# Creating 'safe spaces': A qualitative study to explore enablers and barriers to culturally safe end-of-life care

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## Abstract

**Background:** Internationally, efforts are being made to promote equity in palliative and end-of-life care for Indigenous peoples. There is a need to better understand the experiences of Indigenous service users and staff.

**Aim:** To explore the views of Māori health practitioners and whānau (family group) caregivers regarding barriers and enablers to culturally safe palliative and end-of-life care.

**Design:** A Kaupapa Māori qualitative study.

**Setting/participants:** Interviews were conducted with 103 participants from four areas of the North Island of Aotearoa New Zealand. Participants comprised bereaved whānau (family) of Māori with a life limiting illness and Māori health practitioners.

**Results:** Māori health practitioners undertake cultural and connecting work to promote culturally safe palliative and end-of-life care for Māori patients and their whānau. This work is time-consuming and emotionally and culturally demanding and, for most, unpaid and unrecognised. Non-Māori staff can support this work by familiarising themselves with te reo Māori (the Māori language) and respecting cultural care customs. However, achieving culturally safe end-of-life care necessitates fundamental structural change and shared decision-making.

**Conclusions:** Our findings indicate that efforts to support equitable palliative care for Indigenous people should recognise, and support, the existing efforts of health practitioners from these communities. Colleagues from non-Indigenous populations can support this work in a range of ways. Cultural safety must be appropriately resourced and embedded within health systems if aspirations of equitable palliative and end-of-life care are to be realised.

## Keywords

Palliative care, cultural safety, culturally competent care, New Zealand, terminal care, hospice and, palliative care nursing, qualitative research, culture, Indigenous peoples

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**What is already known about this topic?**

- Indigenous peoples experience barriers to accessing palliative care and can view hospices as culturally unsafe spaces.
- More research is needed to explore the barriers and enablers to culturally safe palliative and end-of-life care from the perspective of Indigenous and ethnically minoritised service users and staff.

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**What this paper adds?**

- Indigenous Māori health practitioners working within Western healthcare settings in Aotearoa New Zealand undertake a significant amount of cultural and connecting work to promote culturally safe palliative and end-of-life care for Māori patients and their whānau (families).
- Cultural work is valued but also time-consuming and emotionally demanding for Indigenous health practitioners and, for most, unpaid and unrecognised.
- Culturally safe end-of-life care necessitates fundamental structural change and power redistribution to address the ongoing effects of racism and colonialism on Māori end-of-life experience.

**Implications for policy, practice or theory**

- Adopting a cultural safety lens helps illuminate that for equitable end-of-life care to be achieved, structural level change, power sharing and leadership is needed.
- Everyone who works in a palliative care setting needs to understand the cultural work already undertaken by Indigenous health practitioners. Indigenous people must be involved in decision-making, as a foundation to realising aspirations to achieving culturally safe, equitable palliative and end-of-life care.
- There are a range of ways that allies in palliative care settings can support and advocate for culturally safe care practices, and these principles can be applied to ethnically minoritised groups and also more broadly to health and social care systems in Aotearoa New Zealand and internationally.

## Background

Indigenous people can struggle to access adequate symptom relief, information and emotional support at the end-of-life and are less likely to receive palliative care than non-Indigenous people.[1–3] Explanations for this disparity include racism, identified as a feature of palliative care in a recent editorial in this journal.[4] Racism is a socio-historical process which propagates the aspirations and cultural practices of majority population groups in ways that disadvantage Indigenous and ethnically minoritised peoples.[5,6] Within this context, palliative care services can be viewed as having imposed a particular understanding about good dying – rooted in Western Christian culture[7] – onto Indigenous populations.[8]

In Aotearoa New Zealand, Indigenous Māori cultural care customs that had a spiritual element were banned through the Tohunga Suppression Act of 1907. By the time the Act was repealed in 1962 many Māori had lost their knowledge of traditional healing practices, including those supporting end-of-life care. Te Tiriti o Waitangi (Treaty of Waitangi) formalises the relationship between the Crown and Māori, but adherence has been inconsistent. Māori experience poorer health and shorter life expectancy than non-Māori. Racism also negatively shapes Māori healthcare experiences.[9,10] Palliative care development in Aotearoa has followed the UK model, although recent efforts have been made to ensure services meet the needs of Māori. It was within this context that the Te Ārai Palliative Care and End of Life Research Group Kāhui Kaumātua (Māori elder group) expressed concerns about the loss of end-of-life tikanga and kawa, or cultural care customs among Māori and asked TMM to lead a study to explore this issue.

