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"The doctors will tell you things that they understand – Not what we understand." Community voices on developing a palliative care model for Cook Islands Māori in New Zealand

Amy Evelyn Henry, PH.D.[1], Mayor Pokino, M.H.SC.[1], El-Shadan Tautolo, PH.D.[2], Jan Dewar, D.H.SC.[3], Josephine Herman, PH.D.[1] and Ioana Mulipola, D.H.SC.[1]

[1]Faculty of Medical and Health Sciences, The University of Auckland, Auckland, New Zealand; [2]Centre for Pacific Health & Development Research, Auckland University of Technology, Auckland, New Zealand and [3]School of Health, Victoria University of Wellington, Wellington, New Zealand

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Corresponding author: Amy Evelyn Henry; Email: amy.henry@aut.ac.nz

Abstract

Objectives. This study aimed to identify the enablers and barriers to accessing primary and specialist palliative care services for Cook Islands Māori in New Zealand, and to collaborate with community members to explore the practical application of a tailored palliative care model

Methods. Three focus group interviews were held with Cook Islands Māori community members ($n = 18$). A culturally responsive research methodology, Tivaevae, was used to guide data collection and analysis. An advisory group was established to provide cultural and clinical oversight.

Results. This study presents the findings from the first phase of model validation, exploring Cook Islands Māori peoples' use of palliative care services in New Zealand. The study identified key moments when families needed clear and accessible health information, during prognostic disclosure and during moments of responsibility transfer. These key moments provide opportunities for families to develop the tools to care and plan. This, in turn, enables family members to choose their preferred place of care and to develop family or community-guided care pathways based on Cook Islands Māori culture and faith.

Significance of results. While improvements in cultural safety and cross-cultural communication have been made, there are still groups who experience barriers to accessing palliative care. Identifying key moments when care can be enhanced is key to developing systems that can deliver culturally responsive care for minority groups. Conceptual models show the beliefs, motivations, and values that guide care. However, models must be usable for both community members and clinicians, and critically, must support meaningful and positive outcomes.

Introduction

Internationally, several models have been developed which seek to improve access to palliative care for specific indigenous or minority groups (Clarke and Holtslander 2010; McGrath 2010; Kelley et al. 2018; Moeke-Maxwell et al. 2020). Such models typically act as an addendum to existing palliative care systems, supporting the development of understanding, access, and a shared language. These models are created for, or adapted by, specific communities and not intended to be generalizable or transferable. Despite this, indigenous models often share key features: the importance of relationality, collectivism, the role of family, the importance of spirituality (Clarke and Holtslander 2010; Moeke-Maxwell et al. 2020), and personal advocacy and empowerment (McGrath 2010). These models address issues of access and understanding and enable minority groups to navigate palliative care using familiar language and concepts. Despite their importance to communities, there has been little research aimed at validating cultural models; little is known about how these models are used in practice and the impact on the care of indigenous and minority communities.

Despite calls to ensure palliative care services are accessible to all (World Health Organization 2018), many minority groups face barriers to primary and specialist palliative care (Oduro et al. 2025). In New Zealand, there are known gaps in the service delivery of palliative care for Pacific peoples (Foliaki et al. 2020). A recent literature review on Pacific people's palliative care use

found that palliative care is still largely informed by Western models of care (Churchward et al. 2026). This assertion is similarly supported by Shah et al. (2025), who found that such models do not meet the relational needs of ethnic minority communities living in New Zealand. Service design and organizational routines have likewise been shown to function in ways that do not support the involvement of larger families or the spiritual needs of families (Churchward et al. 2026). Further, at the interpersonal level, misunderstandings and breakdowns of communication lead to gaps in care (Foliaki et al. 2020; Fanueli et al. 2026). These gaps were found to be more prominent for families with lower levels of English language proficiency or low health literacy (Churchward et al. 2026).

