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Evaluation of a Cook Islands Māori model of palliative care: a protocol

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ABSTRACT

Introduction: Access to palliative and end-of-life care is a recognised human right, yet significant disparities persist for Pacific peoples in Aotearoa New Zealand. While understanding of different cultural perspectives has grown, gaps remain in the delivery of culturally appropriate palliative care in Aotearoa New Zealand.

Aim: This research aims to examine the effectiveness, cultural appropriateness, and practical feasibility of the Cook Islands palliative care model, *te vaerua kōpū tangata ora,* within palliative care practice.

Methods: This study will use a Cook Islands Tīvaevae research methodology to guide semi-structured interviews with twenty five 5–35 Cook Islands community members and ten palliative care clinicians. This approach will support a rich, relational and culturally grounded exploration of how a Cook Islands Māori palliative care model can be integrated into clinical practice.

Outcomes: Recommendations to improve culturally responsive palliative care will be formulated in collaboration with community members and clinicians. The study will contribute to the limited body of knowledge on Pacific cultural understandings of palliative care and provide practical insights into applying an Indigenous Pacific model within the palliative care system.

Keywords: Palliative care, end-of-life care, Pacific health, Indigenous methodology, Tīvaevae, Cook Islands, nursing

INTRODUCTION

Research in palliative and end-of-life care that offers insight into the existing palliative care knowledge of diverse community groups is an area worthy of exploration. The development and adaptation of Pacific approaches in the field of palliative care that are grounded in Pacific paradigms are likely to deliver novel insights into palliative and end-of-life care. The model *te vaerua kōpū tangata ora*, which translates as "the wellness of the family spirit". The model is a culturally responsive, holistic palliative care model designed specifically for Cook Islands Māori in New Zealand (NZ).[1] The model emphasises holistic, family-driven care and considers the spiritual wellness of the family while centring the family member receiving palliative care as they move through a spiritual transition. The model incorporates of the role of the *tupuna* (ancestors) and the importance of maintaining family harmony. The model was developed using grounded theory methodology alongside the Cook Islands research methodology, *Tīvaevae*. The model was formulated as a conceptual model through interviews with Cook Islands Māori caregivers, Cook Islands Māori clinicians and traditional Māori healers (n=28), and has been published elsewhere.[2] The objective of this study is to assess the suitability of the model to the wider Cook Islands Māori community in Aotearoa, NZ and to determine the suitability of the model to the clinical setting.

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Pacific peoples' use of palliative care services

The World Health Organization (WHO)[3] describes palliative care as an ethical necessity that should be accessible to all and adapted to suit the needs of local cultures. Community engagement is promoted as the primary strategy for meeting the needs of local communities and cultures.[4] In line with the recommendations from the WHO, the current NZ Palliative Care Strategy states that all people in need of palliative care "should have access to quality palliative care services that are culturally appropriate".[5] The strategy also highlights the need to understand Pacific cultures. However, there is currently limited research on the palliative care needs of Pacific peoples and even less research focusing on palliative care for Cook Islands Māori in NZ.

There are limited data on palliative care use among Pacific peoples in Aotearoa NZ. However, available evidence suggests distinct patterns in how Pacific communities engage with palliative care reflecting, cultural norms of caring for family members at home.[6] Pacific peoples with cancer are more likely to die at home than NZ Europeans.[7] For example, earlier research reported that 30% of Pacific peoples died at home,[8] while another found even higher rates, up to 42%, compared to 36% of Māori and 27% of NZ Europeans, within one NZ city.[9] This pattern aligns with broader evidence showing that many Pacific peoples volunteer significant time to caring for family or community members and providing for their communities.[10] The survey found that over 20% of Pacific families regularly care for an older family member or community member, while more than 10% regularly care for a member with an illness and around 10% regularly care for a person with a disability.[10] Given these cultural norms and caregiving patterns, palliative care planning and policy need to account for Pacific concepts of care, service and family responsibility to ensure the equitable distribution of palliative care resources.

