Māori elders' perspectives of end-of-life family care: *whānau* carers as knowledge holders, weavers, and navigators

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Abstract

Background: There is growing interest in palliative care within Indigenous communities, and within Aotearoa New Zealand, of the significant role that Māori (Indigenous people) families play in caring for older relatives. This study explored the centrality of culture in how Māori extended families (*whānau*) in Aotearoa New Zealand interpret and enact family-based care roles within the Māori world (*Te Ao Māori*).

Methods: Applying Māori-centered and community-based participatory research principles, we examined 17 interviews with older Māori who shared experiences of palliative care for a partner or family member. The thematic analysis used a cultural-discursive framework incorporating Māori principles of wellbeing and values expressed within the care relationship.

Results: The findings centered on three *whānau* roles in palliative care: *whānau* as (1) Holders and protectors of Māori knowledge; (2) Weavers of spiritual connection; and (3) Navigators in different worlds.

Conclusion: The study problematizes the notion of a single 'primary caregiver', privileges *whānau* as an inter-woven relational, dynamic care network, and encourages health professionals to recognize the cultural embeddedness of dominant approaches to palliative care.

Background

Palliative care services in Aotearoa New Zealand are offered by publicly funded district health boards and primary healthcare providers (e.g. partly funded general practitioners), as well as locally organized 'no-charge' hospice services (part-district health board and part donation funded); the latter represented by the non-governmental organization Hospice New Zealand. Services include inpatient and home-based care that supports family carers.[1] There is growing interest in palliative care within Indigenous communities,[2] and within Aotearoa New Zealand, increasing evidence of the significant role that Māori (Indigenous people) families play in caring for their elders.[3]

In Aotearoa New Zealand, individuals caring for a family member are more likely to experience poor health than those who do not.[4] Although caring for extended family (*whānau*) is standard for Māori, caregiving can be stressful.[5,6] Yet, the relationships between *whānau* and a family member receiving care can also be sustaining when care is culture-centered.[7] For instance, it has been argued that protective factors for older Māori with dementia include living within the Māori world (*Te Ao Māori*) and experiencing core values of connectedness (*whanaungatanga*) and nurturing care (*manaakitanga*).[7,8] Nathan posits that such protective cultural factors may also help Māori *whānau* to support family members with care needs.[9] However, numerous studies indicate

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that healthcare and support systems dominated by Western worldviews, values, and everyday practices can impede such culture-centered care for Indigenous communities.[10] Western colonization, with its sense of 'a certain ownership of the entire world',[11(p56)] disrupts the lived world of Indigenous peoples who must navigate foreign norms, values, practices, and systems. This study investigates these disruptions by exploring the central role culture plays in how Māori *whānau*, providing palliative care in Aotearoa New Zealand, interpret and enact their care role as they navigate their older relative's palliative care needs, the family needs, and the formal health and support systems.

Literature review

Palliative care is holistic and includes physical, social, emotional, and spiritual domains,[12] and such care aligns with Māori values, *whānau* relationships, and care practices.[13] We begin with a literature review focused on the cultural foundations of *whānau* care via Māori worldviews before examining the meanings of care roles evident within current international scholarship.

Māori worldviews: whānau care in context

To understand Māori *whānau* care roles, they first need to be situated within the dynamics of *Te Ao Māori* and Māori notions of wellbeing (*hauora*), cultural roles, as well as practices (*tikanga*) related to kin relationships. Central to *Te Āo Māori* is the interconnectedness of the spiritual world and material physical world of *Te Ao Mārama*.[14,15] This connectedness is evident in the relationships among God (Supreme Being, *Atua* or *Io*),[14,15] the people (*ngā tangata*), and the land (*whenua*) which confer identity and belonging.[14] The spirits' journey from the world of potential (*Te Kore*) to the worlds of becoming (*Te Po*) and of being (*Te Ao Mārama*), and return, on death, is mirrored in everyday processes and human actions.[15] That is, the potential for action, and action becoming and being in the material world, lies within any moment. For instance, care actions begin as potential, and the communicative processes that connect *kaumātua*, *whānau*, and external care providers together shift the palliative care journey and care coordination into the world of being.

Second, Māori dimensions of wellbeing connect individuals with the collective (*whānau*), the spiritual (*wairua*), and the lived worlds. This connection manifests in Māori *whānau* knowing and accessing their cultural heritage and living in *Te Āo Māori*; experiencing close and extended familial relationships; and enjoying spiritual, physical, emotional, and mental wellbeing and healthy lifestyles.[16–18] These dimensions of wellbeing underpin culture-centered *whānau* care.

Third, individuals are connected through bonds of association and obligation via lines of descent (*whakapapa*) to ancestors (*tipuna*); ties of kinship,[13,14] with wider groups of relations (*whānau whanui*); and ties to close family (*whānau te rito*) (e.g. great-grandparents, grandparents, parents, aunts, uncles, siblings, nieces, nephews, and cousins).[16,17] As Mead[13] indicates, such relationships rest on reciprocity: The collective and individuals within it can expect to *be supported* and to *give support* when needed. Correct enactment (*tikanga*) of responsibilities and obligations embedded in these supportive relationships enhances, sustains, and restores a person's sacred attributes (*tapu*); the strength and standing (*mana*) of the *whānau*; and family members' relationships with each other.[13,14] These relationships, responsibilities, and obligations are foundational to *whānau* care of *kaumātua*.