Recently, there has been a focus on ethnic-specific research that addresses and seeks to understand the unique health needs of communities. In New Zealand, the Pacific population makes up 8.9% of the population (Statistics New Zealand 2025). New Zealand has historic relationships with the people of the Pacific through shared genealogy with New Zealand Māori and through colonial relationships. The Islands of the Cook Islands, Niue, and Tokelau remain part of the New Zealand realm. The Cook Islands are a self-governing nation in free association with New Zealand. Cook Islands Māori are New Zealand citizens, and because of this shared citizenship, many reside in New Zealand. As New Zealand citizens, Cook Islands Māori have free access to the New Zealand health system, including rights of travel to access health care treatment unavailable within the Cook Islands (Masters 2012, 2014). Understanding this unique relationship is therefore a key part of ensuring the Cook Islands Māori community in New Zealand has equitable access to palliative care.

Understanding the underlying concepts and motivations for accessing health care services such as palliative care is an important first step toward developing a palliative care framework that can be applied in practice. To address this, a conceptual model of care developed in a previous study (Henry et al. 2025) was used to understand the underlying drivers or motivations for families when caring for a family member. The current study seeks to deepen the understanding of the enablers and barriers to accessing palliative care within the New Zealand health system while maintaining cultural values and concepts. By exploring Cook Islands Māori community members' understanding of palliative care services, this study seeks to determine when and where along the palliative care journey the implementation of a cultural model of care would have the most impact.

Methods

The current research is part of a larger study investigating the use of a palliative care model for Cook Islands Māori in New Zealand. Further information about the study is reported elsewhere (Henry et al. 2026). This phase of the study used the Tivaevae methodology, an indigenous methodology named after the traditional quilt in the Cook Islands (Futter-Puati and Maua-Hodges 2019). Pacific methodologies are grounded in Pacific worldviews and indigenous epistemologies that are aligned with Pacific peoples' understanding and sense-making (Sanga and Reynolds 2017). The Tivaevae methodology is relational by design; this is evidenced in the method of knowledge creation. In practice, a tivaevae (quilt) is sewn by a group; the practice of collectively creating a tivaevae is a metaphor for the research process. This collective creation is a process of co-constructing meaning. The process of knowledge creation is underpinned by 5 key values: Taokotai – collaboration, Tu akangateitei – respect, Uriuri kite – reciprocity, Tu inangaro – relationships and Akairi kite – shared vision (Te Ava et al. 2011). These values can be used as a guide alongside the researcher's own positionality (Houghton 2023), to ensure suitable respect is shown and the research has meaning to the community from which it originates.

Recruitment and data collection

Participants were recruited through purposive and snowball sampling over a 5-month period. Local community networks were used to disseminate information on the study. A total of 18 participants were interviewed who met the following criteria: over the age of 18 years, of Cook Islands Māori ancestry, and willing to participate in a focus group interview on palliative care. Experience using palliative care services was not a requirement to participate in the study; this was to ensure a range of community members could participate and not only those who have accessed palliative care services. As many Pacific communities prefer caring for family members at home (Churchward et al. 2026), experience as a primary carer or as part of the wider family support system was expected, and many participants reported having cared for a family member at end-of-life.

Participants who met the criteria were invited to attend one of the focus group meetings. In total 3 focus group interviews were conducted. All participants provided written informed consent to participate in the interview. Two focus group meetings were conducted in person at local community facilities in Auckland, New Zealand. One meeting was held online via Microsoft Teams. The inclusion of an online focus group was to allow persons who had expressed interest in the study but were unable to meet in person to participate. Each interview started with a prayer and introductions. The discussion was facilitated using a semi-structured interview guide. However, participants were able to talk freely to follow a line of thought rather than a linear trajectory. The interviews were audio-recorded and lasted from 60 to 90 minutes. Each interview was attended by 2 researchers of Cook Islands ancestry. The in-person meetings were also attended by a member of the advisory group who provided translation and cultural guidance.

Data analysis

The audio recordings were transcribed using a professional transcription service; the transcriber signed a confidentiality agreement prior to transcribing. The transcripts were analyzed using NVivo software. Data analysis was conducted by 2 researchers independently, and the data analysis summary was reviewed by the research team.