Differences in how Pacific peoples understand and conceptualise palliative and end-of-life, impact on their use of palliative care services.[2,11] There are few resources tailored specifically for Pacific communities, and there is a lack of understanding within Pacific communities of NZ-based palliative care services.[6] In addition, there is a reported lack of resources in Pacific languages and a lack of palliative care community engagement with Pacific communities.[6,12]

Background

The Cook Islands holds a unique place within the sociopolitical environment of Aotearoa NZ. Cook Islands Māori are connected to NZ Māori through familial, cultural and historical ties. The Cook Islands comprises 15 islands in the South Pacific. The Cook Islands were annexed to NZ in 1901[13] and later became a self-governing nation in free association with NZ in 1965.[14] Due to the cultural and historical relationship between Māori of NZ and the Cook Islands, the Cook Islands were governed through the Department of Native affairs, NZ. During this period many prominent NZ Māori politicians held roles in visiting and governing the Cook Islands, including Sir Apirana Ngata,[15] Te Heuheu Tūkino,[16] and Maui Pomare.[17] This historical relationship between the Cook Islands and NZ continues today.

Today, an estimated 94,176 Cook Islands Māori reside in NZ,[18] around 27,000 Cook Islands Māori in Australia,[19] compared with approximately 17,000 people residing in the Cook Islands, [20] The Cook Islands is part of the NZ realm, as an independent nation in free association with NZ. Part of being a realm nation includes Cook Islands Māori having unrestricted rights to NZ citizenship and residency. Given the high proportion of Cook Islands Māori residing in NZ, a health system that is responsive to the needs of Cook Islands people is essential for the wellbeing of the Cook Islands people, both in NZ and in the homelands. Health models and policies that reflect the relationships between NZ and Pacific nations are important steps towards acknowledging our shared history and future within the realm of NZ.

METHODS

The study will use the Tīvaevae methodology to examine how the palliative care model. *te vaerua kōpū tangata ora,* can be translated into practice. Tīvaevae is a Cook Islands Māori research methodology designed by Teremoana Maua-Hodges[21] and has been used by numerous researchers of Cook Islands and non-Cook Islands descent. Over time, the Tīvaevae methodology has been further developed, as researchers have adapted the model to their research and developed it into a methodology that can be applied across wide range of research contexts. Tīvaevae is the name given to a traditional Cook Islands quilt, traditionally made by a group of women.[22] Five key values of the Tīvaevae were developed by Te Ava[23]and will be used to guide this study. These values are *taokotai* – collaboration; *tu ngateitei* – respect; *uriuri kite* – reciprocity; *tu inangaro* – relationships; and *akairi kite* – a shared vision, [24]

The Tīvaevae methodology is based on Cook Islands Māori traditions and paradigms. Like the creation of a Tīvaevae (quilt), it is developed through working together as a group. Te Ava and Rubie-Davies describe a shared vision as the

objective of the methodology. [24] The ontological underpinning of the Tīvaevae is embedded in *akairi kite* (a shared vision). It is within the relationships formed that our realities are tested against each other, created and shaped. It is for this reason that the model, *te vaerua kōpū tangata ora*, will be strengthened by the methodology. Similar to other methodologies, such as constructivist grounded theory and co-design, the Tīvaevae methodology recognises that knowledge is constructed by participants and the researcher through constant comparison of emerging data.

Study design

Study aims and objectives

The aim of this research is to examine the effectiveness, cultural appropriateness and feasibility of the Cook Islands palliative care model, *te vaerua kōpū tangata ora,* in palliative care. The objectives of the research are to:

- To examine cultural acceptability by exploring community members' perceptions of the model's alignment with traditional beliefs and practices.
- To examine feasibility by identifying barriers and facilitators to implementing the model within existing healthcare systems.
- To compare clinicians' perceived outcomes between the model and conventional palliative care approaches.
- To determine the transferability of the model to the wider Pacific community in NZ and internationally.