In this paper we adopt a cultural safety lens, which is an Indigenous-led approach formulated in Aotearoa,[11] to explore the use of tikanga and kawa (cultural care customs) at end-of-life by Māori. A cultural safety approach can support structural-level change in systems and organisations, particularly within health and education. The approach, which shares similarities with the concept of 'cultural humility' developed in the Unites States,[12] extends beyond cultural competence,[13] which prioritises understanding and engaging with the customs of ethnically minoritised groups to demand individual and organisation-level reflection and action around power and privilege.[14] This includes making room for, or centring, Indigenous ways of being and knowing in healthcare.[15] A cultural safety approach is in lines with a recent call for palliative care to recognise 'the plurality of past and present local problems and issues relating to end-of-life care, as well as the plural possibilities of how they might be overcome'[16] (p. 77). A culturally safe approach is achieved when the end-user and their family experiences the physical and social health care environment as spiritually, psychologically and physically safe.[14] In this paper, we contribute to current efforts within palliative care to promote equity by using a cultural safety lens to identify barriers and enablers to culturally safe end-of-life care from the perspective of Māori, the Indigenous people of Aotearoa. We recognise that what is important for Māori will not be the same for other Indigenous groups. However, the broader principles of acknowledging and enabling the work Māori do, as Māori, for Māori, and with Māori, could be translated into other cultural, geographical, and professional contexts.

## Aim

To explore the views of Māori health practitioners and whānau (family group) caregivers regarding barriers and enablers to culturally safe palliative and end-of-life care and the work Māori health practitioners undertake to support culturally safe end-of-life care.

## Methodology

The study was informed by a Kaupapa Māori research methodology which centres the lived experiences of Māori and privileges Māori epistemologies and ontologies – or ways of thinking and knowing about the world.[17–19] Māori researcher TMM with significant end-of-life research experience led the research team, supported by the Te Ārai Kāhui Kaumātua (Māori elder advisory group). Tauiwi (non-Māori) researchers MG (English/Welsh) and JW (Pākehā or NZ European) provided specific methodological support and were asked to lead this paper to disseminate findings internationally.

### Setting and ethical issues

The study was conducted in four different geographical locations in the North Island of Aotearoa, New Zealand (Mid-North, Hawkes Bay, Wellington and Whanganui)[19] between 2017 and 2019. Ethical approval was given by the University of Auckland Human Participants Ethics Committee (reference number 019834). A koha (gift) of petrol and food vouchers was provided to participants. Cultural and spiritual safety[20,21] was ensured through ongoing dialogue with Te Ārai Kaumātua and the Indigenous communities involved in the study. Examples included establishing whakawhanaungatanga (relationship connections) and practising karakia (prayers, incantations, chants) and waiata (singing).[1,21,22] All participants provided written consent. Consistent with core ethical values of Kaupapa Māori research, following completion of the study the research team presented findings back to each of the participating communities and launched the study website (https://www.teipuaronui.co.nz).

## Recruitment and participation

In each region, we partnered with Community Research Collaborators selected for their Indigenous palliative care expertise and personal mana (status and prestige) and because they are trusted contacts within their community. Each Community Research Collaborator invited local participants who had expertise and/or recent bereavement experience to participate in the study. These potential participants included bereaved whānau of Māori with a life limiting illness and Māori health practitioners (see below). The Community Research Collaborators made

sure to verbally reassure potential participants that they did not have to take part and several people did decline because they were too busy to take part in an interview.