The concept of a shared vision from Tivaevae methodology guided the coding process for this study. A shared vision has been described as a community-led vision to be understood from the perspective of the community (Kokaua-Balfour et al. 2025) and, in this study, focused on the practical potential of the community's vision. The first interview was coded independently by 2 researchers. The codes from the first interview were used to create a code book. The code book was then used as a guide to code the subsequent interviews. This was followed by tuitui te tivaevae (to sew each section); this describes the process of the draft codes being checked against new data, allowing patterns to emerge. A summary of the codes and preliminary themes was presented and reviewed by an advisory group which consisted of 2 Cook Islands community members with health practice and research experience and the

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research group. This stage was followed by akamānea te tivaevae, when the tivaevae is tidied, and decoration added (Maua Hodges 2018). The themes were then refined with a focus on developing a shared vision. The findings of the focus groups are presented as a collective voice; therefore, quotes are not attributed to individual participants. This is to capture the developing shared vision and present the work as a collective effort.

Results

Three major themes were found from analysis of the focus groups. These were navigating health information, community-guided care pathways, and realm-based health care.

The theme of navigating health information explored the need for greater access to resources, information, and enhanced communication. These issues were discussed frequently; 148 coded references referred to the need for greater access to information. In contrast, palliative and end-of-life care preferences had 42 coded references, and 60 coded references relating to cultural, spiritual, and community support grouped under the theme of community-guided care pathways. The third theme, realm-based care, had fewer coded references, 30 in total. This theme was determined to be important due to the unique position of the Cook Islands people living in New Zealand. Of the 18 participants, only 1 participant was male. This may have been influenced by the recruitment method, as the local community groups included traditional arts and craft groups. Additionally, caring may be seen as a traditional role for females.

Theme 1 – Navigating health information

The most prominent finding from this study was the lack of information and understanding of palliative care. The theme was divided into 3 subthemes. As the focus of this study is practical application, the subthemes were developed by noting when these knowledge gaps were the most prominent or had the greatest impact on access to information (see Table 1). The 2 key points in the care process where communication breakdowns had a notable impact on family outcomes were at the time of prognostic disclosure and when the responsibilities of care were likely to shift to the family or to the clinical team. The third subtheme, cultural contexts of health literacy, refers to the ease with which health information was found and understood along the journey.

Prognostic disclosure is considered a key component of palliative care planning for clinicians and patients. Prognostic acceptance is associated with positive outcomes for patients, including improved quality of life (QOL), patients' ability to make informed decisions and to prepare for end of life (Hui et al. 2021). As 1 participant stated when reflecting on the experiences of other community members, *"the inequity is they're not being carefully explained, not just their condition, but their care plan" (Int2).* Similarly, another participant stated, "there's *no person in between the doctor and the hospice*" expressing the need for greater support to understand the plan of care for their family member, to understand their options and make an informed choice. They continued, *"I think even the fear of knowing 'Hospice'. When they hear it,"* indicating that without access to information, assumptions may fill the information gap. This highlights the need for culturally appropriate communication to ensure families can understand their options, their right to make an informed choice, and their right to an explanation of their condition.

The second subtheme, responsibility transfer (see Table 1), builds on the previous subtheme and includes the process of openly communicating with a person and their family on the likely course of their illness, particularly when the tasks of caring shift from the nurse or clinical team to the family or from the family to the health care team. Pre-emptive, open communication during this handover of care allowed families to plan. When pre-emptive care was delivered in a way that aligned with the person's communication needs, participants expressed trusting the service and a positive experience, as shown in the following quote. "*She had a good experience with that care because…they took her through the process of making her understand the place, the care to be given, where this particular room is, what's available in the room.*" This highlights the benefit of developing relationships and trust with families as part of communicating and negotiating a plan of care.

When a family member becomes palliative, care responsibilities shift back and forth. Family provides emotional, cultural, and daily support; health professionals step in for symptom management and comfort care. As the illness progresses, families become increasingly responsible for clinical tasks. When the responsibility of caring moves beyond daily cares, this may be challenging for families and may go beyond what they believed their role would be as family members. In the following example, a daughter discussed being in the position where they were expected to administer subcutaneous pain relief: "*(we) were just a bit reluctant to give her more pain medication. It was the first time, right, so we don't know.*" For one other focus group member, families being asked to administer subcutaneous medication was a surprise, as this was seen as the role of the nurse, not the family.