Whānau care roles are rooted within this cultural context. Derived from the verb *tū* meaning 'to stand or position oneself', Tate defines roles (*tūranga*) as 'functions performed or stances adopted by persons in encounter'.[14(p136)] Key roles include initiating action (*kaikākiri*); supporting action (*kaitautoko*); and challenging action, frequently by proposing alternatives (*kaiwhakatara*).[(p39)] Such roles may play out within *whānau* palliative care, where values of connectedness (*whanaungatanga*), sacredness (*tapu*), and standing (*mana*) guide those caring for a *kaumātua* – someone with elevated status.[13]

The values of *tapu* and *mana* are inextricably linked to how a *whānau* responds to the challenges of supporting their *whānau* member during their journey to a spiritual place. Such challenges center on *whānau* both grieving and caring for their relative as the person is preparing to leave and enter to the spiritual pathway. Thus, *tapu* and *mana* are central to *whānau* caregiving and embraced in care processes, especially when physical care may compromise those needs (e.g. the person is moving to a different spiritual space, and therefore in a *tapu* state; touching them requires explicit consent). *Tapu* is a complex

value that has its origins in spirituality and is expressed in everyday practices to guide *whānau* relationships and shape collective wellbeing.[14] Enacting *mana* activates *tapu relationships* (e.g. spiritual, relational, practical) and serves to enhance that which may have been diminished as the result of illness. *Mana* within *whānau* relationships is influenced by kinship patterns such as the standing of *kaumātua* and of older and younger siblings. Such patterns mediate *mana* and thereby guide how relationships are negotiated and familial responses are shaped.[13,14]

In sum, within *whānau* relationships, care embraces and sustains the *tapu*, *mana*, and *wairua* of all parties. *Manaakitanga*, 'nurturing relationships, looking after people, and being very careful about how others are treated',[13(p29)] also underpins *whānau* interaction and relationships[18–20] as do love (*aroha*), respect (*whakaute*), and guardianship (*kaitiakitanga*). However, despite these rich accounts of *Te Ao Māori*, Māori dimensions of wellbeing, and *whānau* relationships, empirical work that connects these cultural dimensions to how *whānau* talk about their care roles is sparse.

Meanings of care roles

Most literature about meanings of the family care role and other unpaid caregivers focuses on the lack of clarity around who is a 'caregiver'.[21] Barer and Johnson's[22(p27)] oft-cited critique lambasts 'vague' definitions such as 'unpaid helpers', 'those providing some level of care', or 'households'. Because not all family carers identify as 'caregivers',[23] many definitions focus on task performance.[24] Tasks include monitoring care, taking action, providing hands-on care, making adjustments, accessing resources, working with the person receiving care, and negotiating the health system.[25] Although such tasks highlight the care role's complexity, the focus is on what family carers *do*, rather than the relationship between family carers and the person receiving care.

Hence, other richer definitions distinguish between caring *for* and caring *about*,[26,27] where caring *for* emphasizes the material tasks or service provision associated with care (e.g. ensuring personal care, preparing meals) and caring *about* focuses on the relational or emotional support aspects of care (e.g. showing affection, being with). A further aspect of care is service liaison.[28] Although such task-based definitions allow for in-depth understandings of various facets of care,

they do not focus on how family carers make sense of and interpret these roles.

An emerging strand of care literature, however, examines family carer perspectives. One study of family members caring for an older adult with complex medical needs documented a shift from a relational care role (e.g. child, wife) to a more professionalized 'lay nurse' care role.[29] Similarly, Nikora *et al.*[5] identified many roles carried out by Māori *whānau* caring for a person with a disability. In addition to the role of medical provider/administrator, which resembles a lay nurse, roles included companion, personal care assistant, advocate, community link (transport and delivery), and 'a pair of eyes': 'cultural interpreters (. . .) who facilitate cultural obligations; (. . .) maintain a spiritual sense of being and ensure wellness of wairua'.[5] Other catch-all roles included personal gatekeeper ('consent giver') and 'counselor'.[5(p51)]

The roles of advocate, 'a pair of eyes', and interpreter fall within a broader role of navigator-negotiator because they involve engaging with health professionals and services through tasks such as keeping care diaries, supporting relatives at medical appointments, and managing medication.[5] The navigator-negotiator role also incorporates roles such as primary decision-maker, family spokesperson, expert in identifying the patient's wishes and expressing care needs,[29] along with advocate for the older person receiving care,[5] mediator between the older person and health professionals,[31] navigating 'additional hurdles' to access services,[5(p58)] and carrying out patient navigator tasks that are usually the domain of professional providers.[5] Overall, the navigator-negotiator role requires a family carer to manage competing perspectives and aspects of care provision with the older relative, other family caregivers, healthcare professionals, service providers, and a support network of family and friends.[31]

Although culture is central to understanding the meanings of care roles, few scholars examine how cultural worldviews and practices underpin role construction for 'co-cultural' group members or individuals whose cultural perspectives are underrepresented during interactions with dominant group members.[32] The literature on culture, ethnicity, race, and family care tends to view culture as a series of norms, values, and practices that shape decisions to care[33–36] and explain why family care is meaningful or burdensome.[37,38] Others explain away culture by arguing that family care in

itself constitutes a 'culture' that transcends cultural differences.[39] There is, nonetheless, a small body of research about how culture structures co-cultural group members' interpretations of the care role. For example, Williams *et al.*[6] situate their study as a bi-cultural, Māori and non-Māori, study of how family carers acted as informal patient navigators for relatives receiving palliative care. Williams *et al.* identify patient advocate, appointment scheduler, and patient manager roles. However, Williams *et al.* do not link these care roles to specific cultural norms. Likewise, Mendez-Luck *et al.*[40] describe how Mexican women home carers of older adults conceptualized family care as a construct of cultural beliefs and social norms. Their participants saw themselves as guardians of health, who were 'directly responsible for the positive changes in their elderly relatives' health'. (p231) They enacted this role by 'keeping company' with and 'watching out' for the older person. Again, how culture underpins this guardianship role is not explored in depth.

In contrast, Arkles *et al.*'s[41] phenomenological analysis of Australian Aboriginal and Torres Strait Islander perspectives about caring for a relative with dementia describes the cultural norms of reciprocal care in kin relationships and the importance of place for relational belonging and continuity. Even so, only a few lines explain how these norms play out in care roles premised on cultural beliefs of 'care as nourishment', 'care as custodianship' (relational governance), and 'care as holding' (being present together).

Culture-centered approaches are essential, particularly for Indigenous family carers who struggle to provide palliative care for older adults within colonized systems.[42–44] In light of current empirical research about culture-centered palliative family care, this study explores how culture shapes the ways in which Māori *whānau* carers in Aotearoa New Zealand interpret and enact care roles, expressed by the following research question: How do *whānau* enact care roles within the Māori world (*Te Ao Māori*)?

