionals' attitudes showed a commitment to the parents leading the process and partnerships.
Pritchard-Wiart and Phelan (2018) Canada Scoping review	*n* unknown (0–21 years) Physical disabilities Professionals (unknown) Paediatric rehabilitation	Reviewed papers that looked at family-centred care, goal-setting theory, social cognitive theory, mastery motivational, personal construct theory, self-determination theory.	– Very few sound theoretical frameworks for goal setting in rehabilitation. – Principles of family-centred provides strong rationale for collaborative practice. – Self-determination theories show children are more engaged and focused if they are part of goal setting, but this is not well described.
Rodger et al. (2004) Australia Cohort study	17 male, 5 female (27–49 months) Autism Families (22) Home facilitators: Doctoral students (22) Home-based early intervention	Modified COPM as a framework for goal setting.	– Provided a clear yet flexible structure for both parental goal identification and prioritisation. – It still requires family-centred practices to be truly collaborative. – If parents are to be "true" partners with professionals in assisting their children's development, conscious effort on the part of professionals is required on top of this process.
Rodger et al. (2012) Australia Qualitative research	8 children Mixed disabilities Parents (8) Occupational therapists (2), speech and language therapists (2), speech and language pathologists (2), psychologists (2), social workers (2), programme officers (2) Early childhood	Family goal-setting tool with four key themes: – The facilitation of goal setting. – Strengths-based focus. – Family-centred processes. – Empowerment of families.	– Greater ease in goal setting. – Reduced parental anxiety. – Promoted more multi-disciplinary focus. – Allowed for a strength-based focus. – Increased the holistic approach to setting goals. – Empowered families, increasing their ownership of goals.

Author(s), date, country, evidence level	Participants (*N*) children (age), disability type, families (*n*), professionals (*n*), context	Collaborative family-centred goal-setting frameworks or approaches [a]	Outcomes for disabled children and families
Skouge et al. (2007) Hawaii Expert opinion with case examples	1 male (12 years) Development disabilities Family (1) Professionals (unknown) IEP transition to college	Use of a multimedia portfolio to give a voice to youth and their families – a self-determination model as part of family-centred practice.	– Student-led presentation of their skills led to a more collaborative IEP process. – Child and parent were at the centre of planning. – Increased collaboration and consultation with families.
Weatherill et al. (2012) Australia Qualitative research	7 children (5–16 years) Mixed disabilities Parents (7) Principals or teachers (7), physiotherapists (2), occupational therapists (3), speech and language therapists (3), service providers (2) School-aged therapy services	Reviewed four current models/frameworks of practice: – Life Needs Model (LNM): A holistic design for transition points. – Relational goal-orientated model: A family-centred collaborative system to set goals. – Quality of life model: Setting of short-, medium-, and long-term goals for child participation. – Collaborative model of service delivery: based on family centred. Produced a "bespoke" programme design for school-aged therapy service delivery including goal setting in a child-centred process.	Child or parent is at the centre as the experts. Increased collaboration.
Wells and Sheehey (2012) Hawaii Expert opinion	*n* unknown (5–21 years) Mixed disabilities Families (unknown) Professionals (unknown) School services for transition IEPs	MAPS – model/framework of person-centred planning used to engage parents in the planning process for IEPs.	Increase active participation by parents and students.
Whitbread et al. (2007) USA Training programme review	*n* unknown (5–21 years) Mixed disabilities Parents and educators (1328) Education	Description of training as a framework to foster collaborative partnerships with parent and professionals: Steps in the special education process. Laws and process affecting special education. The IEP. Person-centred planning. Family–school partnerships.	Addressed the training needs of parents and educators. Increased a positive outlook on future collaboration.

Note. COPM = Canadian Occupational Performance Measure; GAS = Goal Attainment Scale; IEP = independent education plan; IFSP = individualized family service plan; MAPS = making action plans.

[a] Conceptual/theoretical frameworks used for parent collaboration in goal setting; and, family-centred processes as a framework, utilised in goal setting.

centred approach to enhance the child's strengths and dreams; (b) using goal-setting tools to identify the child's current ability; (c) applying structured processes to achieve collaborative FCP; and (d) accessing external support during collaborative, family-centred goal setting. These key elements for collaborative goal setting are outlined below.