Study design overview

The study is divided into four phases: gap analysis, adaptation, feedback and review, and implementation.

Phase one – gap analysis: This phase will review the cultural and clinical appropriateness and transferability of the model into practice through qualitative focus groups with members of the Cook Islands Māori community and palliative care clinicians. This process involves a deep understanding of and affirming the model's cultural relevance, effectiveness, and appropriateness within the community it serves. The first phase of validation ensures that the model is not only grounded in Indigenous knowledge systems but is also practical, sustainable and meaningful for the community, and clinicians, fostering trust and supporting its integration into healthcare practice.

Phase two – adaptation**:** The model will be adapted for use in the clinical setting, creating a practice-based framework for the implementation.

Phase three – feedback and review*:* The model will be disseminated through community focus groups for final feedback and review.

Phase four – implementation: This phase involves reviewing the application of the model, in practice by interviewing clinicians over an eight-month period. Interviews will occur at 3 –4 months and 6 –8 months after education on the model has been provided.

Phase one: *Tāmoumou te Tīvaevae* (to secure)

Three to four group interviews will be conducted as the first set of interviews (*tāmoumou te Tīvaevae*) to secure the foundation of the Tīvaevae and will include community members (n=15 –20). These interviews will introduce the current model, *te vaerua kōpū tangata ora*. The model is currently a conceptual model; the purpose of these interviews is to ground it through relational knowledge and lived experience. The interviews will be recorded and analysed in real time and after the interviews. A summary of the interview focus and inclusion criteria is provided in Table 1.

Table 1. *Tāmoumou te Tīvaevae* – community interviews

Focus: Implementation of *te vaerua kōpū tangata ora*

Number of participants	**15 –20 community members**
Focus of interviews	Spiritual needs of the family Psychosocial needs of the family Physical needs of the family Practical needs of the community Needs to be determined by the community
Inclusion criteria	Cook Islands heritage Interest in or experience with palliative care, aged care, end-of-life, chronic healthcare or primary healthcare

The second set of interviews (*tuitui te Tīvaevae* – to sew) will present the model alongside the findings from the community to clinicians (n=10). Clinicians will therefore be interviewed after the foundation has been established by the community. This method, similar to Kaupapa

Māori, is to honour Cook Islands knowledge and recognise community members as experts in creating a Tīvaevae. The clinicians will then be interviewed about the clinical application of the model. The focus of the interviews and inclusion criteria are detailed in Table 2. The focus of the interviews will be adapted to address the needs identified through the community interviews.

Phase two: *Tuitui te Tīvaevae* (to sew) – amending the model

This phase will establish the practical steps for applying the model in practice. The data collected from the previous interviews will be analysed and used to amend the model.

Table 2. *Tuitui te Tīvaevae* (to sew) – clinician interviews

Focus: Dependent on the needs identified by the community

Number of participants	**10 clinicians (registered and/or unregistered)**
Focus of interviews	Review what the model aims to achieve Review the practical clinical implementation of the model Consider the role of health care providers in implementation Consider the expected outcomes of the model The plan for sustainability
Inclusion criteria	Currently working in generalist or specialist palliative care, community palliative care, hospice, primary healthcare, community NGO health care providers, aged care, chronic or long-term health care Clinicians defined as registered clinicians, e.g. nurses, doctors, social workers, or non-registered clinicians, e.g. healthcare workers and community liaison personnel

Phase three: *'Akamānea te Tīvaevae* (to decorate) – community interviews

The model will be presented to the community (n=10 –15) for final review (see Table 3). This will include a presentation of the model followed by a focus group review. Collaboration and working with the community are part of the creation process for making a Tīvaevae, discovering shared objectives and engaging with the varied perspectives of others.[24]. The model will be finalised, and education resources will be created.