Methods

This paper is part of a health literacy and communication study in palliative care of Māori *kaumātua* (older adults, defined as Māori aged 55 years and over). The Rauawaawa Kaumatua Charitable Trust – University of Waikato study adopted two community-focused approaches as an overarching methodology: Kaupapa Māori (Māori-centered) and community-based participatory research (CBPR) approaches. Kaupapa Māori approaches normalize Māori worldviews, language, and cultural practices[45] and validate and legitimate Māori as Indigenous peoples.[12,46] Māori-defined processes ensured the research used culturally safe procedures for participating *kaumātua* and *whānau*.

CBPR respects research partners, recognizes the unique strengths that each partner brings, and combines knowledge and action for social change.[47] The research team comprised Māori and Pākehā (New Zealanders with settler heritage), with most members being community-based Māori researchers. Consistent with CBPR principles, an advisory board comprising 10 *kaumātua* and healthcare workers ensured the study incorporated culturally safe procedures. All participants received an information sheet and gave written consent. The Northern Y Regional Ethics Committee (NTY/ 11/08/085) granted ethical approval.

Data collection

The broader study included 21, 60- to 90-min, semi-structured interviews with Māori who shared their experiences of palliative care of a partner or other *whānau* member. This paper focused on 17 of these interviews (4 men; 13 women; see Table 1 for participant information) where participants explicitly mentioned Māori values or identified practices as Māori (172 pages of single-spaced transcripts). Interview questions included 'What were your understandings of/ thoughts on end-of-life-care?' 'Who was involved in the care you experienced?' 'What support did you receive?' and 'When were you supported with or denied your cultural practices?'

Kaumātua were invited through the Rauawaawa Kaumatua Charitable Trust's networks to an interview at its premises. The setting was familiar to *kaumātua*, with most attending weekly social and educational events. Culturally secure participation for Māori was facilitated by Māori communication protocols (*tīkanga*) and invitational, conversation-generating enquiry methods.[12] Procedures included sharing food with *kaumātua* before and after the interview[12,48] which offered more time for conversations (*kōrero*) and relationship development before discussing palliative care. Interviews used formal Māori communication protocols such as introductions and making

Table 1. Participant demographics and *whānau* receiving and giving care.

Participant	Age	*Whānau receiving* palliative care	*Whānau involved* with palliative care[a]
K01F[b]	63	Grandfather	Parents, uncles, aunties
		Cousin (male)	His wife, cousins, "Our relation"
		Brother	Sisters, his grandchildren
		Niece	Cousins, sisters
		Daughter-in-law's father	Son, *whānau*[c]
K02F	60+	Husband	"Us his family"
		Father	Sisters, brother-in-law, his grandchildren
K03M	63	Father	"Other *whanaunga*" [relatives]; older sister, brothers, nephew
		Older brother	Brothers, sisters, his son
K04M	73	Wife	Daughters, friends
K05F	83	Mother	Sisters, brother, daughters
		Daughter	Son-in-law
K06F	55	Mother	Husband, sisters
K08F	60	Mother	Eldest sister (main carer), sisters, "All the *whānau*"
K09M	68	Wife	Adult children
K11F	75	"Extended family"	Cousins
		Niece	Brother
K12F	60s	Mother	Sisters
		Sister	Sisters
K13M	70+	Mother	*Whānau*
		Brother	*Whānau*
		Wife	Sister-in-law
K14F	61	Mother-in-law	*Whānau*
		Father	Mother, brothers, son
		Sister-in-law	Husband, daughters
		Brother-in-law's wife	Not stated/ "we"
K15F	55+	Husband	*Whānau*, son, daughters
K18F	68	Mother	Aunties, husband
		Niece	Sisters
K19F	55+	Neighbor	His daughters

(Continued)

Table 1. (Continued)

Participant	Age	*Whānau receiving* palliative care	*Whānau involved* with palliative care[a]
K20F	69	First and second husband	Not stated/ ˝we˝
		Uncle	Not stated/ ˝we˝
		Cousins	Not stated/ ˝we˝
		Relations	Not stated/ ˝we˝
K21F	64	Husband	Daughters

[a]The relationship is with the participating *kaumātua* unless otherwise stated. E.g., auntie, sister, and nephew of the participant.
[b]K#F = female, K#M = male.
[c]The participant mentioned '*whānau*' but did not specify.

connections (*whakawhanaungatanga*), greetings (*mihi*), prayer (*karakia*), and using Māori language (*te reo*) when *kaumātua* wanted. Interviews ended with *karakia* and food.

Data analysis

Although we center an Indigenous Māori worldview, we kept that worldview in conversation with differing cultural epistemologies. The analysis used a cultural-discursive framework to provide a coding lens for analyzing talk about end-of-life care. The framework's discursive dimension centered on talk as a central resource for people to reveal their concerns and goals in words and meanings shaped by shared cultural beliefs.[49] It is in talk that the culturally centered lived world is expressed in language. Therefore, the initial coding focused on how *kaumātua* spoke about care situations, practices, their actions and those of *whānau* caring for a family member receiving end-of-life care. The framework's cultural dimension focused on expressions of *Te Ao Maāori* worldviews, Māori cultural practices, and roles[13,14,48]; principles of wellbeing such as extended kin relationships (*whanaungatanga*) and spirituality (*wairuatanga*)[13,14,18]; and values expressed within the care relationship such as nurturing others (*manaakitanga*) and love (*aroha*).

The thematic analysis was rigorous in several ways. In the original study, two Māori and two *Pākehā* analysts worked independently and then together to identify codes to translate them into themes using a constant comparative process.[50–52] This cultural-insider/cultural-outsider collective approach privileged Māori values and concepts as the primary analytical lenses in identifying and

discussing initial codes and themes. In qualitative research, data analysis relies on interpretation, and therefore the data remained open to ongoing revisions.[52] On this basis, the researchers revisited the data to focus on the cultural dimensions underpinning *whānau* care roles within *kaumātua* talk about end-of-life care. Coding *kaumātua* descriptions of their and *whānau* actions and tasks led to themes concerning expressions of Māori worldviews and *whānau* care roles.

