

Te Whare Kaiao—an Indigenous-informed paediatric palliative care framework for Aotearoa New Zealand

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ABSTRACT

AIM: This paper describes the development of an Indigenous-informed paediatric palliative care framework for Aotearoa New Zealand. Te Whare Kaiao (the living whare) builds upon the foundational framework of Te Whare Tapa Whā, recognising the core components integral to the delivery of quality paediatric palliative care.

METHODS: Te Whare Kaiao was developed in partnership with health professionals, whānau/lived experience experts and the Te Ārai Kahui kaumātua, using Kaupapa Māori community participatory research principles.

RESULTS: We identified the importance of highlighting that paediatric palliative care is about supporting children to live and reach their full potential. This is reflected in the symbolism used to depict Te Whare Kaiao.

CONCLUSION: Te Whare Kaiao will be utilised in multiple different ways to inform clinical care delivery, empower communities and support research in children's palliative care within Aotearoa.

Box 1: Whakataukī.

*“He kokonga whare I kitea,
He kokonga ngākau e kore e.”*

The corners of a house can be seen, but not the corners of the heart.

This whakataukī (Māori proverb) reflects the idea that we are not always certain about the inner thoughts or feelings of others. This encourages us to be mindful of the ways in which we engage. This whakataukī reminds us to enact care, love and respect for others. In addition to this, it gives value to kindness and patience, for we are never sure what other people are going through. In our kindness and compassionate gestures, we can bring light to others in their times of darkness.

Paediatric palliative care in Aotearoa New Zealand is predominantly delivered by general and subspecialist paediatric services with support from a very small specialist paediatric palliative care workforce. Until 2023, there was no health professional education available to support delivery of quality palliative care for children with serious illness and their whānau (family, including extended family). Following requests for palliative care education to the specialist service by most regional paediatric services within the publicly funded health service, an evidence-based, culturally sensitive education programme was developed and delivered in six regions across Aotearoa to over 300 clinicians.¹ This programme embedded the well-

known Māori model of health and wellbeing, Te Whare Tapa Whā,² into all aspects of curriculum delivery and course design.

Te Whare Tapa Whā

Te Whare Tapa Whā is a well-recognised Māori framework of health and wellbeing that was developed in 1984 by leading Māori health advocate Sir Mason Durie.² This work was in response to research conducted by the Māori Women's Welfare League during the 1970s,³ which identified a number of challenges within the Western model of health that dominated the Aotearoa health system, including barriers and structural racism against Māori.³ Te Whare Tapa

Whā incorporates all aspects of hauora (health), demonstrating the relational interconnectedness in all aspects of our lives.² The framework describes health as a wharenuī (ancestral meeting house with four pou [pillars]—taha wairua [spiritual wellbeing], taha hinengaro [mental and emotional wellbeing], taha tinana [physical wellbeing] and taha whānau [family and social wellbeing]).² Importantly, the model also recognises the wharenuī is grounded within te taiao (the environment) and situated on the whenua (the land). This acknowledges that we are all situated within a physical environment, connected to the land and the community around us. The original Te Whare Tapa Whā model is a foundational framework to guide approaches to health and wellbeing in Aotearoa, which recognises the importance of a holistic approach to support our tamariki (children) to grow, succeed and thrive.²

Te Whare Tapa Whā is a generic framework that can be applied in any clinical setting and is used to support clinicians to translate knowledge from education into their clinical practice.⁴ As such it was woven into our research team's paediatric palliative care education programme from the outset. Towards the end of the 2-day education programme, small group work considered what "good" palliative care for a child and their whānau would look like. Evaluation of the programme identified that the use of Te Whare Tapa Whā supported translation of knowledge into clinical practice and challenged participants to reflect on the care provided to both Māori and non-Māori children.⁴ However, it was recognised that more could be done to build upon the generic Te Whare Tapa Whā model to address the specific needs of children with serious illness receiving palliative care and their whānau.