The third subtheme, cultural contexts of health literacy, presents the role of health literacy for individuals and for the community. Participants described being unsure where to find information or who, besides their primary health care doctor, they can ask for information: "*It's the first priority for people to know, where they go to from the doctors.*" Participants in all 3 focus groups discussed the need for accessible information in a format that can be reached by the community: "*(there is a) need for more social intervention in terms of the information dissemination using the platforms or the mediums that we have available now.*" The first focus group discussed the need for access to advanced care planning to avoid what was described as "*ugly funerals*" where families were underprepared for the death of their family member. The second focus group focused on community access to "*how to – information*," focusing on informing people where to go for help and making the process easier.

Theme 2 – Community-guided care pathways

As this study focused on understanding Cook Islands community members' understanding of palliative care, practical suggestions were brought forth by the community participants. Community-guided care pathways highlight the essential role of the wider community in shaping palliative care experiences and decision-making. Participants emphasized that care is not solely a family matter; it is supported by church groups, community groups, and cultural networks. This theme includes the hardships for families who were isolated from wider support groups.

The importance of faith, prayer, and spiritual connection in how Cook Islands families understand and cope with end-of-life experiences was noted throughout the interviews. Participants highlighted the role of pastors, church communities, and spiritual

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Table 1. Participant quotes supporting Theme 1: Navigating health information

Subtheme: Prognostic disclosure	
Representative quotations	**Codes**
The doctors will tell you things that they understand – not what we understand. Even though sometimes doctors don't be honest with you, or maybe I don't understand.	*Health information delivery*
There are cases where our people, the inequity is they're not being carefully explained, not just their condition, but their care plan.	*Care plan discussion*
Make sure people are aware of the condition that he's currently in and how it could get worse because I think when he went home a lot of them, expected that he would get better.	*Expectation mismatch*
I would probably want them to advise what's the best option. Not something we just heard from the doctor, but advise the person what are options out there for them.	*Presenting options*
Who was your GP, and they didn't explain it to you? One auntie, I go, Auntie….Auntie, what kind of cancer do you have? And she goes, oh, I don't know.	*Right to information*
Subtheme: Responsibility transfer	
Your parent is dying and then you get told, but you have to administer this to them, to ensure that they are comfortable. But how do you, as a child? Because I actually thought the nurse would come.	Shifting care to families
"Okay, between now and the morning, what do we do?" They didn't actually tell us, "Do this." All they said was, "We'll call you back." "A nurse will call you in the morning," that's what they said.	Expectations placed on families
It's a big expectation that we provide really short times for people to try these things, and they're already in a stressful situation.	Preparing families to be able to care
What about the day that you don't come and something happens	Clear expectations of services
Subtheme: Cultural contexts of health literacy	
The Hospice helped me go back and fight with the doctors. They have, to have that information as well to go to them, to let them know what is happening with the patient. I find that makes me stronger to go and fight for him.	*Developing critical health literacy*
I think it depends which doctor because our Island doctors have that Pasifika approach. They go, "Okay, so what did I say?"	*Checking understanding*
I always wondered why he didn't get a hospital bed, because she cared for her husband at home, and why he didn't get a framing because he was fragile. None of those services were provided.	*Reflecting on access to resources*
She wished she was aware. That would have been a help for her. Because at the time she was looking after my aunty and my grandfather, and all the grandchildren. So, it was just her being the sole parent in the family at the time.	*Awareness of access to support services*

practices in offering guidance, easing emotional burdens, and providing reassurance for both the patient and their loved ones. The importance of spirituality was additionally a concern raised when considering using hospice services, "*if we are looking at the spiritual side of things it's that whole holistic*".... *"Are they going to take care of A, B and C, how many times a day?"*

The subtheme, looking after our own, represents the strong desire among Cook Islands families to care for loved ones at home during palliative and end-of-life stages (see Table 2). Participants expressed that home is not only a place of comfort, but a culturally meaningful space where family, spirituality, and identity remain intact. Participants voiced caring for families at home as being part of family and cultural identity, as shown in the following quote. "*For Cook Islanders, we don't like to give our family to somebody else to look after. That's just us. We have to look after our own.*" The idea of family members being cared for outside of the home was additionally discussed as an issue of trust *"it's trusting are they going to get that care in that space? How do we know?"* Trust in this sense was discussed as being able to provide care in a way that was seen as safe care. Conversely, participants who had positive experiences with hospice expressed changing their view about hospice care, as shown in the following quote "*But when I walked into hospice and saw the beautiful care, I would rather… I told my husband*".. *"If cancer comes back, I want to take me (to hospice).*"