Two other processes supported the trustworthiness of the findings. First, the themes of the second thematic analysis were discussed with two members of the Māori cultural advisory board. Second, the findings and draft paper were shared with the advisory board for feedback, guidance, and reshaping. These verification processes resulted in minor adaptations in the themes.

Findings

The study investigated how *whānau* enact their care roles in palliative care within *Te Ao Māori*. The findings show that participants' talk about *whānau* provision of palliative care was culturally bound within Māori worldviews, values, and practices. Three central *whānau* care roles emerged: *Whānau* as (1) Holders and protectors of Māori knowledge; (2) Weavers (*kaiwhatu*) of spiritual connection (*wairua*); and (3) Navigators (*kaitiaki*) in different worlds.

Theme 1: whānau as holders and protectors of Māori knowledge

This theme focuses on how *whānau* carers utilized their holistic (i.e. spiritual and material)

knowledge of their *whānau* member to meet their evolving care needs. They did this by (1) protecting spiritual (*wairua*) and cultural wellbeing and (2) enacting relational knowledge.

Subtheme 1: protecting spiritual and cultural wellbeing. This subtheme describes the expertise enacted by and accorded to older *whānau* members in end-of-life *whānau* care. Older *whānau* members' spiritual and cultural experience and knowledge of *Te Ao Māori* accumulated over a lifetime were central to *whānau* care. As one woman's plea to her children demonstrated: 'Never leave out your aunties and uncles. You are somebody when you have the (. . .) old people behind you. They give you dignity and can advise you' (K05 F). With support from older relatives, *whānau* carers enacted the principles, values, and practices of *Te Ao Māori* to protect spiritual and cultural wellbeing (*hauora*). Another carer stressed a holistic approach to *hauora*: '[The] medical thing is alright in its place, but (. . .) you gotta have that *wairua aroha* (spiritual love) (. . .) to lead, guide and direct you, to know what is best' (K15 F). She concluded that protecting the spiritual dimension of wellbeing was not only 'just as important as the medication' (K15 F) but came first in determining 'what is best' for relatives receiving care. Another *kuia* (older woman) also described her response to her aunt's distress:

> She would look in one corner of the room and (. . .) then the other (. . .) I would ask her what was wrong. She said, 'They're all around'. And I would say 'Who's all around you Auntie?' 'Oh, Mum', her grandmother and her father and they were all there. And I said, 'It's all right. They haven't come to frighten you. They're not frightening us'. (K14F)

By insisting that the visions were 'not frightening us', the niece normalized the experience and confirmed the spiritual dimensions of the situation. Such spiritual and cultural guidance and support, although often the knowledge domain of older *whānau*, happens when *whānau* (of any age) are in tune with *wairua*.

Subtheme 2: enacting relational knowledge. Providing care for *whānau* in palliative care was also shaped by intimate relational knowledge *whānau* members had developed over time. The first layer of relational knowledge refers to *whānau* members' awareness of and deference to the preferences and needs of the person in care. This relational knowledge positioned *whānau* as the natural first carers; as one participant noted, 'as a *whānau* (. . .) we think of ourselves first to do it instead of asking outside the family' (K01 F).

Deference to care needs was significant in the broad context of *tapu* (sacredness) and *noa* (ordinary). Because the head is *tapu*, certain *tikanga* (protocols) do not allow contact with, or passing 'ordinary' objects over the head or touching by others (without express consent). Carefully observing correct practices was essential when 'old fashioned' (K01 F) and 'old-time' (K02 F) Māori men insisted that 'only his wife touches his body' (K02 F) and 'looks after him' (K15 F) rather than using a nurse. In one instance, the wife bathed her husband when needed; in the other, the wife had her own bed at the hospital (K15 F).

The value and respect for *kaumātua* knowledge meant that *whānau* carers privileged the autonomy of the older person receiving care and deferred to him or her when making care decisions. As one *kuia* said, 'My father (. . .) wanted to be fully aware of what was going on; he didn't want the morphine, so we took it off him' (K14 F). The same *kuia* reinforced her mother-in-law's choice not to die at home because she thought she might frighten her young grandchildren. In contrast, another *kuia* supported her father's decision to die at home without using palliative care services: 'We took him straight from the hospital after midnight (. . .). He wanted to go home then and there because they [hospital staff] didn't think he was going to last the night' (K01 F). In both cases, the *whānau* members supported their father in the face of contrary health provider advice. These situations lead to the second layer of relational knowledge in this care role: sharing knowledge with formal service providers.

The frequency and time spent caring afforded *whānau* carers an intimate, first-person knowledge of their *whānau* member in care. One *kuia* said this knowledge meant 'we may know something a little bit better than, than they [services] do (. . .) we may have another suggestion that they haven't got' (K05 F). Similarly, another explained the importance of challenging medical personnel when they failed to address the needs of the person in care:

> Sometimes there are things that you know best, for your *whānau*, you know best (. . .) The doctor said, 'You gotta use it' and I said, 'No (. . .) I'm not using

it. Can't you see the pain that he's going through when you put him on that hoist?' (K15F)

After 25 years of marriage, the wife knew how to read her husband and used her relational knowledge to challenge the care practice. Although the doctor may have been concerned about the wife lifting her husband without a hoist, she prioritized his needs.

In another example, a *kuia* commented that in the '20 years [my sister] looked after [our father] (. . .), he never had a bedsore [while] he was bedridden' (K02 F). This care knowledge ensured that their father was well looked after at home and later on in hospital when 'she was so persistent in (. . .) looking after his toiletries' (K02 F). A *koroua* (older man) noted that hospital staff were impressed by the program that his youngest daughter set up: 'The hospital said, "Gee, we should have had you working here" because it was all about getting (. . .) to work out all medication that [my wife] was to take (. . .) so there was no pain the whole time' (K04M). Relational care expertise directly positioned *whānau* as primary carers.