Discussion among the small groups in the education programme held in 2023–2025 led to a vision to develop a Te Whare Tapa Whā model specific to paediatric palliative care. Education programme participant evaluation revealed clinicians were surprised that paediatric palliative care was focussed on living and not just end-of-life care. Participants also reported a need for multidisciplinary teams to have holistic paediatric palliative care assessment resources to support identification of child and whānau needs throughout the trajectory of a child's illness and to support interactions with health and community support services. It was important to us that any framework was developed in partnership with tangata whenua (people of the land), our

Indigenous community in Aotearoa.

Aim

We aimed to develop a culturally sensitive holistic paediatric palliative care framework to support health professionals to provide assessment and care reflective of child and whānau preferences.

Methods

Permission was sought from the original author of Te Whare Tapa Whā, Sir Mason Durie, to expand this framework and develop a model specific to paediatric palliative care. Sir Mason Durie was supportive of this work (telephone communication with TMM, February 2025) and he encouraged the adaptation of Te Whare Tapa Whā for paediatric palliative care. Kaupapa Māori community participatory research principles guided the design and methods of this study.⁵ One workshop was conducted at a wharenuī to identify Indigenous participants' preferences for a culturally informed paediatric palliative care framework based upon Te Whare Tapa Whā. This workshop included four Te Ārai Kahui kaumātua (Māori elders) who form an integral part of our research group.⁶ Kaumātua had varied experience from careers in education, palliative care and tikanga Māori (Māori cultural care and customs). Alongside their professional experiences, several kaumātua had personal experiences of caring for a seriously ill or dying child within their whānau. The workshop also included one hospice kai rongoā (Indigenous healer) and a Māori grandmother with lived experience expertise who was caring for her grandchild who was receiving palliative care.

The kōrero (conversation) in the workshop was led by a paediatric palliative care clinical academic (GA) and Māori researcher with lived experience of caring for her mokopuna (grandchild) (TMM). The workshop followed tikanga Māori principles with a formal mihi whakatau (welcome), sharing of kai (food) followed by whanaungatanga (introductions/connections) and kōrerorero (discussion). The workshop opened with background information about paediatric palliative care in Aotearoa and an overview of the education research project and associated health professional workshops undertaken. Concepts discussed in health professional workshops within each pou of Te Whare Tapa

Whā were presented broadly to identify integral components of the framework. TMM then introduced her vision for a living Te Whare Tapa Whā framework to promote dialogue. The voice of whānau and kaumātua were prioritised in the space and open sharing of personal stories and perspectives was encouraged.

Following the kaumātua and whānau workshop, the research team collated the information gathered in the workshop through discussion and field notes. A thematic inductive analysis was used to analyse the data.

Results

Workshop participants all supported the need to develop Te Whare Tapa Whā into a framework specific to paediatric palliative care. Both health professional discussion and the workshop contributed to the vision for a new illustrative version of the framework to be developed. The agreed focus was on recognising that paediatric palliative care is about supporting a child to live their life to the full through providing a “living” framework. It was important that this framework illustrated the interconnected and relational dimensions of holistic paediatric palliative care.

Several core components of a framework were recognised in the workshop. These included the need to:

- acknowledge that hauora and wellbeing live within the child;
- enact care, love and compassion into the care provided, recognising whānau as the experts in their child’s care;
- recognise that health professionals and whānau need to provide care in partnership;
- acknowledge that caring for our tamariki is about bringing traditional knowledge, whānau knowledge and contemporary knowledge together, combining our baskets of knowledge.

It was important to kaumātua and whānau that the Whare Tapa Whā graphic illustration featured a whare (house) surrounded by living organisms, rongoā (traditional plants used in natural healing) and fresh wai (water). The whānau and lived experience expert participant in the workshop shared their whānau pūrākau (story) of caring for AJ. This pūrākau has been shared widely through paediatric and palliative care networks to contribute to practice change.

AJ’s pūrākau highlighted the importance of including other *tohu* (symbols) to support the framework:

Following the workshop *kōrerorero*, the Te Ārai Kāhui gifted the name Te Whare Kaiao to the framework, which translates to the whare that is alive, or the house of the living organism. This recognises the notion that paediatric palliative care is about supporting children to get on with “living”.