Table 3. *'Akamānea te Tīvaevae* (to decorate) – community interviews

Focus: To refine and finalise the model

Number of participants	**10–15 community members**
Focus of interviews	Final review of the model by the community Determine whether the key components hold true Discuss how the model will be implemented in practice Gather feedback
Inclusion criteria	Involved in previous community interviews Cook Islands heritage Interest in or experience in palliative care, aged care, end-of-life, chronic healthcare or primary healthcare

Phase four: *'Akāiri'anga* (to put in place)

This phase will include presenting the model to clinicians and community members. Specific teaching and engagement with clinicians will promote and facilitate adoption of the model (see Table 4).

Table 4: *'Akāiri'anga* (to put in place) – presenting the model

Focus: To evaluate the model in practice

Teaching, testing and evaluating	
Number of participants	10 clinicians
Inclusion criteria	Currently working in generalist or specialist palliative care, , community palliative care providers, hospice, primary healthcare, community NGO healthcare providers, aged care, chronic care or long term healthcare
Focus: teaching	Create guidelines and teaching materials that articulate the purpose and use of the model, including: • Pacific values and traditions as expressed by the community

	• Strategies for delivering the model • Techniques for involving families and communities • Examples of implementing care
Focus: testing	Interviews will be undertaken at 3–4 months and at 6–8 months after education of the model Perspectives on using the model Identify the enablers of implementing the model in practice Identify the barriers to implementing the model in practice. Changes in patient outcomes (subjective review) Changes in personal practice Changes in organisational practice Other data collected Participant demographics
Focus: evaluation	Review of the collated interview data Identify the barriers to implementing the model in practice. Identify the enablers of implementing the model in practice Changes in patient outcomes (subjective review) Changes in personal practice Changes in organisational practice

Recruitment

Phases one, three and four: Recruitment for these phases will involve purposive and snowball strategy for both groups. For in-person meetings, community members and clinicians will be recruited from Auckland, NZ, where the greatest number of Cook Islands Māori families reside.

Community members: Community members will be recruited through community organisations. networking and advertising within the community.

Collaboration: Work with and seek guidance from steering group members to design and implement the recruitment process. Advertise the study on Cook Islands platforms. Attend community events to explain the study in person and answer questions.

Clinicians: Clinicians with experience providing palliative care, will be recruited from hospices, community primary healthcare and NGO practices.

Sample size

In this qualitative study, rich description and in-depth exploration of both community and clinician perspectives are sought. The sample size is therefore guided by the need to balance feasibility with meaningful depth of understanding. Consistent with the Tīvaevae methodology, which emphasises a collective and shared vision,[23] the sample size was determined with consideration of this concept. Data saturation will be considered to have been reached when interviews yield no new insights and no additional codes are generated during analysis. The previous study in which the model was developed[1] interviewed 28 participants, including community members who had experience using palliative care services, clinicians and traditional medicine practitioners, providing a strong foundation of community knowledge. This study builds on those foundations to further develop and refine a shared vision.

Data collection

Phases one, two and four: Data collection will use a semi-structured interview guide that will be continually adapted as the interviews progress.

Interviews: A semi-structured (*'āpa'āpa* – half full) interview guide has been created to provide consistency and structure while remaining flexible and responsive to participants' contributions. The guide is grounded in Cook Islands Māori concepts developed by Te Ava Te Ava,[23] including *tu inangaro* (relationships), *tu akangateitei* (respect), *uriuri kite* (reciprocity), and *akairi kite* (shared vision), which serve as guiding principles for applying the Tīvaevae methodology. The layering concept of *'akapapa'anga* (genealogy or the act of layering) is also incorporated as a foundational step. Powell describes *'akapapa'anga* as "the relationality between individuals or cultural elements who are all part of an ever-growing whole or body" (p. 132) emphasising the interconnectedness that underpins the knowledge-building process.[25]. The semi-structured guide will remain dynamic and adaptable, shifting as new insights emerge in a

continuous circle of knowledge creation. This approach aligns with other iterative qualitative methodologies, such as grounded theory, by recognising participants as contributors to and co-creators of emerging knowledge. Conceptually, this process mirrors the making of a Tīvaevae – adding stitches to build a pattern or unpicking areas where the pattern has not yet fully formed – reflecting the collective development of understanding.