The third layer of relational knowledge involved learning from formal sources. When *whānau* carers saw the need or opportunity to enhance their role by adding new knowledge to their cultural knowledge and lived experience, they were open to learning specialist care techniques. As *whānau* carers noted,

> It's not easy taking care of a sick person, if you want to wash him you [have] got to lift him (. . .) the palliative care they know how to turn them without hurting them. (K05F)

> We as a family can only do so much. The rest is up to the nurses and the doctors and it's good to know that they are there. (K01F)

Both carers acknowledge professional providers' skills. Another carer commented, "I got frightened the first time my mother got physical with me and I sort of forgot, (. . .) after I calmed down I said [to myself] (. . .) "You know how to do it. You've been taught how to [manage] your mother" (K06 F).

By adding formal care providers' know-how to their own cultural and relational expertise and choosing how and when to use it, these participants developed new knowledge to better care for their *whānau* members. Overall, however, this theme demonstrates the importance of a lifetime lived in *Te Ao Māori*, which enabled *whānau* carers as cultural and relational knowledge holders to play a critical and leading role in end-of-life *whānau* care.

Theme 2: whānau as weavers of spiritual connection

This theme captures the weaver role where *whānau* carers nurtured *wairua*, or the *whānau*'s spiritual connection. Sustaining *wairua* meant weaving together holistic, physical, and relational health for all *whānau* members. They did this by (1) weaving *whanaungatanga* (connectedness); (2) weaving responses to competing needs and roles; and (3) weaving together practical *whānau* support.

Subtheme 1: weaving whanaungatanga *(connectedness).* To weave *whanaungatanga* (connectedness) and care, the *whānau* drew upon and replenished others' spiritual energy (*wairua*) in everyday actions. *Whānau* members wove *wairua* into the collective fabric of *whānau* connectedness and care by gathering, attending to emotions, and sharing song (*waiata*) and prayer (*karakia*). *Whānau* members noted that 'the environment became positive when we were all there together' (K15 F) and 'there was no (. . .) negativity within the room, because we are a caring family, and because that's our father sitting there, grandfather, great-grandfather [*koro*] (. . .) everybody felt for him' (K02 F). Participant K12 F said she felt the 'energy of the *wairua*' and 'all those people in there are lovingly helping you'. Thus, the closeness in being together with their *koro* enhanced *whānau* ability to care.

Emotional and spiritual support for other *whānau* featured in these gatherings. One *kuia* shared: 'At night before we had *karakia* [prayer], we talk about the day's events and then before we have *karakia*, we ask if anyone wants to say anything and how they're feeling' (K01 F). She also said, 'All the *mokos* [grandchildren] used to get together and have a big family thing and have (. . .) *kapa haka* [cultural song and dance]' (K01 F). Another *koroua* mentioned his father's older brother (*tuakana*) 'bringing other *whanaunga* [relatives] with him and they had *karakia*' (K03M). A *kuia* emphasized the importance of a *whānau* member with 'a peaceful *whakaaro* [thoughtfulness] (and) good *mānawa* [warm heart]' (K05 F) who could calm emotions in

stressful situations. In being together, *whānau* drew on *whānau wairua*, and by talking, praying, and singing together they replenished their *wairua*. These elements were important, especially when facing competing needs.

Subtheme 2: weaving responses to competing needs and roles. This subtheme concerns *whānau* caregivers nurturing the interconnected strands of spiritual, physical, and relational wellbeing for *whānau* members. To maintain the holistic *hauora* of the *whānau* member in care, *whānau* members wove *whānau wairua* by 'calling in' and excluding *whānau* members at different stages of care. Sometimes, these different stages involved balancing competing care, relational, cultural, and emotional needs of *whānau* and the relative at the center of care. For instance, when participant K03M accidentally found out that his brother had cancer, he called on senior *whānau* to support younger family members caring for their dying parent, even though the younger members wanted to exclude them:

> My *tuakana* [older brother] (. . .) got cancer and he never told anyone, not even his wife. When his family found out, he only had a few months to live. It became very emotional for them to accept what was going to happen with their father. They couldn't act because (. . .) they became too emotionally involved; all they could think about was he was going to be gone, taken and so all they wanted to do was lock him away and tie him down (. . .). I just happened to come along one day and I said, 'What do you mean 'just family'?' and I said, 'Yeah well, we're his family (. . .) He's got six brothers and two sisters and where are they? I'm the only one here'. And so, I organized for his brothers and his sisters to come. (K03M)

Whānau were not able to share their *wairua* with each other when some members were excluded. Disharmony resulted when families 'hug their own *whānau* and not let it out (. . .) don'*t* let others in to *awhi* [surround, embrace]' (K12 F). This vignette, however, shows how the participant called in his brother's other siblings, and wove together wider *whānau* care and thereby supported his brother's children.

In some situations, *whānau* members had to exclude other *whānau* to protect the wellbeing (*hauora*) and *wairua* of the relative in care. In one instance, senior *whānau* members worked hard to manage *whānau* needs in the face of end-of-life wishes of their mother:

> Our mother said, 'No more singing, no more talking', so we had to stop the whānau from coming in. They didn't like that; there was a lot of *kōrero kino* [disagreement] saying that we (. . .) didn't want them to see their grandmother. But we had to explain things nicely to them (. . .) you know, we're all emotion[al]. . . but we stood, stood our ground and (. . .) it had a calming effect. (K05F)

In this case, the needs of her mother took priority over the needs of younger *whānau* members and the *wairua* of the situation was maintained. Although everyone was emotional, this *kuia* and her *whānau* drew on their respect for their mother and their standing (*mana*) within the *whānau* to ensure their mother's needs came first. This situation highlights both the *whānau* tensions and stress when meeting their loved one's needs and the role of *kaumātua* in speaking respectfully to *whānau* so that emotions are not further heightened by what is happening. The *whānau* were asked to respect their grandmother and her wishes, and to leave the disagreement (*kōrero kino*) behind.

