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The Tīvaevae methodology and its application to palliative care research

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Abstract

Health researchers have an ethical responsibility to ensure their research aligns with the health and wellbeing needs, solutions, and aspirations of the communities they study. This ethical responsibility is often heightened in palliative care research. This article reflects on the use of the Tīvaevae methodology – a Cook Islands research methodology – in a study which aimed to understand what palliative care means to Cook Islands families in New Zealand. There is limited research on the needs and understanding of palliative care for Pacific peoples and a near absence of literature that focuses on the needs of Cook Islands peoples in palliative care. More broadly, there is little documented on Cook Islands cultural understandings and knowledge on death, dying, and end-of-life care. As the majority of Cook Islanders reside in New Zealand, and new generations of Cook Islanders in New Zealand find themselves in the position of becoming caregivers to palliative (and often older) family members, understanding what their needs are will be important for families and clinicians alike. In this article, I argue that the Tīvaevae methodology can be used as a guide in the process of contextualising the concept of palliative care to understand palliative care within a Cook Islands context.

Keywords: Tīvaevae; Palliative care; Hospice; Pacific health; Tapu; Noa

Introduction

Mouria tā'au peu tūpuna

'Akaora ia tā tātou 'anga'anga tuitui

Ko koe uaorai te ka kite i tā'au tuitui tīvaivai.

Hold on to your ancestral traditions.

Revive all our forms of artwork.

Only you know your way of sewing tīvaivai (Cuthers, 2006: 2).

There is limited research in New Zealand on the needs and understandings of palliative care for Pacific families. Some evidence exists to show that Pacific peoples are low users of palliative care, end-of-life care, and hospice services (Foliaki et al., 2020). However, as health data often groups Cook Islands people under the term 'Pacific peoples', the uptake of palliative care services by Cook Islands families is not fully understood. What *is* known is that Pacific peoples are more likely to describe a desire to care for their own and frequently describe palliative care as not being "the Pacific way" (Foliaki et al., 2020; Henry, 2019). The lack of palliative care research for Pacific peoples is reflected in policy, wherein policy aimed at addressing the palliative care needs for Pacific peoples is limited.

As the majority of Cook Islanders reside in New Zealand, access to culturally safe palliative care services is necessary to ensure Cook Islands people have access to palliative care resources. Equally, it is necessary to ensure we maintain our traditions and customs during palliative and end-of-life care. The impact of losing traditional customs that are applied around the time of serious illness and death may not be fully realised until these practices are foregone. Ritual and custom at the end-of-life and after death have been shown to aid in maintaining connection to the ancestors, maintain family harmony, and aid in coping with grief (Henry, 2024). Furthermore, retaining a connection to the ancestors has been shown to promote care of the elderly, especially care of parents (Hu and Li, 2021; Wen Li et al., 2021).

Palliative Care in New Zealand

Palliative care is an area of holistic care for individuals and their families who have a life-limiting diagnosis. It is defined by the World Health Organisation as:

An approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and

treatment of pain and other problems, whether physical, psychosocial or spiritual (World Health Organization, 2014: 13).

In New Zealand, palliative care practice has largely followed international trends heavily influenced by models of care from the global north, most notably the modern hospice movement. Palliative care as a philosophy of care is closely linked to English nurse and physician Cicely Saunders' (2006) concept of a good death. Saunders is considered to be the founder of the modern hospice movement and the concept of a "good death" incorporates constructs such as "total pain", the idea that pain can be a symptom of broader, holistic needs beyond physical pain such as mental, spiritual, and existential suffering (Castro et al., 2021). To put these concepts into context, they were developed during a time when modernity and individualism were heightened, and individual achievement represented cultural ideals of progress (Metzger, 2023). Arguably, this mindset was manifested within the clinical practice of palliative care as a greater emphasis on autonomy and freedom, with individual spiritual transcendence being the final achievement of the individual (Metzger, 2023). These beliefs were formed to separate the idea of the modern hospice movement from its religious origins, namely the connection to the church, and the biomedical clinical practices of the hospital. The modern hospice movement prioritised holistic care that was not bound to religious ideals or clinical ideals. Rather, the ideals of autonomy, self-determination and choice were prominent considerations (Metzger, 2023).