Theme 3 – Healthcare within the realm

This theme captures the ways Cook Islands families navigate palliative care across national borders, drawing on connections to both Aotearoa New Zealand and the Cook Islands (see Table 3). Participants described healthcare as inherently transnational, influenced by mobility, family dispersion, and cultural identity. Decisions about palliative care were shaped not only by services available in New Zealand, but also by obligations, beliefs, and practical considerations tied to the homeland. The desire to return home to the Cook Islands meant families had to plan early if they wished to live out their days at home, before being deemed unfit to fly, as shown in the following quote "*if that's what you feel like you want to do, then go, go like, go now, don't wait. Because the longer you wait, you may not have the opportunity. Like that window closes really, really quickly.*" This highlights the need for early planning to ensure families could return home.

For some families, returning to the Cook Islands for end-of-life care was expressed as an aspiration motivated by cultural belonging, the desire to *"go home"* or the wish to be surrounded by familiar land, language, and community. Others highlighted the logistical and medical challenges that make such a return difficult, including limited specialist services, travel barriers, and the need for stable medical support. This is captured in the following story from a participant describing supporting a community member during

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Table 2. Theme 2 – Community-guided care pathways

Subtheme – Community-guided care pathways	
Representative quotations	**Codes**
I strongly support the need for more social intervention in terms of the information dissemination using the platforms or the mediums that we have available now.	Community platforms
Why can't they have the same thing for cancer patients? So, if we're staying in (location), we go straight to (location)…. So, there's no more confusion. Like there's no point having it centralised because it will just be all full. You need to branch it out.	Locally based resources
Pushing it through like the church leaders, I mean, our faith is a big part of who we are in the Cook Islands. So, trying to educate our church leaders to educate our people.	Faith-based education pathways
Community groups, the leaders of community groups just to get that message out.	Community-based communication channels
Subtheme – Spiritual strength and guidance at end of life	
I like the idea about going through the Orometua (Church minister) through the churches.	The minister as part of the outreach team
Not feel as if we couldn't not have prayer in the room or we couldn't not have a chance to have, like, devotions together. You know I'd want. I would want that in the room. And I want my families to have that as well. So, I think that cultural spiritual context.	Acceptance of faith in hospice
You know, church is there also as well to help them taking praise, service, and encouragement and all that. So, which is good.	Spiritual support
Subtheme – Looking after our own – preference for home-based care	
Bring them home. We never leave our family. We never leave our mamas and papas in the hospital. We bring them home to pass away.	Service to the family unit
There was always this expectation you'd better look after them at home or you would appear like you don't love them enough.	Honour
At that time, she wasn't responsive, so she wasn't able to say, "No. Leave me here." My dad wanted to take my mum home. So, we took my mum home on Thursday. My mum passed on Saturday.	Family decision making

Table 3. Theme 3 – Healthcare within the realm

Theme 3 – Healthcare within the realm	
He's sleeping on the couch in the sitting room of his brother-in-law's, his wife's brother's home here, because he had to come for leukemia care. He didn't know a lot of things.	Transferred without clear plan of care
There's no more care for you here in New Zealand, then go home, go home and enjoy your life back at home.	End-of-life returning home (to the Islands)
Our Cook Islanders who come here seeking for medical attention with cancer, lots of them were like that. They were just accommodated. And we know most of our Cook Island families' homes are overcrowded and underfunded.	Accommodation for person transferred to NZ
The whole referral system, because people are getting lost here in the system.	Keeping track of persons transferred to NZ

a specialist appointment "*do you understand that means that you have to stay here? So, she's going to put you on a waiting list for a transplant. You can't go back home for Christmas, Uncle, you've got to stay here.*" Conversely, some Cook Islands Māori coming from the Islands to New Zealand experienced difficulty navigating the New Zealand health system, as shown in Table 3. The quotes discuss people being sent from the Cook Islands health system to New Zealand for cancer treatment without a clear plan for accommodation or financial support. The complexities in deciding where to seek treatment or to return to the Islands created tension and were emotionally complex decisions about where care should occur and where a person should spend their final days.