Central to these situations, however, was upholding the *mana* of the person in care by respecting their standing within the *whānau*. The first situation offered an example of respecting *whānau* relationships, and the second, of respecting the wishes of the person in care. Although both cases could have resulted in diminishing the standing of the different *whānau* members, including the person in care, the outcomes were such that the *mana* of all was upheld as the *whānau* members came to accept new roles in a changing situation.

When dealing with competing needs within the *whānau*, parents, aunties, and uncles exercised their respective positions, cultural and relational rights, and responsibilities. Even so, some *whānau* found it hard to let in others who could support them with the care role.

Subtheme 3: weaving together practical whānau support. The third subtheme focuses on how *whānau* integrated and coordinated various types of support. Integrating practical support required *whānau* to coordinate contributions and 'all work together' (K05 F) to maintain the care space. It was generally accepted that 'it's your *whānau*, you just do it' (K12 F) and 'family is the first that you call on to help' (K05). *Whānau* coordinated who was present in the primary care space and there were 'advantages of having a big family' with 'tak[ing] it in shifts' (K01 F). Participant K02 F

explained how it worked: 'We always had some-one there, if it wasn't us, it was my brother, if it wasn't him, it was my nephew'.

Weaving together practical support also involved *whānau* offering material, informational, and financial support. For instance, instead of hospital food, 'we always got our food brought in from our families' (K02 F). In addition, *whānau* kept 'a basket of fruit for the kids (. . .) we'd organize that ourselves, for anybody that came so that nobody would go hungry' (K12 F). *Whānau* also shared information about services: 'My cousin [helped] by printing out each area [if] we need any help' (K01 F). When K18 F's mother was dying, 'my husband reconnected [her] phone so that we could have access to the telephone'.

Financial support was often crucial. Some *whānau* talked about challenges in looking after extended *whānau* as well as their partner, parent, or other relative receiving palliative care. *Koroua* K09M's situation was not unusual:

> A lot of my family came home to stay at home waiting for [my wife] to pass away thinking it was only going to be a couple of days and they stayed right through that whole four weeks. And you know, feeding family—it was real hard.

Likewise, participant K05 F observed that 'sometimes our families they don't even have the means. They're already bogged down in bills'. In these situations, '*whānau* helped. We needed the bit of money too and that was what our *whanaunga* [relatives] offered us, the support and sometimes a little bit of money and *kai* [food]' (K03M). Care was a call (*karanga*) to bring *whānau* together in close and challenging situations where all contributions to support the *whānau* member in care and *whānau* involved in caring were important.

Theme 3: whānau as navigators in two different worlds

Finally, the care role required *whānau* to navigate two different worlds, as they moved between distinctive symbolic and communicative spaces to achieve desired care outcomes for the relative receiving palliative care. They did so by (1) demonstrating their ability to communicate in the medical-palliative care and Māori worlds (2) negotiating access to medical-palliative care information and care in ways that respected *whānau* values and needs.

Subtheme 1: communicating in Te Ao Māori *and medical/palliative care worlds.* This subtheme captures the communication challenges faced by *whānau*, who had to manage the, often incommensurate, cultural divides between Māori and medical-palliative care worlds. Several participants noted their ability in managing the divide. For instance, participant K05 F explained, 'I can look at things from a *Pākehā* [European New Zealander] view, and I can look at things from a Māori view, because, first of all I'm Māori'. Here the *kuia* acknowledges the dominant system while proclaiming Māori as her primary worldview. Other participants also valued Māori perspectives that needed to be respected and mobilized within palliative care provision. As participant K18 F said, 'I think we are unique in being able to do that and to teach *Pākehā* a thing or two about palliative care from a Māori perspective'.

The inability of most formal care providers to navigate both cultures meant that it was usually up to *whānau* to overcome cultural divides. Participant K0 F5 implied that medical-palliative care professionals did not always show respect for *whānau* decision-making processes and values, when she said: 'They need to have a consideration for the *whānau*, what we like, what we desire, and our culture (. . .) because it's important to be working with us'. Participant K14F mentioned,

> I've found the foreign nurses are better to work with. They can relate to us, whereas our own *tauiwi* [European New Zealanders], they don't know how (. . .) Some have been good, but you only need one and it throws you out and then the *whānau* get angry and they wonder why.

She followed up with a poignant example where a doctor's lack of respect for the *whānau's* decision to maintain life support failed to acknowledge their *mana* and ignored the *tapu* of the *whānau* member in care:

> [The doctor] said, 'If he was to have a heart attack, did we want to revive him?' I said 'Yes', because we wanted to keep him for as long as we could. And she said, 'He could come back as a vegetable' and I said, 'Well, that's our problem. It's not yours, it's ours (. . .) Well, you're playing with our *wairua* when you're doing that'. (K14F)

Together, the participants' experiences illustrate everyday challenges that *whānau* carers faced in communicating values and principles of Māori

worldviews within medical-palliative care worlds. In so doing, participants' comments highlight the apparent inability of healthcare professionals to appreciate Māori worldviews.

Subtheme 2: negotiating access to medical/palliative care services. This subtheme shows how *whānau* need to communicate across culturally distinctive care worlds shaped how they negotiated access to palliative care services. Several participants (e.g. K02 F, K03M, K05 F, K09M, K11 F) alluded to cultural discomfort and direct racism experienced as *whānau* carers and users of the dominant health system. Against a backdrop of stereotyping, *whānau* carers' access to and experience of the system was frequently negative. K03M offers his perception of an interaction with a *Pākehā* health professional that illustrates the prevalence of the negative framing of Māori men's health:

> I thought I should go and get checked out, well I mean I'm overweight (. . .) the *Pākehā* [European New Zealander] [thinks] 'Here's a Maori, he's overweight, he's over 60 and he's a smoker and he's a male. You know, there's no hope for you boy'.

This comment illustrates the effect of living within a dominant non-Māori culture where prevailing descriptions of Māori and Māori health are negative. Such prior experiences with the health system help to explain participant K02 F's response after her husband was diagnosed with cancer: 'because I was in a *Pākehā* environment, there's no help for me anywhere'. Her perception was that the *Pākehā* health system, being non-Māori, could not meet her needs.