From the creation of the modern hospice movement, largely developed in England, a philosophy of care developed from cultural understandings of what end-of-life care and palliative care should look like. Given this context, palliative care practice can be understood as being a philosophy of care which developed within a cultural context. With this understanding in mind, palliative care philosophy and practice and how the current palliative care health services and models available in New Zealand were established, can be better understood. By contextualising palliative care practice in New Zealand as originating from a cultural context, different concepts of palliative care can be given equal prominence rather than questioning how communities can fit into established structures, particularly when engaging with communities from discernibly different cultural contexts as compared to the global north. Furthermore, "palliative" means "to cloak" or "cover". The term refers to the covering of physical disease and relates to a time when tumours or other ailments would simply be covered when no longer treatable (Stolberg, 2017). "Palliative" has no direct translation in Cook Islands Māori and a literal translation is unlikely to be meaningful in Cook Islands Māori without the historical context of the term. Therefore, defining what palliative care means from a Cook Islands perspective is important in helping to determine what is significant to Cook Islands families. In this article, I argue that the Tivaevae methodology aids in the process of contextualising palliative care within a Cook Islands context.

The Tīvaevae

The making of tīvaevae and the formation of a tīvaevae pange has been described as an activity, a process, and a reason to come together to make connections and build a sense of place; in other words, to “stitch together new lives” (Underhill-Sem and Underhill, 2015: 3). The making of a tīvaevae is a collective activity that reflects the relationships between the creators, the natural environment, the recipient of the tīvaevae, and the ancestors (Rongokea, 1992). Tīvaevae also extend beyond the physical realm and are a symbol of reciprocity, objects that are communally made and communally treasured.

Research in Cook Islands communities draws on indigenous knowledge, ways of knowing, ways of being, and ritual. One of the challenges of applying Pacific methodologies as an emerging researcher is the task of defending your findings, your methodology, and the underlying philosophical paradigms of your research against dominant philosophies and ways of knowing (Leenan-Young and Uperesa, 2023). Equally challenging is knowing if justifying your research and ways of knowing against these dominant philosophies is useful; is comparison a way to expand on indigenous ideas or is it a process of dilution?

A similar challenge in palliative care research exists. This is particularly noticeable in comparisons between the biomedical model, a reductionist view which views health as the absence of disease (Wade and Halligan, 2004); the more holistic palliative care philosophy and the community’s knowledge and concepts of wellbeing at the end-of-life. For families, trying to negotiate between upholding cultural and family traditions and accepting palliative care services can be a challenge. My study explored the different spaces of palliative care philosophy, the biomedical model and Cook Islands family traditions of caring for their own to understand how we as clinicians can better aid and assist Cook Islands families in navigating the end stages of life. This study was unique in that it was guided by the values and principles of the Tīvaevae methodology, with a focus on the Tīvaevae as a metaphor for the importance of seeking to understand the hidden layers and underlying meaning.

Tīvaevae are prized possessions used as prominent decorations for important events and often gifted on special occasions throughout a person’s life, including weddings and haircutting ceremonies (Rongokea, 1992). Depending on the context, tīvaevae can enter the tapu space when used at funerals and to cover the headstone at a family member’s unveiling (usually one year after their death) (Herda, 2011). Tīvaevae can also be used to shroud the body or coffin at death and may be specially sewn or kept for this purpose, considered to be given with aro’a (Horan, 2012). The use of tīvaevae at the time of death to shroud a loved one is suggested to be a modern recreation of the traditional practice of binding the dead in bark cloth (Herda, 2011). If a tīvaevae is used for this purpose and then kept by the family, it may take on a different meaning and become a symbolic reminder and representation of the deceased family member. Similarly, a tīvaevae made by a family member who is no longer

alive may take on a new meaning and become symbolically connected to that person. Finally, the *tīvaevae* is a symbol of reciprocity, of *aro'a* given at the time of birth and death and is symbolic of the continuum of life. These concepts of the *tīvaevae* having a place in *tapu* and *noa* spaces and being part of the continuum of life were found to be important concepts in the research when discussing the role of the ancestors in the lives of the living.

Applying the Tīvaevae Methodology

The *Tīvaevae* methodology was used to guide the aforementioned qualitative study on Cook Islanders' understanding, knowledge and beliefs on palliative care in New Zealand. In total 28 interviews were conducted with Cook Islanders residing in New Zealand. The sample included families, health care practitioners and persons who held knowledge on traditional health practices. The study was undertaken for the requirements of a PhD on palliative care for Cook Islands families.

This section focuses on the layers of the *tīvaevae* as a metaphor for understanding the hidden meaning or history of a research topic. Developing an understanding of the cultural context of palliative care health models and palliative care philosophy is a useful starting point for Cook Islands research based in New Zealand. Understanding the cultural context of palliative care in this study aided in de-centring what was the assumed norm (i.e., Western cultural values, as discussed in the section prior). This allows for other interpretations and understandings of the end stages of life (i.e., palliative care) to be equally valued.