Researchers then took the above concepts and worked in partnership with a local graphic artist. A graphic artist, Sasha Maya, was selected, who worked closely with schools to develop artwork representative of a school’s values in supporting and nurturing tamariki to reach their full potential. This artist’s previous work and relationship with tamariki in Aotearoa to date was a natural alignment to our aspirations for Te Whare Kaiao.

Throughout the development of the framework and images, regular consultation was sought from workshop participants and the wider Te Ārai Kāhui that support our research.

Te Whare Kaiao

The concept of the living whare was brought to life through the inclusion of specific natural elements that are culturally symbolic within Te Āo Māori (Māori world). Te taiao (the natural environment) encapsulates the cyclic nature of life, the seasons and natural transitions associated with plant and animal life. Many of the elements incorporated into Te Whare Kaiao (seen in Figure 1) hold deep cultural and spiritual significance to Māori. For example, the *pōhutukawa* tree, although commonly known as Aotearoa’s Christmas tree because of its bright red flower clusters, was included because it is one of the stars that form Te Kāhui o Matariki (Pleiades star cluster). This appears during Matariki (the Māori New Year), which is the time when Māori traditionally farewell their deceased.⁷ In this Indigenous narrative, during the previous year the celestial captain Taramainuku travels the night sky in his *waka* (canoe) Te Waka o Rangi (the canoe of Rangi) casting his net and sweeping up all the souls of the newly deceased. He drags the net with the departed souls behind his celestial *waka* as he travels to Rarohenga (the underworld). As the new year approaches Taramainuku opens his net to release the souls.

Traditionally, Matariki is an important time of the year, when mourning Māori celebrate their

Box 2: The value of whanaungatanga in caring for our boy—Davina Collins.

AJ is 20 months old and has a hypoxic brain injury. Over the course of the last year, AJ has struggled with dystonia, seizures and frequent respiratory infections. Despite this he is a little boy full of mischief, smiles and an ability to laugh and enjoy time with his whānau. AJ has spent long periods of time in hospital and when at home has been supported by a team of community health professionals. Communication and whanaungatanga is integral to the care of any child and their whānau. Without this, mistakes can be made and distress caused for both AJ and us as a whānau.

It is essential we can connect and come together as a team—whānau and health professionals as one whānau around the child. We need to bring our baskets of knowledge together—the whānau of being the experts in their child and the health professionals their skills, training and experience. We must work together as a team. When big decisions need to be made, it is important we have trusting relationships with health professionals who are working with us.

“We row this waka [canoe] together as a whānau (family & health professionals). We need to be on the same waka and heading in the same direction.”

*The most important ways in which whanaungatanga can be established is through taking time to get to know AJ and us as his whānau. Get to know AJ as a little boy, beyond his illness. Get to know us as a whānau—what matters to us, our beliefs and values. We need health professionals to always respect our culture and acknowledge that just because we are Māori, we don’t all do things the same. Different iwi, different tribes have different perspectives and different ways of doing things. We would love to be cared for by more Māori clinicians. When that’s not possible, engaging with kaiaatawhai (cultural support team) and kaumātua (Māori elders) is really important to us and is a huge support in connecting with hospital staff. **We need health professionals to not be judgemental and authentically connect with us, listening to our perspective and our experiences of caring for AJ.***

We know that we won’t always have a health professional that knows AJ or us as a whānau, especially when we have to come to the emergency department in the middle of the night or weekends, but what helps in these situations is communication, hearing what we are saying and health professionals taking the time to connect with us.

Listening is the most important way you can connect. AJ’s voice needs to be heard—in day-to-day care, in decision making always.

“We are his voice—we are speaking for AJ, understand our voice for AJ.”

Figure 1: Te Whare Kāiao graphic illustrating the concept of the living whare.