Discussion

To our knowledge, this is the first study which aimed to understand the palliative care enablers, barriers, and community aspirations of Cook Islands Māori community members in New Zealand. This study aimed to develop practical solutions for improved access to palliative care for Cook Islands Māori. We have reported new findings which could be used to guide future practice and confirmed previously known understandings for Pacific people's palliative care. The first finding themed navigating health information highlighted 2 key moments when communication had a notable impact on the palliative care journey, during prognostic disclosure and during times of responsibility transfer. These key times along the palliative care journey require adaptation depending on the family's health literacy and the cultural responsiveness of the clinician or organization (see Figure 1). Highlighting the significance of these time points along the palliative care journey may allow clinicians and services to taper services to ensure adequate preparation and time is allocated to these key moments.

It has been shown that early access to integrated palliative care improves a range of measures including QOL and symptom control

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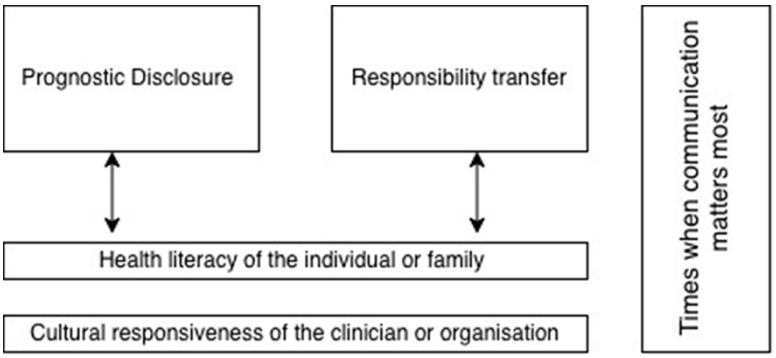

Figure 1. Key communication times and mediating factors.

(Temel et al. 2010). While this has been known for some time, minority groups have continued to experience poorer access to palliative care. More recent studies have sought to understand key delivery times for palliative care interventions. The large, randomized controlled study by Temel et al. (2024) investigated a stepped care model. The study found introducing palliative care at the time of diagnosis and at key times along the palliative care journey based on hospital admissions or assessed QOL needs provides similar QOL outcomes as early palliative care interventions (Temel et al. 2024). In this study, participants reported family members not understanding their prognosis and what care was available to them, identifying a gap in communication and subsequent follow-up with a palliative care team.

Prognostic disclosure is important for palliative care planning. Patients and families need timely prognostic information to plan for their family members' care needs and to understand the dying process (Engel et al. 2023). Previous studies show prognosis communication occurs less regularly when there is ethnic discordance between patient and clinician (Ingersoll et al. 2019). Additionally, prognostic misunderstandings between patients and clinicians occur more frequently for persons from minority groups (Gramling et al. 2016). For the Cook Islands Māori community members in this study, the need for clear prognostic information was important for planning if the family member wanted to return home to the Cook Islands or for families to plan for their family member to be cared for at home. The desire to care for family members at home by Pacific families is well documented in the literature (Foliaki et al. 2020; Henry 2020; Fanueli et al. 2026).

International research has identified the need for improved communication in palliative care for minority populations (Mayeda and Ward 2019). In the New Zealand context, the literature similarly highlights the importance of strengthening communication, providing culturally responsive care, and increasing the Pacific health care workforce (Churchward et al. 2026; Fanueli et al. 2026). Participants in this study focused on trust and relationships, shifting the focus from a "good death" to "good relationships" as the key concern for community members. Culturally responsive care practices have been found to bridge understanding between clinicians and minority groups (Clarke and Holtslander 2010; Kelley et al. 2018). However, there is limited understanding of the role of such practices in palliative care and how they are applied in practice. While this study focuses on Cook Islands Māori in New Zealand, understanding the key times when communication may need to be enhanced and culturally responsive care prioritised, are lessons that can be applied to other minority groups. This study has shown the need for further research into how gaps in communication at key points along the palliative care trajectory may explain some of the disparities seen in palliative care understanding, access and use for minority groups.

Limitations of this study

As a qualitative study with a sample size of 18, the findings from this study are not generalizable. This study offers a view into the lived experience of members of the Cook Islands Māori community. The findings from this study provide insights into these experiences and highlight areas for future research.

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