The literal *tīvaevae* was transformed into a theoretical research methodology by Maua-Hodges (2018) and has since been built upon and expanded by various authors (Futter-Puati and Maua-Hodges, 2019; Te Ava et al., 2018). Alongside the articulation of the principles and values which make up the *Tīvaevae*, the layers of the *Tīvaevae* have been pulled apart and inspected, as discussed by Futter-Puati and Maua-Hodges (2019) and expanded upon by Joseph (2022). The *Tīvaevae* methodology is comprised of three distinct layers that come together to form the finished study, with each layer representing a vital component of the final conceptual *tīvaevae*. The first layer seen represents what is outwardly displayed to the world (Futter-Puati and Maua-Hodges, 2019). Similarly, Joseph (2022) compared this layer to the *persona*, the way a person may choose to act, react, and be in the world. The first layer is described as "the story they want to share" (Joseph, 2022: 45).

The second layer, on the reverse side of the *tīvaevae*, represents that which cannot be seen from the outside but lies just beneath the surface. This layer reflects the complexity of participants' stories, including their personal, social, and historical context. This layer is described by Futter-Puati and Maua-Hodges (2019) as displaying the realness, the complexity and varying skill levels of the *tīvaevae* group. This may be applied to both the research

participants or the researcher. This second layer can be conceptualised as the underlying concepts and ideas which are found between words or through actions.

The third layer of the *Tivaevae* is the backing, described as the foundational layer which protects the other layers of the *tivaevae*. This layer protects the stitches from becoming loose or unravelling (Joseph, 2022) and therefore protects the *tivaevae* design that can be seen from the outside. In a research context, this layer can be interpreted as understanding the area of research and determining what are the underlying paradigms or assumptions of the field. Additionally, this may include centring Cook Islands worldviews and avoiding deficit-focused research. For health research in New Zealand, it is important to understand the influence of the New Zealand health system to better understand how these constructs influence how health is conceptualised for families. Furthermore, the backing layer can be used as a metaphor for the researcher developing an understanding of the underlying assumptions of the research area in the broader context and history of New Zealand. Palliative care in practice often sits between the biomedical model, and the more holistic palliative care philosophy. These models and methods of care have their own history, their own *papa'anaga*. As the focus of this article is on Cook Islanders living in New Zealand, it is essential that we explore how these conflicting models can harm and hinder Cook Islanders accessing (or needing to access) end-of-life care. This will further help to dispel the notion that these models of care are without *papa'anga* or are universal paradigms.

The process of contextualising the topic area of palliative care from a New Zealand perspective aided in situating palliative care practice as part of a tradition of care. While palliative care in New Zealand is likely to be distinct, understanding the underlying paradigms was a useful exercise for making the culture of palliative care visible. This was further aided by completing a literature review on the theories of palliative care from an international perspective, and a literature review of the models of care. These reviews facilitated in developing understanding of palliative care in context and found the theoretical underpinning of palliative care to be closely tied to Western theories of health. Models of care were predominately focused on specialist palliative care and generalist palliative care delivered in the community. The exception to these more dominant models were indigenous models of palliative care which had been developed for indigenous populations from New Zealand, Canada, and Australia (Henry, 2024). Due to the New Zealand locality, understanding the dominant cultural norms of palliative care, clinical care culture, and New Zealand-based Cook Islands culture became an important consideration in shifting between understandings of the complexities of the varying views on palliative care. The next section reflects on navigating between two cultural worlds, or “research at the interface” as coined by Mason Durie (2004), and focuses on navigating a culturally sensitive research space such as death and dying.

The final stage of the Tīvaevae methodology is referred to as o'ora te tīvaevae (Maua Hodges, 2018) and symbolises the presenting and gifting of the tīvaevae. This may be interpreted as presenting the research findings back to the community, acting on the findings to seek change, and serving the community who gifted the knowledge on which the study was based. This may include paying respects to all of those who contributed, including the ancestors, through acts of service. This final stage represents the reciprocal underpinning of the Tīvaevae methodology and can be summarised in the following quote:

Whenever you come to learn about needle work or tīvaivai making or any special art and craft work like embroidery, cushion making or tie dying, remember do not ever become selfish and keep those gifts to yourself, they do not belong to you. They are God-given. Remember, always share these gifts with others so that they may learn from you (Cuthers, 2006: 2).