Adopting a child-centred approach to enhance the child's strengths and dreams

A child-centred approach to FCP, such as focusing on the child's strengths and dreams, was described across six studies and was reported to be an important ingredient in the development of holistic and collaborative goals (Chambers & Childre, 2005a; Gregg et al., 2011; Meadan et al., 2010; Skouge et al., 2007; Weatherill et al., 2012; Wells & Sheehey, 2012). Weatherill et al. (2012) describe how a focus on the child's strengths and abilities improved relationship building and trust by highlighting to families that professionals understood their child and that their child was at the heart of the goal-setting process. While Chambers and Childre (2005a) showed that a child-centred strengths-based emphasis ensured that the child's interests and dreams were the focus for family-professional discussions, they also noted that using structured methods, such as a framework, helped to ensure a child-centred approach. Similarly, two studies reported that incorporating a structured portfolio that was family led and illustrated the needs and dreams of not only the child but the wider family, was holistic and supported child self-determination (Chambers & Childre, 2005a; Gregg et al., 2011; Skouge et al., 2007). In these studies reporting child-centred care, families felt empowered and more confident in the goal-setting process, which enhanced collaboration between families and professionals (Chambers & Childre, 2005a; Gregg et al., 2011; Meadan et al., 2010; Skouge et al., 2007; Weatherill et al., 2012; Wells & Sheehey, 2012).

Using goal-setting tools to identify the child's current ability

Goal-setting assessment tools were frequently used ($n = 9$ studies) to provide a structured and supportive approach for collaboration between families and professionals. The assessment tools reported across the included studies were the Canadian Occupational Performance Measure (COPM) (An et al., 2016; An et al., 2019a; Darrah et al., 2001; Jones et al., 2019; McDougall & Wright, 2009; Nguyen et al., 2021; Roger et al., 2004), the Goal Attainment Scale (GAS), the International Classification of Function, Child, and Youth (ICF-CY) (McDougall & Wright, 2009; Øien et al., 2009), the Functional Goal Setting Tool (FGST), and the Functional Goal Setting Tool: Autism Spectrum Disorder version (FGST: ASD) ($n = 2$) (Jones et al., 2019; Roger et al., 2012).

All goal-setting tools were valid and reliable objective measures used to either investigate or evaluate specific goals. The COPM was shown to support families to identify their child's current ability alongside a therapist and to provide a direction for goal setting (An et al., 2016; An et al., 2019a; Darrah et al., 2001; Jones et al., 2019; McDougall & Wright, 2009; Nguyen et al., 2021; Roger et al., 2004), while the GAS and FGST, rather than reviewing current ability, supported families to set the goals (McDougall & Wright, 2009; Øien et al., 2009). The authors of these studies indicate that the use of these objective measures added value to the goal-setting process. Families found the COPM easy to use, which supported active engagement during goal setting (An et al., 2016; An et al., 2019b). Darrah et al. (2001) indicated goals were more readily achieved as families and professionals were working together on the same success criteria for goal achievement. Studies that used the FGST and FGST: ASD Version found that the objective measures facilitated a holistic, family-orientated strength-based goal-setting approach (Jones et al., 2019; Roger et al., 2012). This, in turn, supported collaborative family-centred processes while prioritising goals (Jones et al., 2019). Two studies report improved holistic collaboration when the GAS was used in conjunction with other objective measures such as the COPM or ICF-CY, and parents felt the process enhanced their autonomy and partnership with the therapists and education team (McDougall & Wright, 2009; Øien et al., 2009). Furthermore, the goals were meaningful and interrelated to the child's life and long-term development.

Applying structured processes to achieve collaborative family-centred practice

Seven studies highlighted structured processes that specifically focused on collaborative FCP (An et al., 2016; An et al., 2019b; Boavida et al., 2014; Byington & Whitby, 2011; Hanscom, 2015; Hebel & Persitz, 2014; Whitbread et al., 2007). Processes for promoting FCP included a four-step family-centred model (An et al., 2016, 2019b), using checklists to set up and run goal-setting meetings (Byington & Whitby, 2011; Darrah et al., 2010; Hanscom, 2015), and specific training for professionals and families (Boavida et al., 2014; Hebel & Persitz, 2014; Whitbread et al., 2007). Similar concepts were shared across the family-centred processes: the importance of knowledge and education regarding the individual's roles and processes, the need for clear communication, and the use of structured strategies for collaborative FCP.