Yet, even with the burden of confronting dominant culture perceptions, some *whānau* carers were not afraid to ask questions, advocate for the *whānau* member receiving care, and control care quality and cultural appropriateness. Questioning often occurred at the beginning of a terminal diagnosis. Participant K06 described, 'constantly asking questions (. . .) we are very good at asking questions, we want to know. You got to ask questions so you can make life easier for the carer and our Mum'. Likewise, Participant K02 F insisted that when interacting with nursing or other staff, 'if you don't get any satisfaction, we go through the doctor'. Here, the *whānau* used the dominant culture care system's hierarchy to escalate their requests.

The care role also involved advocating for the relative in care when *whānau* perceived that care

decisions were inadequate. For example, participant K16 F described a situation: 'we had a change of doctor [who said] 'Oh no, we're not gonna operate'. So we had the big *haka* [in this context, a protest or "noisy fuss"[53]] again (. . .) everyone ignored her again, the nursing staff ignored her'. In another, the medical team sent K02 F's father home to die, and a week later, he was trying to speak:

> My sister and brother-in-law (. . .) took a photo of him on a camera, a movie of him wanting to eat and they took this camera up to the hospital and showed this doctor, and that's when he said, 'Bring him back. We'll put in a butterfly [needle left in the vein for intravenous medication]'. Those sorts of things you [have] got to do yourself.

In another example, participant K06 F's *whānau* also had to 'push' for hospital care, because whenever they took her to hospital, she 'had to leave again'. When the *whānau* finally took her to the Emergency Department, 'from there they took her up to the ward, they assessed her and then next minute they're telling us she needs to go to another ward, that she's not going to last too long'.

Finally, *whānau* attempted to control the cultural appropriateness and quality of care, because 'each death is an individual situation and (. . .) [if] family can be in control of their loved one's leaving, that makes a big difference' (K04M). When the medical team confirmed that further treatment could not 'fix' the underlying renal condition, participant K14 F decided that 'We are taking our father home now', despite the doctor 'storming out'. Controlling care also encompassed physical care. When participant K02 F's *whānau* returned to the hospital, they found that 'he was still dirty, and we blew them up. (. . .) when our father is dirty you clean him straight away, not two hours later'.

The subtheme highlights *whānau* experiences of negotiating for culturally appropriate quality care within a *Pākehā* health system. The situations illustrate the cultural motivations and values and communication efforts of Māori *whānau* carers.

Discussion

This study explored how Māori extended families (*whānau*) in Aotearoa New Zealand interpret and enact family-based care roles as they navigate their older relative's palliative care needs, the family needs, and the formal health and support

systems. Such navigation is driven by Māori worldviews, systems, and self-determination in addition to colonization-created disruptions where Māori must negotiate foreign norms, values, practices, and systems.

The findings documented three culturally centered care roles carried out by *whānau* members providing palliative care: *whānau* as (1) holders and protectors of Māori knowledge; (2) weavers of *whānau* spiritual connection; and (3) navigators in different worlds. To discuss these roles, they must be situated within the dynamics of *Te Ao Māori*. Within *Te Ao Māori*, the roles facilitate the dying *whānau* member's passing from life to death. The roles also facilitate the transition of responses to care needs as they first dawn in world of potential (*Te Kore*), become (*Te Po*) and are then enacted in the lived world of light (*Te Ao Mārama*).[15] The roles also support *whānau* connectedness that strengthens their capacity to care.[14]

Against this background, we first discuss how the roles carried out by *whānau* members providing palliative care connect with the three roles (*tūranga*) that Tate identified as manifesting the correct ways of behaving during encounters in *Te Ao Māori*: Initiation (*kaikōkiri*) support (*kaitautoko*), and challenge (*kaiwhakatara*).[14] Second, we consider how these roles extend and problematize dominant colonizer perspectives on care roles and unpack their practical implications for (inter)culturally appropriate palliative care.

As holders and protectors of Māori knowledge (*mātauranga Māori*), *whānau* initiated (*kaikākiri*) forms of care that respected the knowledge of older *whānau* carers and strengthened the connection between the material and spiritual world. By integrating spiritual support (a dimension that is habitually absent in Western perspectives of the care role), care embraces and sustains all parties' sacredness (*tapu*) and standing (*mana*).[20] This more holistic form of care supports *kaumātua* dignity (*mana*) at a time of greater vulnerability when the demands of physical care can threaten it. This role encompasses Māori cultural values such as care (*manaakitanga*), love (*aroha*), respect (*whakaute*), and guardianship (*kaitiakitanga*)[13,14] which align with values and practices of other Indigenous groups.[41]

In their role as weavers of *whānau* spiritual connection, *whānau* used *support* (*kaitautoko*) and *challenge* (*kaiwhakatara*) roles. Calling *whānau* in (*karanga*) and coordinating *whānau* care (*manaaki*) contributions were support roles, because *whānau* who 'hold each other together' were able to 'interweave our lives to make fibre strong'.[54(p40)] In weaving and strengthening *whānau* connectedness, they were mutually supported in responding to emerging care needs. Although at times *whānau* also had to challenge (*kaiwhakatara*) other *whānau* to keep them out, together they strengthened their basket (*kete*) of knowledge through weaving *whānau* ties. During encounters between *whānau* and mainstream palliative care professionals, *whānau* as navigators in two worlds likewise took on *initiating* (*kaikōkiri*) and *challenging* (*kaiwhakatara*) roles. In seeking out palliative care staff expertise, *whānau* initiated qualitatively different ca from their previous experience and knowledge. *Whānau* also initiated attempts to translate between *Te Ao Māori* and mainstream medicine and had to argue, hold their ground, and challenge health professionals with incompatible cultural worldviews. Together with Marsden,[15] the findings show that *whānau* care roles generate a continual to-and-fro from *potential* to *becoming* (when care roles require *kaikōkiri* or initiating action), from *becoming* to *being* (when care roles focus on *kaitautoko* or support), and from *being* to *becoming* (when care roles involve *kaiwhakatara* or challenge).