This quote can be used to remind researchers of their position of privilege, and their duty to give back. The quote is from my aunty, Māmā Cuthers, on the advice given to her by Māmā Tuarongo Cowan, Māmā Enere and Māmā Akaiti Henry, my great-grandmothers and grandmother. The quote served as a useful reminder during the study as to the purpose of conducting research and the motivation behind pursuing research.

Negotiating Space Between Tapu, Noa, and Mana

Research in palliative care is known to be an ethically challenging research area to conduct research in (Gysels et al., 2013). Beyond the ethical implications of palliative care research, the Tīvaevae methodology aided in reflecting and applying cultural values important when engaging with participants. In addition to the values previously outlined, in the Tīvaevae methodology are other cultural considerations important in palliative care research. For example, tapu, noa, and mana are interconnected and in research are the spaces that are navigated by the researcher, the individual knowledge holder or collective knowledge holders. Tapu, noa, and mana have been described as foundational guiding principles in Pacific research (Tecun et al., 2018). Tapu is described by Whatu (2023) as that which is sacred or a restriction in relation to a person, thing or entity. Noa, in contrast, relates to the absence of restriction or a state of being ordinary. Together, these concepts describe the foundational regulations (Whata, 2023), restrictions, and allowances that govern our relationships. These relationships may be between people alive or ancestral, between the environment, between the tangible and intangible. Tapu and noa are important to consider in any Pacific research and, as argued by Young and colleagues (2022), the consideration of tapu and noa in research furthers our understanding of Pacific paradigms and its role in our health and wellbeing.

Palliative care is known to be a sensitive area to conduct research. The time of caring for a loved family member is profoundly sacred. Therefore, the role of the researcher is to act with aro'a (love), kauraro (respect), tā'aka'aka (humility), 'akamoe'au (to be peaceful), and 'apaitu'anga (to use peaceful ways to achieve your goal of mutual obligation) as outlined by the Tīvaevae methodology (Maua-Hodges, 2018). The role of the researcher is to enable the family members to decide and have determination over what they decide to share, to act with love and respect to maintain the mana of the family and navigate the space between and through tapu and noa. Within my own practice, I do this to protect the family members sharing their stories. For example, if the family members decided to share only small details of their journey during my interviews with them, then this space should be protected, to protect the families from potential trauma of retelling their stories. Sharing this knowledge can be a benefit or burden to families and, because of this, this space must be protected. As noted by Maua-Hodges (2018) research knowledge must be gained using peaceful ways and maintain the researcher's obligations to the family to protect their mana and wellbeing.

Tapu has been discussed as encompassing the unknown, fear and darkness as well as a concept which can influence wellbeing (Young et al., 2022). In palliative care, families who remained in the tapu space discussed the feeling of a darkness or weight which kept them in the space of grief. This was described in my research in the following statements: "the person concerned, that passed away, comes back and haunts the family", and, "I don't know, this is just some spiritual thing, I'm not quite sure, but it happens, straight after when [family member] was buried and also a few years later, my [family member] passed away, the same thing happened when they were buried" (Henry, 2024: 135, 141). While the focus of this article is on the use of the Tīvaevae methodology, there are relationships between the wellbeing of communities, the role of the researcher, and a duty to care.

The goal of this research was to develop an understanding of palliative care from a Cook Islands perspective in a broad sense, and the interview procedure followed a ritualised pattern. Prior to the interviews, I had created a short semi-structured interview guide which was adapted to each interview. As interviews progressed the guide was adapted. Interviews would begin with a formalised greeting, adapted dependant on age, and my relationship with the participants was developed through establishing family and ancestral connections. Prayer (pure) were performed, allowing the conversation to be kept in the space of the everyday (noa). Palliative care was discussed broadly, and families would connect their own experiences to this discussion. From the researcher perspective this was interpreted as moving between that which may be seen as tapu and noa. Guided by the families, the conversation would then return to the everyday with the concluding pure. Depending on the family's availability, we would continue with general conversation, and it was during these times, before and after the recorded interviews, that connections were made and a better understanding of the family's context developed.

Palliative care is a research area in which the researcher must weave into the tapu environment enough space and time to allow for stories to be shared but not weigh down the storyteller. It is then the researcher's responsibility to guide the connection back to the everyday noa space. In this study, sometimes families voiced experiences of individual and family struggles or hardship. Other times, the stories were full of laughter and anecdotes of families coming together. While others spoke of song, aro'a and beauty, accounts of palliative care frequently include all the above.