Four papers illustrated that collaboration between families and professionals was dependent upon their knowledge of family-centred practices, their understanding of the purpose of the goal-setting process, and the individual's perception of collaboration (Boavida et al., 2014; Hanscom, 2015; Hebel & Persitz, 2014; Whitbread et al., 2007). Family-centred practices were reported to improve when there was clarity on roles during goal setting (Byington & Whitby, 2011; Hanscom, 2015; Whitbread et al., 2007). When families and professionals were educated about goal setting, they had a similar understanding of the processes, roles, and outcome expectations (Boavida et al., 2014; Whitbread et al., 2007). Other studies reported that comprehensive training for professionals improved their interviewing and communication skills (An et al., 2019b; Boavida et al., 2014). Furthermore, studies where families felt empowered as the expert of their child reported an increase in family participation in goal setting and school activities (Byington & Whitby, 2011; Hebel & Persitz, 2014).

Four papers reported family-centred practices were enhanced when communication was clear and transparent, such as when the meeting agenda for goal setting was set in advance by both the family and professionals (Byington & Whitby, 2011; Hanscom, 2015; Whitbread et al., 2007). In addition, An et al. (2016, 2019b) described structured strategies that were also beneficial for collaborative FCP and parent participation, for example, agreeing on goals with the use of the COPM and shared planning for goal achievement. Further strategies included finding a mutually convenient time for all participants, ensuring the establishment of a relationship prior to the meeting, incorporating a wider view of long-term dreams, using set processes for meetings (An et al., 2016; Roger et al., 2004), and using checklists before, during, and after collaborative goal setting (Byington & Whitby, 2011).

Accessing external support during collaborative family-centred goal setting

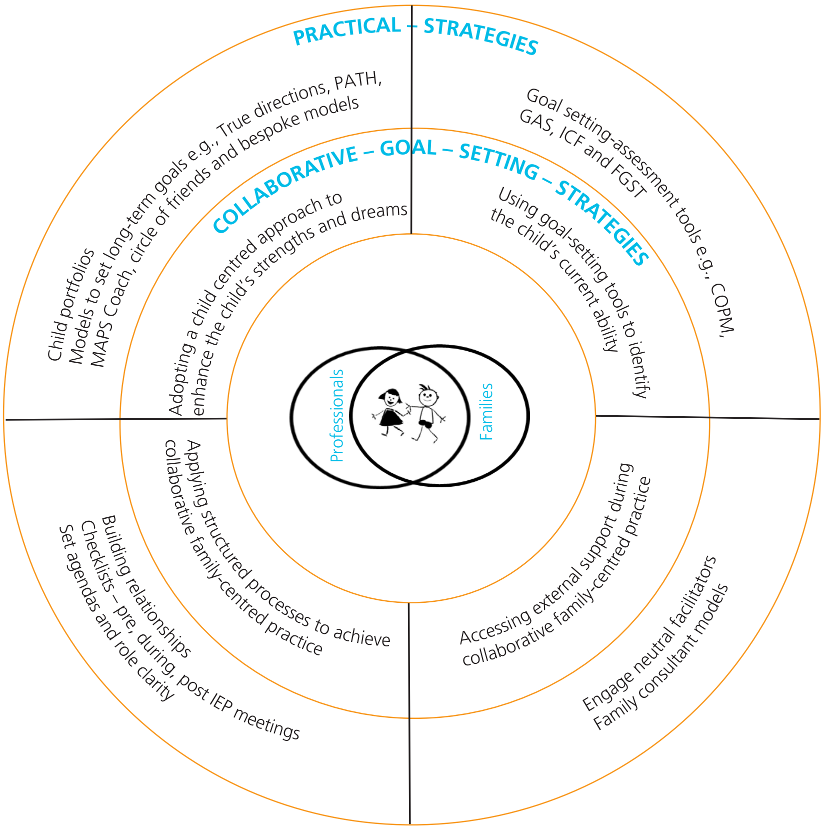
The use of an external facilitator was described by three papers to support the goal-setting process and was deemed beneficial for collaborative FCP (Byington & Whitby, 2011; Kaczmarek et al., 2004; Mueller et al., 2019). Facilitators were equipped with extra skills in communication, listening, and mediation, which improved communication between parents and professionals. In two papers, a neutral external facilitator empowered families and professionals to work collaboratively, especially if there was any form of conflict, and provided an atmosphere that was both fair and inclusive of all parties (Kaczmarek et al., 2004; Mueller & Vick, 2019). A novel example was illustrated in Kaczmarek et al. (2004), namely a family consultant model in which the facilitator was a family representative within the wider community who liaised with the professionals. The facilitator (family advocate) supported families to prepare, to actively participate in the goal-setting meetings, and ensured the family had an opportunity to voice their concerns and prioritise their child's needs (Byington & Whitby, 2011; Kaczmarek et al., 2004; Mueller & Vick, 2019).