In addition to this movement among culture-centered care roles, *whānau* care is also relationally dynamic. Multiple family members collectively provide care (as manifested by the extensive use of first-person plurals in the data, such as '*We* took him straight from the hospital'; '*We* had to explain'). The findings show that *whānau* care roles involve various levels of relational proximity to the relative in care. The *whānau* role of knowledge holders and protectors presents caring as starting with those *whānau* closest (*whānau te rito*) to the person in care, before moving toward wider *whānau* (*whānau whānui*) in the weavers of *whānau* spiritual connection role. Here, *whānau* reciprocal care created a relational network or cloak (*korowai*) of care wrapped around all *whānau* members, expanding and contracting as care needs changed. *Whānau* care roles thus enact caring *about* and caring *for*.[26,27]

This relational ebb-and-flow has practical consequences for healthcare professionals. It is often challenging for health professionals to manage the multiple informal family roles in caring for a relative.[29] However, health professionals need to

appreciate that family care roles are fluid[6,29–31] and many *whānau* members are involved in providing end-of-life care. Moreover, organizations could support evolving *whānau* needs by creating communicative space for *whānau* when they need external support and by offering resources that respect *whānau* self-determination.

The third care role, *whānau* as navigators in two worlds, indicates that the care role reaches beyond the *whānau* to encompass members of the mainstream palliative care community. Collins and Williams's[16] model of concentric circles of care documents multiple 'layers' of informal (primary) support from close family (*whānau te rito*) and formal (tertiary) support from health professionals, with in-between layers of (secondary) support from extended family. Likewise, Wiles *et al.*'s[31] model highlights the navigator role of carers in negotiating with professionals, for example, when gathering information, learning new skills, taking on new roles, and mediating various attitudes and intentions of health professionals, the person in care, and other family members. This study adds to the understanding of the complexity and enmeshed nature of family care roles. We suggest that care comprises various interconnected dimensions where *whānau* translate care needs in culturally appropriate ways. They negotiate with formal health systems (e.g. *whānau* justifying their refusal to use a hoist) and with the *whānau* member in care (e.g. *whānau* seeking to learn new care strategies).

Unfortunately, the study indicates that some healthcare professionals were unable to accept family expertise[31] and engage in culturally appropriate and culturally safe practices.[12] The differences in worldviews generated different expectations of *whānau* carers and professional roles in providing palliative care[1] within *Te Ao Māori*[15] and non-Māori worlds. To move forward, health professionals should recognize that their practice is not culturally neutral but, instead, embedded in their own cultural worldview.[7,46,55] Professionals in the dominant palliative care system might also learn to navigate two worlds by taking a 'braided rivers approach' (*Te Awa Whiria*) that draws on two worlds of understanding to create new knowledge and thereby advance understandings in both worlds.[46] In the process, health professionals, might better serve the needs of *whānau* by inviting and responding to Māori *kaumātua* and *whānau* who seek to inform and guide service providers about how best to support *whānau* providing palliative care at home.[2]

The critical contribution of the study is that it brings co-cultural communication to the fore, in that it offers the perspectives from Māori *whānau* carers who are often co-cultural members during interactions with health professionals who are dominant group members.[32] In this respect, it strengthens the call for recognition of cultural expertise in care situations involving co-cultural and dominant cultural groups. The study also extends current work about Māori *whānau* carers negotiating and navigating two worlds[5,6] and the importance of the spiritual dimension of care in creating spiritual space for the whole family, including the *whānau* member receiving care.

However, the current study has several limitations. First, because participants came from different *whānau* groups, we could not access multiple perspectives within the same *whānau* or assess the extent of agreement on care roles. Second, because all participants were *whānau* carers, we were unable to incorporate health professionals' perspectives of *whānau* care and their experiences with *whānau* carers or describe the professional services that *whānau* were receiving. Third, the study did not include Māori carers unable to live by *Te Ao Māori* worldviews. We encourage future research to explore situations where Indigenous family carers encounter Indigenous care providers with practices, procedures, and relationships colonized by dominant health systems and worldviews. Such colonization creates additional challenges for *whānau* who create a woven network of support for the person in care, and the *whānau* themselves.

Finally, we note that, in some respects, the *whānau* descriptions of negotiations with palliative care services could apply to any family seeking appropriate care and access to services for a relative in palliative care. Yet, such *whānau* carer experiences are ever-present reminders of negative past experiences within the dominant-culture system and the apparent inability of healthcare professionals to work across two worlds.

In conclusion, the study demonstrates how *whānau* carers manage their multiple care roles collectively within *Te Ao Māori* in ways that respect and embrace Māori dimensions of *wellbeing* and *whānau* relationships when caring for a family member needing palliative care. In these collectively organized, culture-centered care roles, *whānau* initiate, support, and challenge each other and health professionals as

they navigate formal support systems. The study problematizes the notion of a single 'primary caregiver', privileges *whānau* as an interwoven relational, dynamic network of care, and encourages health professionals to recognize the cultural embeddedness of dominant models of palliative care and their impact on culture-centered palliative care for Indigenous communities.

Declarations

Ethics approval and consent to participate
Ethical approval was granted by The Northern Y Regional Ethics Committee (NTY/11/08/085). All participants gave written consent to take part.

Consent for publication
Not applicable.

Author contributions
Mary Louisa Simpson: Conceptualization; Data curation; Formal analysis; Funding acquisition; Investigation; Methodology; Project administration; Resources; Supervision; Validation; Writing – original draft; Writing – review & editing.

Kirstie McAllum: Conceptualization; Formal analysis; Visualization; Writing – original draft; Writing – review & editing.

John Oetzel: Conceptualization; Data curation; Formal analysis; Funding acquisition; Investigation; Methodology; Project administration; Resources; Supervision; Validation; Visualization; Writing – review & editing.

Kay Berryman: Data curation; Formal analysis; Investigation; Validation; Visualization; Writing – review & editing.

Rangimahora Reddy: Conceptualization; Data curation; Formal analysis; Funding acquisition; Investigation; Methodology; Project administration; Resources; Supervision; Validation; Visualization; Writing – review & editing.

Availability of data and materials
The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

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