Figure 2: Ārai graphic symbolising the veil between the physical and metaphysical worlds.



loved person's soul being returned to the stars.⁷ The inclusion of the pōhutukawa image, therefore, is an important element in the Te Whare Kaiao framework as it represents the female star Pōhutukawa that connects Matariki to the deceased. The image is a cycle of life tohu of transition from the physical to the metaphysical realm. The presence of pōhutukawa is a symbolic link between earth and heaven. The bright red flowers also symbolise Tāwhaki's blood (a warrior who fell to his death trying to reach heaven) and therefore associates the journey of the wairua (spirit) to the underworld of Cape Reinga. Furthermore, the bark of pōhutukawa was traditionally used as a rongoā (natural healing) plant to assist with anti-inflammatory and antioxidant purposes. Other plants have been included in the Te Whare Kaiao illustration for their significant healing properties (kōwhai and kawakawa) as these are commonly used by rongoā practitioners to support healing and comfort.⁸

The tekoteko (carved figure at the top of the wharenuui) represents Ranginui (sky father) and Papatūānuku (earth mother). This has been included to represent the original tīpuna (ancestors) of humans and to represent a child's relationship with their parents. On local wharenuui tekoteko represent the ancestors of specific iwi (tribes) or hapū (sub-tribes). However, we have chosen a universal symbol of ancestry that all Māori will be able to connect with.

Living creatures are included within the illustrations. For example, we have included the pīwakawaka (fantail) as some iwi associate the appearance of this friendly energetic bird that suddenly appears inside a home as a messenger that portends an impending death. This timely message allows the whānau to prepare for what lies ahead. Another cultural interpretation the pīwakawaka brings is the message of motivation and inspiration to forge ahead to achieve dreams, which is needed when families are caring for a seriously ill child.

The back wall of the wharenuui represents the ārai (depicted in Figure 2). The ārai symbolises the veil between the physical and metaphysical worlds that the wairua crosses on its spiritual pathway home. For many iwi, this wall inside the wharenuui is where the tūpāpaku (deceased person's body) is laid for the duration of the deceased's tangihanga (funeral custom). We also included the huia as this precious manu (bird) is considered one of the most tapu (sacred) of manu. Although extinct, the huia symbolises mana and nobility of spirit befitting the status of wairua transcending to the heavenly realms. The inclusion of the ārai and huia represents the transition from life to death when a child is actively dying; recognising the transition of the wairua to the spiritual realm is also a core component of paediatric palliative care.

Another important element that we have

Figure 3: Waka and kai hoe graphic illustrating the collaborative partnership between whānau and health professionals.



Figure 4: Three baskets of knowledge graphic.



included is wai symbolised in the form of a running awa (river). Representation of pristine running water is significant not only for healing purposes but also to symbolise whakawātea (cleansing rituals) within different places that seriously ill people may be, die or their bodies may lie in state.

We have used other supportive tohu within Te Whare Kaiao to emphasise the relational nature of paediatric palliative care. In one illustration (see Figure 3) a waka and kai hoe (paddlers) are used to express AJ's whānau pūrākau shared above.

This image represents whānau and health

professionals paddling together in the same direction, symbolising the collaborative relationship required to care for a child with serious illness and palliative care needs.

It was also recognised that the knowledge required to care for children and whānau comes from different sources. The illustration of the three kete (baskets) below symbolises the cultural and spiritual mātauranga (Indigenous knowledge) gifted from the highest realm of heaven, retrieved from Tāne (Māori divinity).

The three kete (Figure 4) sit on the mahau (porch) of Te Whare Kaiao's wharenui and as a

Figure 5: Tamaiti graphic illustrating the child's relationship with their environment.



separate icon representing the different types of knowledge: te kete tuauri (the basket of light) contains spiritual knowledge, rituals, prayers and memories that connect people to the world that is not seen through physical eyes; te kete tuatea (the basket of darkness) represents knowledge of harmful things such as mākutu (curses or black magic) or things that could harm people that they need protection from; te kete aronui (the basket of pursuit) represents the containment of knowledge that benefits humanity including kindness, compassion, love, art and peace.

Together, the Te Whare Kaiao illustration and supporting illustrations tell a story not only about optimal palliative care for a child and their whānau but also deeply rich cultural meanings embedded in Māori tribal narratives and spiritual belief systems, and customs associated with living and dying well. To supplement the cultural expression within the illustrative elements of Te Whare Kaiao we have also incorporated te taiao, the natural world, within the silhouette of the tamaiti (child) (Figure 5). This represents the relationship the child has with their own environment including their familial, physical, emotional, social, cultural and spiritual dimensions of oranga (wellbeing).