## Participants

We conducted interviews with 103 participants in 61 qualitative kanohi-ki-te-kanohi (face-to-face, in-person) interviews. Whānau with relevant experience of end-of-life care were invited to participate as a group if they preferred. Final interviews thus included 17 whānau meetings (with between one and seven people), and interviews with 44 Māori health practitioners. These Māori health practitioners include 12 rongoā (natural healing) practitioners, 13 tohunga (expert spiritual healer) practitioners and 19 Māori health and allied professionals (specifically, four nurses/nurse navigators, four Māori health worker/liaison, three doctors, three community support workers/coordinators, three cultural advisors and two health care assistants). We aimed to recruit a diverse range of whānau and Māori health practitioner perspectives and to include participants from different rohe (regions) which is why the sample of participants is relatively large. Some participants represented more than one position; for example, some Māori health practitioners commented on their own whānau experiences.

## Data collection

An interview guide with questions around use of cultural care customs and the barriers and enablers to using them was developed in collaboration with Te Ārai Kāhui Kaumātua. For example, TMM began the discussions by asking participants to describe current or recent end-of-life caregiving activities. When cultural support was required, a member of the Te Ārai Kāhui Kaumātua was present during the interview, especially for those participants who requested an interview in te reo Māori (the Māori language). The discussions ranged in length between 2 and 4 h and were conducted in a location of the participant's choosing, usually their home or workplace. Interviews were recorded, and professionally transcribed by a third party who signed a confidentiality agreement. Two interviews conducted in te reo Maori were translated by a Kaumātua. KM and TMM prepared summary reports which they took back to participants to read and approve, emphasising approval of extracts for publication.[23]

## Analysis and interpretation

Consistent with our kaupapa Māori research methodology, the analysis and interpretation of research data sits within a te Ao Māori (Māori knowledge and worldviews) frame. A coding framework was developed by KM and

TMM in consultation with Te Ārai Kāhui Kaumātua, Community Research Collaborators, and the research team through a number of hui (meetings) to work through the transcripts and the developing analysis and interpretation.

Initial analysis by KM and TMM, supported by NVivo12, identified any data related to end-of-life experiences of Māori health practitioners and whānau in the Western care system. The focus was on Ngā mea āwhina (things that helped), Ngā mea whakararu (things that hindered) and Whakatika ngā raruraru (overcoming problems). This material was further analysed by MG and JW with a focus on different care settings using a reflexive thematic approach.[24] We identified the work of Māori health practitioners as critical in enabling high-quality palliative and end-of-life care in the context of Aotearoa NZ's end-of-life care system and this became the focus of analysis. In broader consultation with the research team and Kaumātua, we identified the concept of cultural safety as a relevant underpinning framework. We then worked through the relevant data, identifying structural and microlevel factors shaping whānau and Māori practitioners' experiences of end-of-life care that was culturally safe or otherwise, and attending to differences between Māori participants.

## Presentation

We identified four core themes: creating culturally safe spaces; flexing Western healthcare systems; what helped Māori health practitioners provide culturally safe care; and what hindered Māori health practitioners in providing culturally safe care. In describing each core theme we present illustrative participant quotes. We have been careful to protect the anonymity of participants.

## Findings

### *Creating culturally safe spaces: Acting as 'Ngaio whakaruruhau'*

Māori health practitioners were central to promoting culturally safe end-of-life care for Māori whānau within Western healthcare settings. They acted as Ngaio Whakaruruhau (professional and expert protectors) to create a safe space in healthcare settings for Māori with life-limiting illness and their whānau. In this role, they navigated between health systems rooted in Western ways of knowing and doing and te ao Māori (Māori knowledge and worldviews), drawing upon their cultural knowledge and expertise alongside their professional training and experience.

The ability to communicate well in both worlds, and translate between and connect them, was acknowledged as key to supporting holistic whānau-centred end-of-life

care. As one community health care worker identified in response to a question about the way they help whānau during a typical working day:

> '. . . just think the main one is communicating. Communication. . . [between] the family, the patient, the, the system in itself. . .'.

