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.

**Keywords**: care roles, culture-centered approach, family care, Indigenous, kaumātua

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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. Western colonisation, with its sense of 'a certain ownership of the entire world', 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, and such care aligns with Māori values, whānau relationships, and care practices. 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 Ao Māori is the interconnectedness of the spiritual world and material physical world of Te Ao Mārama. This connectedness is evident in the relationships among God (Supreme Being, Aorua or Io), the people (ngā tangata), and the land (whenua) which confer identity and belonging. 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. 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 Ao Māori; experiencing close and extended familial relationships; and enjoying spiritual, physical, emotional, and mental wellbeing and healthy lifestyles. 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, 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). As Mead 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. 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’. Key roles include initiating action (kaikākiri); supporting action (kaitautoko); and challenging action, frequently by proposing alternatives (kaiwhakatara). 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. 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. 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. 

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’, also underpins whānau interaction and relationships as do love (aroha), respect (whakahaere), and guardianship (kaitakitanga). 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’. Barer and Johnson’s off-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’, many definitions focus on task performance. 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. 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, 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. 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. Similarly, Nikora et al. 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’. Other catch-all roles included personal gatekeeper (‘consent giver’) and ‘counselor’.

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. 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, along with advocate for the older person receiving care, mediator between the older person and health professionals, navigating ‘additional hurdles’ to access services, and carrying out patient navigator tasks that are usually the domain of professional providers. 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, health-care professionals, service providers, and a support network of family and friends.

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 under- represented during interactions with dominant group members. 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 and explain why family care is meaningful or burdensome. Others explain away culture by arguing that family care in
itself constitutes a ‘culture’ that transcends cultural differences. 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. 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. 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 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. 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 and validate and legitimize Māori as Indigenous peoples. 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. 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. Procedures included sharing food with kaumātua before and after the interview 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 carea |
|-------------|-----|---------------------------------|-------------------------------------|
| K01Fb       | 63  | Grandfather                     | Parents, uncles, aunties            |
|             |     | Cousin (male)                   | His wife, cousins, “Our relation”   |
| K02F        | 60+ | Husband                         | “Us his family”                     |
|             |     | Father                          | Sisters, brother-in-law, his grandchildren |
| K03M        | 63  | Father                          | “Other whanaunga” [relatives]; older sister, brothers, nephew |
| K04M        | 73  | Wife                            | Daughters, friends                  |
| K05F        | 83  | Mother                          | Sisters, brother, daughters         |
| K06F        | 55  | Sister                          | Son-in-law                          |
| K07F        | 55  | Husband                         | Husband, sisters                    |
| K08F        | 60  | Mother                          | Eldest sister (main carer), sisters, “All the whānau” |
| K09M        | 68  | Wife                            | Adult children                      |
| K10F        | 75  | “Extended family”               | Cousins                             |
| K11F        | 75  | Niece                           | Brother                             |
| K12F        | 60s | Mother                          | Sisters                             |
| K13M        | 70+ | Mother                          | Whānau                              |
| K14F        | 61  | Mother-in-law                    | Whānau                               |
| K15F        | 55+ | Husband                         | Whānau, son, daughters              |
| K16F        | 68  | Mother                          | Aunty, husband                      |
| K17F        | 55+ | Neighbor                        | His daughters                       |

(Continued)
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. 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 Māori worldviews, Māori cultural practices, and roles, principles of wellbeing such as extended kin relationships (whanaungatanga) and spirituality (wairuatanga); 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. 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. 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 Tē 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 Tē 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 kaumāna 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 here” because it was all about getting (. . .) to work out all medication that [my wife] was taking (. . .) 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 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 [korō] ( . . . ) 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 *korō* 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, aunts, 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 someone 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 money. 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.

**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 tauiriwi [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, K03 M, K05 F, K09 M, 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. K03 M 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’ (K04 M). 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 Kōre), become (Te Po) and are then enacted in the lived world of light (Te Ao Mārama). The roles also support whānau connectedness that strengthens their capacity to care.

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). 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 (kaikōkiri) 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). 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 (haitakitanga) which align with values and practices of other Indigenous groups.

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’. 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 care 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, 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.

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. However, health professionals need to
appreciate that family care roles are fluid\textsuperscript{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\textsuperscript{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\textsuperscript{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\textsuperscript{31} and engage in culturally appropriate and culturally safe practices.\textsuperscript{12} The differences in worldviews generated different expectations of whānau carers and professional roles in providing palliative care\textsuperscript{1} within Te Ao Māori\textsuperscript{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.\textsuperscript{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.\textsuperscript{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.\textsuperscript{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.\textsuperscript{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\textsuperscript{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 well-being 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.

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

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