Discussion

Te Whare Kaiao is a framework that has been developed from the original Te Whare Tapa Whā to illustrate the essential components of culturally safe care for a child with serious illness and their whānau in Aotearoa. While the initial intentions of this work were to support care of tamariki Māori

and their whānau, kōrero with health professionals, whānau and communities has identified the relevance of this framework for all children with palliative care needs in Aotearoa across diverse ethnicities and backgrounds.

Te Whare Kaiao maintains the same domains as Te Whare Tapa Whā—taha hinengaro, taha wairua, taha tinana, taha whānau—and considers whenua. These domains and how the tasks and considerations reflected in the care of a child with palliative care needs and their whānau are depicted in Table 1.

The illustration and concept of the “living whare” in Te Whare Kaiao challenges health professionals to extend their knowledge and clinical care of children. The key is empowering them to acknowledge that care of children with palliative care needs is about supporting them to reach their full potential to live.

The framework is intended to support delivery of health professional education in paediatric palliative care, support delivery of quality clinical care to children and whānau, inform future research and empower communities to support children with serious illness and their whānau. Each of these domains is explained further below.

Education

Te Whare Kaiao will replace the use of Te Whare Tapa Whā in the paediatric palliative care short course at The University of Auckland. This is the only formal education available in Aotearoa in paediatric palliative care. This will ensure the health workforce receives consistent messaging

Table 1: Te Whare Kaiao—considerations in providing paediatric palliative care.

Taha hinengaro	<p>Child's likes/strengths/important connections and toys</p> <p>Therapeutic support for child and siblings</p> <p>Child's understanding of what is happening—developmentally appropriate</p> <p>Child and whānau hopes, worries and fears</p> <p>Whānau support to be able to spend all their “being” with their child</p> <p>Whānau understanding of what is happening</p> <p>Te Wā Aroha (goals of care and advance care plan)</p> <p>Discuss support services and consider alignment with child and whānau beliefs</p> <p>Mana Motuhake (autonomy and independence)—support strong whānau voice</p> <p>Acknowledge feelings, emotions and uncertainty</p> <p>Listening to child and whānau!</p> <p>Whānau strengths and vulnerabilities</p>
Taha wairua	<p>Karakia (prayers, chants and incantations) and waiata (songs, singing)</p> <p>Kaumātua, chaplain or tohunga (expert [on spiritual wellbeing]) support</p> <p>Mirimiri (massage) and Rōngoa Māori</p> <p>Whānau-led care</p> <p>Appropriate physical space to meet spiritual-, cultural- and faith-based needs</p> <p>Acknowledge whānau beliefs and spiritual messages</p> <p>Acknowledge HOPE always</p> <p>Memory making—maintaining connection for future (photos, castings, dreams, wishes)</p> <p>Clothing, korowai (cloak), pounamu (greenstone)—items of significance that need to be kept with child</p> <p>Health professional support—what's helpful? What's not?</p> <p>What is important to child and whānau</p> <p>Child never left alone</p>
Taha tinana	<p>Symptom management—managing distress, multimodal—medicines and non-pharmacological measures</p> <p>Positioning</p> <p>Personal cares and hygiene</p> <p>Referrals for continuing care if transitioning to different environment, e.g., home</p> <p>Physical environment—lighting, aromatherapy, noise, favourite toys, temperature, home comforts if in hospital</p> <p>Anticipatory planning and medicines available</p> <p>Physical touch and comfort—cuddles</p> <p>Comfort assessment—whānau/clinician partnership</p> <p>Equipment to support comfort</p> <p>Developmental care—support children to reach their full potential, involving siblings</p> <p>Practical medical supplies and resources</p> <p>Nutrition and hydration—benefits and burdens—consider role of comfort feeding</p>

Table 1 (continued): Te Whare Kaiao—considerations in providing paediatric palliative care.