Māori health practitioner participants valued this role and felt it was essential. However, most Māori health practitioner participants undertook this cultural work in addition to their paid professional role, which meant they often worked more hours than they were remunerated for. This reflected the lack of value attached to this cultural work by the health systems in which they worked. The centrality of relationships to Māori also created additional workload, particularly because Māori health practitioners often plugged gaps in a disjointed health system. As an urban GP reflected:

> But I guess also working in a community like this when you give your phone number out, that person is connected to this one to that one, to that one which means a whole whānau can have your cell phone number. So, I guess that's a difficulty for me particularly because I also live in the community. . . I don't know if I want phone calls at midnight to say 'oh my son's just hurt himself', you know so. I think [what is needed is] a better connection with the health systems. I think whānau need funds, resource.

One participant reflected on their role as clinical manager of a Māori navigation service, which meant their role as Ngaio Whakaruruhau (professional and expert protector) was formalised and renumerated:

> . . . Our Haumoana navigators work alongside our staff, in the hospital setting. . . to awhi (support) and manaaki (provide care for) not only our patients and our families and our whānau but also our staff to help them to work alongside our whānau. And to break down some of those barriers.

However, whilst the service was growing in popularity, the extent to which their team was involved with Māori still depended upon non-Māori clinicians:

> We're at a stage now where doctors will actually ask for [the navigators] to come in. . . on a ward round. Be in a, be in a whānau hui (family meeting) if they need to talk about a family about a diagnosis, for example. Now sometimes that's done really well by some consultants and other times it's not. But the fact that our haumoana are visible and are quite well known through the hospital [means] the staff know to ask for that support.

Whether paid and formalised, or unpaid and integrated into an already busy workload, the demands of the Ngaio Whakaruruhau (professional and expert protector) role

were significant in terms of emotional, physical and cultural work. It was particularly complex in situations of heightened emotions where either whānau or professionals were feeling challenged or out of their depth culturally. Several Māori health practitioners shared stories of negotiating and calming others by drawing intensively on their own personal and cultural resources, which left them feeling 'exhausted'.

Māori health practitioner participants also described cultural work undertaken to support the diverse Māori identities of the whānau they worked with. This was contrary to the perception of some of their non-Māori colleagues that, by virtue of identifying as Māori, a Māori health practitioner would know 'everything' about te ao Māori (Māori knowledge and worldviews). However, Māori health practitioners shared how they were negotiating different tikanga (protocol) or kawa (specific customs) for different hapū or iwi (extended kinship group, tribe), as well as different groups' interpretations of these. They also reflected on the need to be sensitive to diversity amongst Māori related to socio-demographic characteristics, as well as the extent to which whānau were connected with their iwi (extended kinship group, tribe), practiced traditional care customs and spoke and understood te reo Māori (the Māori language).

Māori health practitioner participants explained that they undertook this demanding and often unpaid additional work because of values central to a Māori worldview related to mahi aroha, or work undertaken because of love for people. As a community health care worker reflected:

> I think one of the important things for us is as not only Māori as human, is the fundamental kaupapa (purpose), which makes Māori think the way they do, is say that 'aroha (love) is the greatest thing in the world'. Now if we take that concept into service that we provide, or the help we can give, in whatever capacity that might be, to those that are in their hour of need. . . by using whatever tools that we have available.

### Flexing Western healthcare systems to create space for Māori ways of being and knowing

A key aspect of the Ngaio Whakaruruhau role (professional and expert protectors) was to identify ways to Ātea Wharau, or immediately create a culturally safe space, to care for whatever physical, emotional and spiritual needs a whānau may have. This work involved whakaneke, carving out or flexing a healthcare system that is too often rooted in and prioritises Western values. In this way Māori health practitioners acted as change agents for Māori whānau, to enable a Māori worldview to sit alongside a Western worldview. A good example was provided in an interview with two sisters about their father's death in hospital. One of the sisters described how, after their father's death, a cleaner entered the room to whakanoa, or clear the space, by removing tapu (sacred and restricted spiritual matters):

> Once Dad passed, as we left, then this wāhine (woman) comes in . . . she was a cleaner I think she was? But she came in. She was, mm, in her. . . early 60s. . . and she looked at Uncle A and Uncle A looked at her, and he goes "I've completed it, I've already done it". And she goes "Ok". Her other role was to come in to clear.