New collaborative family-centred goal-setting model

The results of this scoping review illustrate a complex picture of key elements for collaborative family-centred goal setting for disabled children in educational settings. We present a novel model of collaborative family-centred goal setting (Figure 2), which connects and expands the four key elements derived from the data to support the clinical practice of professionals (i.e., therapists and educators). The new model is built upon the founding principles of FCP, with the child at the centre of the model supported by the expertise of both family and professionals. Collaborative family-centred goal-setting constructs (represented by the four key elements as identified in this review) surround the child, family, and professionals. The outer layer of the model provides practical strategies for application derived from the included studies for use by professionals for collaborative family-centred goal setting for disabled children.

Figure 2

Evidenced-based Collaborative Goal Setting Model



Note. COPM = Canadian Occupational Performance Measure; FGST = Functional Goal Setting Tool; GAS = Goal Attainment Scale; ICF = International Classification of Functioning Disability and Health; MAPS = making action plans; PATH = plan alternative tomorrow with hope.

DISCUSSION

The purpose of this scoping review was to collate, summarise, and synthesise collaborative goal-setting frameworks and/or approaches for disabled children and their families and provide recommendations for practice. A strength of this study was integrating the key collaborative elements into a model to support practice. The overarching global terminology of FCP was evident across many papers. FCP needs to be unpacked in any organisation to ensure there are effective processes in place. Processes may include checklists for meetings, orientation for staff, appropriate meeting spaces, role clarity, and processes for building trusted relationships. The findings from this review reflect Graham et al.'s work (2018, 2021) on occupational performance coaching (OPC), which did not feature with our search criteria. The fundamental process in OPC is "listening better". Graham et al. (2021) support the use of high-trust partnerships, collaboration, sustainable goals that are about families' dreams, and engagement that is autonomous, features that are also seen in our model of collaborative practice.

Many studies in this scoping review identified that to set short-term goals it is important to first understand the current skills of the child, to know their dreams for the future, and to focus on long-term planning. The use of standardised assessment tools provides a structure for effective communication between families and professionals that enables each party to understand their role in the collaboration (Bronstein, 2003). For example, goal-setting systems, such as the COPM, support families to see the child's current level of ability, which facilitates collaborative goal setting. Likewise, structured tools such as the GAS support professionals and families to navigate where their child is at and where they wish to go next. Maher (1983) recommends the GAS as a practical method to evaluate educational services for disabled children and was positive about the goal-setting flexibility. Carr (2016) notes that 33 years after its conception, the GAS remains an effective, accountable, and efficient process to use in an educational setting. However, the GAS has had a slow uptake in education. Tennant (2007) proposes this may be due to the rigorous training programme that is required for staff and families to be able to define and agree on the expected levels of achievement in order to use the GAS successfully.

The user-friendliness of complex structured goal-setting tools should be considered when in use. Tools such as the FGST and FGST: ASD Version require less training since they simply use pictures or visual supports to prompt families to consider a variety of ideas for goals and to prioritise needs. The pedagogy of visual tools is commonly recommended and widely used within special education (Knight et al., 2014; Schlosser et al., 2020). Visual tools provide an easy format for communication with families and may support them to feel like they are the experts about their child and allow their voice to be heard (Wiart et al., 2010).

As well as careful consideration of the chosen assessment tool, this scoping review has illustrated the merit of external facilitators for enhancing collaborative family-centred goal setting. External facilitators can support professionals and families in shared decision making and promote active parent participation (Mueller & Vick, 2017). When we are "in the moment", particularly if highly emotive, we often do not listen to hear, but listen to speak (Dalton, 2010, 2011). Facilitators can support all participants to stop and listen to one another, facilitating dedicated space and time to collaborate (Schot et al., 2019). As shown in this review, family advocates are an alternative to an external facilitator and can assist with similar processes. Tucker and Schwartz (2013) report the families' desire for an advocate to support the understanding of their life outside of school. Advocates can support families through knowledge of collaborative goal-setting environments such as IEPs and special education (Burke & Goldman, 2018; Gershwin & Vick, 2019). Provision of support for navigating the goal-setting processes is crucial for culturally and linguistically diverse families who may have extra barriers to understanding (Burke & Goldman, 2018; Rossetti et al., 2018; Tucker & Schwartz, 2013). The importance of providing training for external facilitators and advocates has been highlighted in past literature (Burke & Goldman, 2018; Gershwin & Vick, 2019; Goldman & Burke, 2017; Goldman et al., 2020) and was apparent in this review. Finding a balance in which the family feels empowered, rather than disempowered by the "expert" advocate is critical, since feelings of disempowerment lead to less contribution (Burke & Goldman, 2018; Gershwin & Vick, 2019). Evidence of long-term sustainable funding for external facilitators of collaborative goal setting is lacking. However it has been noted that within schools, impartial and neutral professional staff may be able to take on the facilitation role (Mueller & Vick, 2017). A structured model to guide collaborative goal setting, such as presented in this review, may assist external facilitators and family advocates by providing a clear set of strategies to discuss with the family.