Data analysis

Although explicit data analysis methods are not described in the existing literature on the Tīvaevae methodology, a set of guiding principles spans the research process. These guidelines provide a flexible and open strategy that can be interpreted and adapted to suit the needs of individual studies. The Tīvaevae model can be applied across disciplines, providing a culturally grounded approach to conceptual development and synthesis.[21] When applied to the coding of qualitative data, the Tīvaevae process offers a clear outline of the sequential steps – securing, stitching and refining – that can inform a culturally aligned and systematic coding strategy.

There are three key stages in the coding and analysis of qualitative data that align closely with the stages of creating a Tīvaevae, and these can be used to guide the analytical process. The creation stages include *tāmoumou* – to fasten or secure; *tuitui* – to sew; and *'akamānea* – to decorate. As described by Maua Hodges,[21], *tāmoumou te tīvaevae* involves the pange (tīvaevae group) tacking the Tīvaevae together and securing the initial patterns. This is followed by *tuitui te tīvaevae*, where each member of the Tīvaevae group sews their assigned section, collectively checking and monitoring the emerging work. The final stage, *'akamānea te tīvaevae* involves tidying, refining and decorating the Tīvaevae to complete the piece.[21]

Based on this interpretation of the Tīvaevae methodology, the following stages fo data analysis will be applied. Interviews will be conducted in stages. The first stage, *tāmoumou* (to secure), will involve completing a set number of interviews, with the final number guided by *piri'anga* (relationship, connection) and the relationships that emerge between concepts during the interview process. Data analysis will occur concurrently with data collection, allowing for continual checking, refining and validation of new information. Once key concepts have been developed through the stages of *tāmoumou*, the process of *tuitui* (to sew) will begin. In this stage, new interviews will be used to check and refine emerging concepts for accuracy and coherence. Interviews with community members and clinicians will be analysed and reported separately before being merged for the final stage. The final stage, *'akamānea* (to decorate), involves bringing together those who participated in the individual or family interviews for a group discussion to further shape, enhance and "tidy" the Tīvaevae, ensuring that a shared and collectively affirmed vision has been created.

Ethical considerations

Ethical approval was granted by the AUT Ethics Committee, AUTEC (#25/105)

The ethical responsibilities of conducting palliative care research in Pacific communities require the researcher to maintain duty of care to the participants. A duty of care includes ensuring that the research is based on Pacific paradigms and values. The Tīvaevae methodology closely aligns the research with Cook Islands Māori values and principles. This requires the research to be adaptable to meet the needs of the community as the community sees fit.

Research in palliative care raises unique ethical considerations, and gaining ethical approval for palliative care studies has been documented as challenging in the literature.[26] Research in palliative care can potentially be triggering for participants and requires researchers to be sensitive to signs of distress and end interviews if required. Potential risks, including distress from discussing sensitive issues, will be monitored, and a plan to minimise potential harm implemented.[27]

DISCUSSION

This study represents an innovative approach to collecting data on the cultural suitability of a Pacific palliative care model for the community and clinicians. The study addresses an area where little is known, but new knowledge is needed. As populations age and demands for palliative care services rise, addressing the unmet needs of underserved groups is becoming an increasingly urgent priority. Equally important is the engagement of community members to ensure that interventions are culturally responsive and meaningful for the intended community. Engaging communities and working closely with palliative care clinicians will likely identify the strengths and barriers within the current palliative care system and its ability to adapt to accommodate cultural models of care. Secondly, adapting the Tīvaevae for use in the palliative care setting will aid in refining the methodology developing its theoretical foundations and demonstrating its practical application within the healthcare setting.

Data availability: Relevant de-identified research data from this study may be made available upon study completion and publication.

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