When asked if the whakanoa (clearing) was part of the cleaner's official role, the whānau participants responded that they were not sure. However, they both affirmed that this was important work and expressed their relief at seeing that it had been done properly.

Undertaking whakaneke (carving, flexing) work involved a range of skills, including advocacy, relationship building, persistence and having a good understanding of both tikanga (cultural care customs) and the healthcare system. As a nurse reflected, there was also a recognition that sometimes a compromise had to be reached. For example, this might mean supporting whānau to accept that available care could be 'good enough' because 'that's just the world we live in', in other words a world where Western values and ways of doing things predominate).

### What helped Māori health practitioners provide culturally safe care?

Māori health practitioners needed support from Māori colleagues and kaumātua to undertake their cultural work. Whakapapa (genealogical) relationships, which are central to te ao Māori (Māori knowledge and worldviews), also helped. A community health worker for example, often undertook patient visits to her own whānau members, highlighting the strong integration between everyday life and overlap between work and family time. Participants also developed whānau-type relationships with Māori patients with whom they did not have genealogical ties. These warm relationships were important, and meant that practitioners were well placed to provide help when needed, at least partly because they were perceived as being 'safe'. For example, a different community health care assistant explained that:

> '. . . they know who I am. I'm family. And, and it's just yeah. "[she's] here". "[She's] coming. Yeah, I just rung her, she's coming". Yeah, sort of thing. Just to be there. . . "It'll be alright"'.

In another interview, another pair of sisters talked about the care preferences their mother had for their father. This included a preference for Māori nurses, especially

those with a whakapapa (genealogical) connection to their whānau:

**Sister 1:**     *[there] was a real sense of privacy around the whare (house), and who could be in the whare. You know she didn't want somebody from the council coming in to clean. That was available and offered, but that wasn't allowed to happen. If there was a nurse coming in, there was a preference that it was a Māori nurse. And there were people attached to local health services that - no, they couldn't come.*

**Interviewer:**  *So, she was very particular about who she felt could come? And what do you think it was based on? How come one person could come through the door but somebody else couldn't? Was it the service, was it the ethnicity, was it the?*

**Sister 2:**     *Ethnicity.*

**Interviewer:**  *Ethnicity?*

**Sister 2:**     *And whakapapa.*

**Interviewer:**  *Oh, so she, your Mum's very traditional?*

**Sister 2:**     *In that sense. Anything to do with the [particular region]. Anybody from [there]. You know, any whakapapa connection that she can make with you, then, then, she's accepting of it.*

Having a sound knowledge and being confident using tikanga and kawa (customs), was also important. For example, a community health worker shared how, if she is visiting whānau and they start karakia (prayers), it is tikanga or the right way to behave to stop her mahi (work) and join the whānau:

*Karakia, yeah, the family always has karakia. So, I involve myself in it [karakia]. . . I join in. . . you know, I won't go and do mahi while they're having karakia. . . I stop, and I join in.*

She would also draw on her own cultural knowledge about what is important for Māori at end-of-life to provide culturally specific care and support, for example in the form of traditional kai (food):

*I just go and get pūhā (perennial sowthistle), or go and get watercress, or something like that. . . I give it to the family, "Here, cook this up for Nan, go cook this up, here's a pūhā, here's a tuna (eel)". Yup.*

Non-indigenous allies could also provide support to create safe spaces and resources. For example, a tohunga (expert, healer, priest) reflected on care shown by a Tauiwi (non-Māori) specialist when his brother was dying:

*A few years ago my brother. . . passed on. One of the things that I remember quite distinctly was the fact that. . . his specialist came and mihi'd (greeted, acknowledged) the family. Beautiful. And he let all the whānau know where he was at, what was happening. . . . I think he had a love for Māori culture. And he knew how everyone was feeling, all the family was feeling. But to have him come in . . . and I will never forget those last words, 'I'm here to make his passing as seamless as possible'. And so that, that's really wonderful. . . Ah, he was Pākehā. . . Not too many specialists will actually come do a personal home visit.*

A rongoā (natural healing) practitioner spoke about how the Tauiwi (non-Māori) hospital staff shared in waiata (singing) and karakia (prayers, incantations, chants) with the whānau when her Nana was approaching end-of-life:

*[We] were so lucky in [town] because she had the most beautiful staff at ICU in [town] hospital. They were so respectful, you know, all Tauiwi (non-Māori). But they'd known her throughout the years. . . they were so respectful*

One participant also acknowledged the efforts made by Tauiwi (non-Māori) Hospice workers to connect with her whānau by using te reo (the Māori language) and drawing on Māori concepts such as waka (canoe) to help explain care when her father was dying:

*. . . they greeted us with a "Kia ora", (hello!). . . ah. . . "Ka kite", (see you/goodbye) . . . [the] Pākehā [nurses]. And they were using, you know, Māori kupu (words). . . which is **quite funny** like [laughs]. . . you know. But they'd always come out with. . . you know, "We're here for not only you, but the family, and the whānau", and **use those sorta words**, to. . . connect with us. . . Yeah. They did very well. . .You know, and they'd, they'd bring out a **little** framework [of the] waka, **and I'm going, "Oooh true!"***

Her careful choice of language highlights the gap between cultural competence (e.g. using appropriate language, acknowledging the whānau and Māori ways of knowing), and the more systemic and substantive structural changes needed to achieve cultural safety.

### What hindered Māori health practitioners providing culturally safe care?

Barriers to creating culturally safe care were predominantly structural, relating to power imbalances and institutional racism. As noted above, the cultural work undertaken by Māori health practitioners was often not renumerated, reflecting the lack of value attached to this work by the healthcare system in which they worked. Another example was the way in which some non-Māori staff assumed that Māori staff would meet the needs of Māori whānau, meaning that they did not have to. For example, a nurse described how when a whānau caring

for their father at home came into hospital they were identified by staff as needing equipment. However, staff did not take responsibility for either engaging with or supporting the whānau with other aspects of his care, expecting the Māori staff member in another organisation to 'get it sorted. . .and that's what I meant by the institutionalised colonisation is still there because [they're] sitting there going *"Oh you're Māori so you do it"'*.

Many participants also noted that mainstream assessment models used in clinical practice, which were rooted in Western values, often did not meet the needs of Māori. For example, a nurse reflected on the use of depression scales:

> *. . .Oh, I don't use those scales but my colleague, who does work with patients with counselling, she doesn't feel those scales work for them. Oh, they're too um, Pākehā orientated stuff, it's not suitable for Māori.. . .And I find for a lot of Māori people it's just the kōrero [talking]. All they want is to kōrero. . . once you start having the kōrero then the main things come out afterwards. They don't talk about it at the beginning but it's afterwards, what they're really worried about comes out.*

A community support worker talked about managing Western health and safety requirements alongside Māori protocols. In the following example he discussed entering a Māori house wearing shoes, something which contravenes cultural customs

> *. . . we get to a Māori house regardless of which house it is, the first question I ask, "Can we leave our shoes on?" . . . to us it's a health and safety thing. I said, "I know it's stepping over our kaupapa (custom, cultural way of doing things), but we also have responsibilities to ourselves, to our safety. And if we want to be performing what it is that we do, there are certain guidelines that we need to do'*

Working within a Western health system where Māori cultural practices were not normalised, or even understood, also created challenges. For example, a nurse reflected:

> *. . . the most challenging, would be the justification of . . . [using] a custom. Why do I have to justify what I'm doing as Māori?. . . To either the health professional [or] the services? 'Why do I have to tell you that whānau need a bed? Get them a bed'. 'Why do I have to tell you that there's 30 of them coming? Why can't we just adapt?'*

Overall, hospices were seen to be more able to be flexible as they sit outside mainstream health services. However, participants' ability to safely practice tikanga and kawa, their traditional end-of-life care customs, was dependent on hospice leadership. Māori health practitioners spoke of feeling culturally unsafe when their managers were passive, such as ignoring other colleagues making culturally inappropriate requests of them, or not creating environments that enabled practitioners to safely raise their concerns. Conversely, other hospice leaders were helpful when they actively supported Māori health practitioners to have flexibility in their role to support cultural care practice. Examples of active support included providing leave after a death and actively supporting tikanga practices.