Taha whānau	<p>Practical whānau support (considering extended whānau) —meals, food, housing, practical supplies</p> <p>Sibling recognition and support</p> <p>Consider family dynamics</p> <p>Information—how much? When? How would they like information provided?</p> <p>Who is important to have present for a hui? Who is decision maker?</p> <p>Financial support</p> <p>Acknowledge and involve all whānau important to child</p> <p>Acknowledge tipuna</p> <p>What strengthens whānau during difficult times?</p> <p>Explore tikanga and wishes for after-death care</p> <p>24/7 plan for communication and support for whānau.</p>
Whenua	<p>Location of care</p> <p>Hospital setting—consider environment—double room, relaxed visiting policy, whānau able to stay, space for whānau to gather for kai together</p> <p>Supporting home routine to maintain connection to home</p> <p>Bringing home into the room—pillows, duvet, toys, items of significance</p> <p>Where do whānau feel most connected to?</p> <p>Transitional objects—connection to significant place</p> <p>Whakapapa (genealogical descent lines)</p> <p>Where do they want to be after death?</p> <p>Where is the whānau whenua?</p> <p>Community connections and support</p> <p>Key health professional relationships</p>

about the importance of addressing the needs of children and whānau across all domains of Te Whare Kaiao. As highlighted in feedback from previous education, this will also serve as a useful tool in supporting translation of knowledge into clinical practice.

Clinical practice

Te Whare Kaiao will be socialised throughout clinical communities across Aotearoa in paediatric services, non-governmental organisations and any clinicians working with children with serious illness and their whānau. It is hoped expanding on the primary Te Whare Tapa Whā framework and illustrating the vision for children's palliative care will support clinicians to consider all aspects

of a child's oranga. The notion of the living whare supports clinicians to recognise that palliative care for children is a journey of living life, with palliative care being provided from diagnosis of a serious illness, often from birth or even antenatally. Many children live with palliative care needs for many years, and it is important to recognise that palliative care is about supporting children to reach their full potential and achieve childhood milestones at their pace.

Communities

Te Whare Kaiao is also intended to support whānau and communities to recognise a child's needs and consider ways in which they can access culturally appropriate support to care for

their child. Once funding is secured, this framework will form the basis of a brochure supporting whānau to understand core components of caring for their child through a Māori lens. The need for this brochure has been recognised by clinicians working with whānau Māori in Aotearoa and also in Australia, where there is a growing population of whānau Māori.

Research

Te Whare Kaiao is the first framework to recognise the needs of a child with a serious illness receiving palliative care in Aotearoa. To date, there is limited research within the field of children's palliative care in Aotearoa. We hope to use this framework as a lens to explore whānau experiences of caring for a child with palliative care needs or at end-of-life in Aotearoa. The use of Te Whare Kaiao in this context will support perspectives to be gleaned from whānau about

their cultural, spiritual, psychosocial, whānau, physical and community care needs throughout their child's healthcare experience.

Conclusion

Te Whare Kaiao is a framework for children's palliative care that builds upon the original Te Whare Tapa Whā model first described by Sir Mason Durie. Te Whare Kaiao uses symbolism within Te Āo Māori to express the importance of paediatric palliative care supporting a child to live and reach their full potential, addressing all four domains of Te Whare Tapa Whā in the context of te taiao and whenua.

Te Whare Kaiao will be utilised in multiple different ways to inform clinical care delivery, empower communities and support research in children's palliative care within Aotearoa.

COMPETING INTERESTS

GA has received an Auckland Medical Research Foundation Travel Grant to attend an ICPCN conference. GA is an appointed executive member of Paediatric Palliative Care Australia and New Zealand. RD is chair of Paediatric Palliative Care Australia and New Zealand.

ACKNOWLEDGEMENTS

The authors wish to acknowledge the Auckland Medical Research Foundation for providing financial support through a project grant, and the Te Ārai Kahui kaumātua for their support of this work.

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<https://nzmj.org.nz/journal/vol-139-no-1633/te-whare-kaiao-an-indigenous-informed-paediatric-palliative-care-framework-for-aotearoa-new-zealand>

CITATION

Aburn G, Moeke-Maxwell T, Gott M, et al. Te Whare Kaiao—an Indigenous-informed paediatric palliative care framework for Aotearoa New Zealand. *N Z Med J*. 2026 Apr 17;139(1633):12-22. doi: 10.26635/6965.7271.

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