LIMITATIONS

Scoping reviews, by their nature, are limited with the research not being appraised but assimilated; therefore, there is a component of author interpretation (Arksey & O'Malley, 2005). A third of the studies were expert opinions, which are valid but less scientifically robust – which adds to the limitations of the scoping review. Over half the studies were from the USA and Canada where the IEP system is legislated, and this may not translate to other countries with different IEP policy requirements or into the wider rehabilitation setting.

We were unable to register our scoping review because at the time of the protocol development there was no platform available to do so. Further robust scientific evidence such as randomised control trials, cohort studies, or qualitative research is required to validate the frameworks recommended in the expert opinion studies and our newly developed collaborative goal-setting model.

CONCLUSION

This scoping review aimed to explore key features and application of collaborative family-centred goal-setting frameworks used in an educational context for disabled children and their families. We have illustrated the diversity of goal-setting frameworks and identified processes that may be used to increase overall FCP including checklists for meetings, orientation for staff, appropriate meeting spaces, role clarity, and processes for building trusted relationships. A model of collaborative goal setting for disabled children has been developed using the four interconnecting collaborative constructs for supporting goal setting in an educational context identified in this scoping review. Practical recommendations for professionals working with disabled children and their families in education were provided. Future research should seek to explore these areas in greater detail to add to the small body of knowledge about collaborative goal setting, including IEP processes and FCP for disabled children and their families.

KEY POINTS

This scoping review has illustrated key elements of collaborative goal setting including:

1. family-centred practice as a key component to collaborative goal setting
2. family-centred goal setting as a strength-based, short-term goal setting reflecting the child's long-term dreams
3. structured processes to achieve collaborative goal setting (i.e., using standardised outcome measures)
4. engagement of external facilitators that may support families during goal setting.

DISCLOSURES

No funding source for this research. The first author (LR) works in a specialist school in a leadership capacity. There are no conflicts of interest that may be perceived to interfere with or bias this study.

PERMISSIONS

None.

CONTRIBUTIONS OF AUTHORS

Design conceptualisation, software use, data curation, project administration, LR; supervision, AC and LC; methodology, validation, analysis, writing – original, review and editing, visualisation, LR, AC and LC.

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Appendix A

SEARCH TERMS

Concept 1	AND Concept 2	AND Concept 3	AND Concept 4
Collaboration OR	Goal setting OR	Children OR	Disability OR
shared decision-making family centered/centred family focused/focussed family–professional partnership	education goals therapy goals rehab* goals IEP independent education plans independent education program individual* education program individual* education plan	adolescen* young kid* youth child* young adult paediatrics pediatrics student* school students school age* elementary school high school middle-school middle school primary school	physical disab* disab* impair* moderate need* movement impair* long-term conditions special health care need developmental delay cerebral palsy autis* special ed* special need* mobility impair* developmental disab* autism spectrum

Appendix B

MEDLINE SEARCH

1. “Shared decision making” OR “family centered” OR “family centred” OR “family focused” OR “family focussed” OR “family professional partnership”
2. education OR therapy OR rehab*
3. Goal* OR “IEP” OR “Independent education plans” OR “Independent education program*” OR “individual* education program” OR “individual* education plan”
4. adolescen* OR young OR kid* OR youth OR child* OR paediatric* OR pediatric* OR student* OR “school student*” OR “school age*” OR “elementary school” OR “high school” OR “middle school” OR “primary school” OR “young adult”
5. “physical disab*” OR disab* OR impair* OR “moderate need*” OR “movement impair*” OR “long term condition*” OR “special health care need*” OR “developmental delay” OR “cerebral palsy” OR autis* OR “special ed*” OR “special need*” OR “mobility impair*” OR “developmental disab*” OR “autism spectrum”
6. 1 AND 2 AND 3 AND 4 AND 5

Filters: English and > 1999 and school aged child.