## Discussion

### Main findings

This study contributes to current efforts to promote equity in palliative and end-of-life care by exploring the work Māori health practitioners undertake to support culturally safe end-of-life care for Māori whānau (families) in Aotearoa New Zealand. We identified that many Māori health practitioners undertake their paid role and additional highly-skilled, emotionally demanding cultural work, which is time-consuming and often not renumerated. This work involves 'flexing' the Western health care system to Ātea Wharau (create culturally safe spaces for) Māori. As such, they are Ngaio Whakaruruhau, skilled practitioners, who bring their cultural knowledge and expertise into their paid work. This issue has been identified in other contexts, such as the work of Maori scientists, as aronga takirua, or a cultural double-shift.[25] Although this study is undertaken within the unique context of Aotearoa New Zealand, our findings have broader potential implications for international efforts to support culturally safe palliative and end-of-life care and care in general. Indeed, it is reasonable to infer that Indigenous practitioners in other places may experience something like this but located in their own contexts. Looking at the extensive work on cultural humility in an international context[12] we also argue similar experiences may occur for ethnically minoritised and other Indigenous peoples, and for minoritised groups also. The aronga takirua cultural double shift is also likely to be undertaken by Māori practitioners throughout the health and social care system, beyond palliative and end-of-life care.

The findings of our study, as well as international evidence, show that culturally matched health professionals[26,27] improve patient satisfaction[28] and health outcomes.[29] However, there has been scant acknowledgement of the time-consuming and demanding nature of this cultural work.[30] Whilst the Māori health practitioners in our study valued this work as a form of mahi aroha (love for people), it needs to be supported in structurally-embedded ways. In Aotearoa New Zealand there is scope for the paid Haumoana (navigator) role to be expanded within palliative care and in the broader health and social care system. However, we found navigators' work is contingent upon individual clinician attitudes, indicating a need for an institutional power shift. Similar recommendations have been made in response to inconsistencies in

support for other culturally specific services, such as translators.[31]

Our findings highlight systemic and individual ways health practitioners from majority populations can contribute to culturally competent, and safe, end-of-life care. A number of cultural *competencies* that supported Māori health practitioners and whānau were identified, including learning basic phrases in te reo Māori and waiata (songs), treating cultural practices with respect, and being prepared to visit whānau at home. Such work aligns with 'allyship'. Tackling the wicked problem of racism to achieve culturally *safe* care, however, also requires allies to use their social power to advocate for structural level change.[32] Our participants highlighted the importance of a supportive employer/manager who understood and created space for their cultural work.

Finally, our study adds to the evidence that racial stereotypes impact culturally safe end-of-life care. Assumptions that 'Māori look after their own' at end-of-life or that all Māori implicitly understand the appropriate tikanga or ways of working for all other Māori mirror narratives about ethnically minoritised people in other countries which have been forcibly challenged.[33] Such stereotypes position Indigenous peoples and also ethnically minoritised groups as more caring than the majority population, and homogenise and essentialise entire cultural groups. In damaging and insidious ways these stereotypes also lead to assumptions that statutory services are not required. Our study also illuminated institutional racism, for example through the adoption of assessment tools rooted in Western values – an issue identified as problematic for Indigenous peoples in other countries[34] – and environments in which Māori care customs had to be justified or hidden.

### Implications for practice

Indigenous Māori health practitioners working within and alongside Western healthcare settings in Aotearoa New Zealand are central to supporting culturally safe palliative and end-of-life care for Māori. There was little evidence that this time-consuming and emotionally and culturally demanding work was appropriately recognised. Non-Māori staff can support culturally *competent* care by familiarising themselves with te reo Māori (the Māori language) and respecting cultural care customs. However, for truly equitable and culturally *safe* end-of-life care to be achieved, supportive leadership and systemic change is needed. The ongoing effects of colonialism and racism upon Māori need to be mitigated by true power-sharing. Our findings point to a potentially fruitful area of research in other countries where there is likely to also be a need to better recognise the cultural work of Indigenous and ethnically-minoritised practitioners as a foundation to realising aspirations to achieving culturally safe, equitable palliative and end-of-life care.