In this research, the stories shared by families were almost always family stories. This included the deceased family members. The stories and data collected therefore belonged not only to the storyteller but to the deceased. The process of individual consent for family knowledge is questionable in that the process separates the members of the family as individual consent givers. While it could be assumed that the family members present give collective consent, the missing family members – most notably, the deceased – are not able to provide this consent. Further to this, families may share information which may have been considered private to the deceased during their life. In this case, the researcher should apply the concepts aro'a and kauraro to the shared stories and allow those interviewed to check the data to maintain integrity and be mindful of maintaining the mana of the tūpuna.

Palliative care research heightens the duty of care responsibilities of the researcher and, as I found in my studies with Cook Islands families (Henry, 2024), includes protecting the mana tūpuna (status, reverence of the ancestor) in order to protect the family. This concept became increasingly evident as participants discussed the place of the ancestors in their lives throughout the study interviews. The place of the ancestors in their lives was similar to the concept of ancestral veneration, the belief in the ongoing presence of the ancestors in the lives of the living (Hu and Li, 2021; Lim, 2015). Ancestral veneration is also the act of showing respect and honouring the ancestors through service, and my participants discussed their presence in relation to being an everyday norm, to being a source of support or, as discussed previously, a source of unease. The role of the ancestors in day-to-day tasks was discussed in the following quote: "Although they have passed, they are still part of the family, so the graves are clean, they are re-dressed" (Henry, 2024: 135). This was further normalised as routine in another quote: "It's almost like, they are never actually, never, not really, never have died and gone away, have they?" (Henry, 2024: 135). This connection to the ancestors or people of the past is referred to in the following poem by Tongareva poet, Alistair Te Ariki Campbell (1989: 3):

It will be like this one day
when I sail home to die –
the boat crunching up on to the sand,

the wading through warm water
to the beach,
the friendly voices
round me in the darkness,
the sky dying out
behind the trees of Omoko,
and reaching out of hands.

The Tivaevae Methodology and Palliative Care for Cook Islanders

The Tivaevae methodology in this study provided a way for me to contextualise what palliative care is in the New Zealand clinical setting and a way to better understand what cultural barriers Cook Islanders were confronted with when accessing palliative care services. One of my key findings was that the presence of the ancestors and maintaining a positive relationship with them was a prominent way of understanding palliative care from a Cook Islands perspective. However, while participants in the study discussed the importance of being able to speak freely about their connection to the ancestors, these beliefs were perceived by families as not welcome by palliative care clinicians or being outside of what was perceived to be, palliative care. An example of these beliefs are the continued relationships with tūpuna, even after death. These relationships were discussed as a cultural norm for Cook Islands peoples. Yet, practices which connected us to the deceased were also discussed as a deviation from cultural norms: “What is very conflicting is that we also believe in other things. I don’t know what the proper term is, but I know it’s things like tūpāpaku (ghost spirit) like spirits, like ghosts and the dead” (Henry, 2024: 174). A similar statement was found from an interview with a Manganian priest, who said, “As good Christians, we should not believe in ghosts. But in the body, we do” (Clerk, 1995: 163). In the palliative care setting, these beliefs in the ancestral spirit having continued presence could be misinterpreted as families struggling to let go of their loved one or maintaining misguided hope. These beliefs, evidently conflicting with some Western views of the human soul after death, may be misinterpreted as symptomatic of existential distress rather than a construct of our cultural context.

Conclusion

This article has discussed the use of the Tīvaevae methodology, the underlying paradigms of the methodology as understood by the writer, and it has reflected on the application of the Tīvaevae methodology in palliative care research. The Tīvaevae methodology provides company, Cook Islands philosophy, and a strong theoretical grounding to Cook Islands palliative care research in New Zealand. As the Tīvaevae methodology grows and a community of writers stitch new designs, reinforcing or unpicking the original patterns, the concepts of what it means to conduct research in a Cook Islands way will develop and presumably change over time. However, the values underpinning the Tīvaevae will likely remain even if the outward design changes. The relationships between writers and between articles will continue to develop our understanding of ways of knowing. For this study, the Tīvaevae methodology acted as a foundation and guide for the study to develop greater understanding of the cultural context of palliative care by de-centring palliative care philosophy understood from a Western perspective. It sought to develop an understanding of palliative care from a Cook Islands perspective without comparing Cook Islands beliefs against Western norms and standards. De-centring palliative care philosophy in this way, allowed for the voices of the participants to be considered without comparison. One of the key findings of the research is that by using the Tīvaevae methodology and centring Cook Islands voices in health research, we can better understand the diverse needs of Cook Islands families within their own context.

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