### Strengths and limitations

This study was undertaken using Kaupapa Māori methods which promote culturally safe research for Māori and foregrounds the voices and experiences of a diverse group of Māori with personal and/or professional experience of palliative and end-of-life care living in different rohe (regions) of Aotearoa New Zealand. We only interviewed Māori health practitioners who were currently working; future research could include Māori who no longer work in palliative and end-of-life care to explore whether the cultural demands placed on them featured in their decision to leave.

### Conclusion

This study explored the work Māori health practitioners undertake to support culturally safe end-of-life care. Whilst conducted in Aotearoa New Zealand and focused on palliative and end of life care, the findings have broader local and also international implications for promoting culturally safe palliative and end-of-life care,[4] and more broadly in health and social care. We have identified the usefulness of adopting a cultural safety framework; further research could explore the use of this approach in relation to palliative care with Indigenous peoples and ethnically minoritized groups from other countries. Indeed, further research is needed to identify, recognise, and support, the existing work of practitioners from Indigenous communities outside Aotearoa, and from communities who are minoritised. Change should be developed in partnership with, and with leadership by, the intended beneficiaries. Colleagues from majority populations can support this work in a range of ways. However, cultural safety must be appropriately resourced and embedded within health systems if aspirations of equitable palliative and end-of-life care are to be realised.

### Glossary

| | |
|---|---|
| Aroha: | Love, compassion, empathy, kindness, charity, sympathy |
| Aronga takirua: | Double facing, double purpose, double shift |
| Ātea: | Space, open area, clear, free from obstruction |
| Awhi: | Embrace, cherish, surround, support |
| Haka: | Ceremonial dance |
| Hapū: | Kinship group, clan, tribe, subtribe, primary political unit in traditional Māori society (a number of whanau sharing common ancestral descent) |
| Iwi: | Extended kinship group, tribe |
| Kanohi-ki-te-kanohi: | Face to face, in person |
| Karakia: | Prayers, ritual chant |
| Kaumātua: | Māori elders, person of status |

| | |
|---|---|
| Kaupapa Māori: | Māori approach, Māori practice, principles, skills, values |
| Ka kite: | See you again |
| Kaupapa: | Topic, programme, cultural way of doing things |
| Kawa: | Protocol, customs |
| Kia ora: | Hello, cheers, best wishes |
| Kōrero: | Talk, discuss, converse, inform |
| Kuia: | Older woman, grandmother, female elder |
| Kupu: | words |
| Mahi: | Work, practice |
| Mahi aroha: | Work undertaken out of a love for people |
| Manaaki: | Support, take care of, protect, show respect and generosity towards |
| Matakite: | Visionary, prophetic, seer |
| Mihi: | Greet, pay tribute, acknowledge, thank, speech of greeting |
| Ngaio: | Expert, professional, thorough |
| Pākehā: | New Zealander of European descent |
| Pūhā: | Perennial sowthistle (dark leafy green vegetable) |
| Rongoā: | Natural healing, Remedy, medicine, cure, treatment, solution |
| Tangihanga (tangi): | Rites for the dead, funeral, mourning |
| Tauiwi: | Non-Māori, colonist, foreigner |
| Tapu: | Be sacred, prohibited, restricted, set apart, forbidden |
| Te Ao Māori: | The Māori world |
| Te Reo Māori: | The Māori language |
| Tikanga: | Correct procedure, custom, method, practice |
| Tohunga: | Skilled person, chosen expert, healer, priest |
| Tuna: | Eel |
| Wāhine: | Woman, female |
| Waiata: | Song, singing |
| Waka: | Canoe, conveyance, vehicle |
| Whakaneke: | To cause, relocate, to move, to shift, relocating |
| Whakanoa: | To remove tapu or restrictions, to free things |
| Whakapapa: | Genealogy, lineage, descent |
| Whakaruruhau: | To protect, shield, shelter |
| Whakawhanaungatanga: | Process of establishing relationships, relating well to others |
| Whānau: | Family group |
| Wharau: | Temporary shelter, shed, |
| Whare: | House |

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