



Perspectives and experiences of Māori and Pasifika peoples living with cardiac inherited disease: a qualitative study

Jessee Fia'Ali'i, Mikaela Law, Claire O'Donovan, Jonathan R. Skinner & Elizabeth Broadbent

To cite this article: Jessee Fia'Ali'i, Mikaela Law, Claire O'Donovan, Jonathan R. Skinner & Elizabeth Broadbent (2024) Perspectives and experiences of Māori and Pasifika peoples living with cardiac inherited disease: a qualitative study, *Psychology & Health*, 39:6, 728-748, DOI: [10.1080/08870446.2022.2105336](https://doi.org/10.1080/08870446.2022.2105336)

To link to this article: <https://doi.org/10.1080/08870446.2022.2105336>



Published online: 01 Aug 2022.



Submit your article to this journal [↗](#)



Article views: 512



View related articles [↗](#)



View Crossmark data [↗](#)



Perspectives and experiences of Māori and Pasifika peoples living with cardiac inherited disease: a qualitative study

Jessee Fia'Ali^a, Mikaela Law^a , Claire O'Donovan^a , Jonathan R. Skinner^b and Elizabeth Broadbent^a 

^aDepartment of Psychological Medicine, Faculty of Medical and Health Sciences, The University of Auckland, Auckland, New Zealand; ^bCardiac Inherited Disease Group New Zealand, Green Lane Paediatric and Congenital Cardiac Services, Starship Children's Hospital, Auckland, New Zealand

ABSTRACT

Objective: Cardiac inherited diseases can have considerable psychosocial effects, including lifestyle limitations, anxiety and depression. Most research to date on patient experiences of CID has been conducted with people from Western cultures, yet culture can shape patient views and experiences of health. The aim of this research was to explore the experiences and perspectives of Māori and Pasifika living with a cardiac inherited disease (CID).

Methods and Measures: Semi-structured interviews were conducted with 14 Māori and 14 Pasifika patients living with a cardiac inherited disease and seven of their family members, using Talanoa and Kaupapa Māori methodologies. Themes from the interviews were identified using interpretative phenomenological analysis.

Results: Three common themes were identified as important in shaping participants' perceptions and experiences of CID: (1) difficulty in understanding the disease as separate from symptoms, (2) considering ancestors and future generations and (3) the role of spirituality and religion.

Conclusion: This study highlights a gap between indigenous patients' understanding of CID and the western biomedical approach. Patients' understanding and treatment behaviours depend on symptoms, familial ties and spirituality. The findings support the need for transparency and culturally appropriate practices in healthcare. Considering these aspects may help to reduce health inequities for these populations.

ARTICLE HISTORY



Received 22 September 2021

Accepted 17 July 2022

KEYWORDS

Cardiac inherited diseases; ethnic minorities; Māori; Pasifika; illness perceptions

A diagnosis of chronic illness can come as a shock, and individuals are faced with an uncertain future, and a change in role to becoming a patient (Petrie & Jones, 2019). Suddenly, they must become familiar with their illness and the tasks associated with its management, such as taking medication. The experience of symptoms may cause patients to disengage from social activities and lead to psychological distress. One kind of chronic illness is cardiac inherited disease, which describes a range of rare cardiac conditions that compromise the efficiency of electrical and musculature

CONTACT Elizabeth Broadbent  e.broadbent@auckland.ac.nz  Department of Psychological Medicine, Faculty of Medical and Health Sciences, The University of Auckland, Auckland, New Zealand.

© 2022 Informa UK Limited, trading as Taylor & Francis Group

functioning in the heart (Wilde & Behr, 2013). These muscular defects cause a variety of symptoms including fibrillation, shortness of breath, fatigue, unheralded syncope and heart failure (MacIntyre & Lakdawala, 2016; Maron et al., 2006).

The most common class of CID is Hypertrophic Cardiomyopathy (HCM), followed by Dilated Cardiomyopathy (DCM) and Long QT Syndrome (LQTS); however, there are many other classes (Elliott et al., 2020). The progression of the disease and the manifestation of symptoms depend mostly on the inheritance status of faulty genes, whereas environmental factors only play a minor role (Elliott et al., 2020). There is no cure for CID; the condition, symptoms and associated risks can only be managed by specific interventions including pharmacotherapy, medical devices, surgery and behavioural interventions. In a registry of patients with CID in New Zealand, 15% and 11% were Māori or Pacific respectively, which correlates with population statistics (Rucinski et al., 2020). However, Māori may have different clinical and genetic LQTS profiles from those of European participants. Rare LQTS variants are more common in the Polynesian population (both Māori and Pasifika) despite similar testing and clinical disease severity to European and other ethnicities, which may explain their higher frequency of syncope and life-threatening cardiac events (Winbo et al., 2020).

The psychosocial impact of cardiac inherited disease (CID)

As with most chronic conditions, CID can present challenges and barriers that can impact quality of life. Many life domains can be affected, including occupational, educational, familial, personal, spiritual and cultural (Megari, 2013). For example, significant cardiac symptoms can reduce the capacity to undertake home- and work-based tasks (Arora, 2016; Subasic, 2013; Ware & Sherbourne, 1992). CID can also reduce participation in sport and result in the loss of full-time employment (Johnson & Ackerman, 2013). Given the incurable nature of CID, these restrictions and life changes are often chronic and highly pervasive. People living with CID tend to have poorer levels of self-reported health status relative to other cardiac and general populations (Hamang et al., 2010; Steptoe et al., 2000) and increased risk of depression and anxiety (Hamang et al., 2011; Ingles et al., 2008; Rasoul et al., 2015). Patients with CID experience a mixture of emotions, concerns, limitations and a desire for more knowledge. In Norway, many patients had concerns about their lack of knowledge, their family members and children and about the competence of some in the healthcare system (Andersen et al., 2008). Patients with CID in the USA expressed both appreciation and apprehension of the device, the importance of a regular schedule to maintain a sense of self, feelings of isolation and a desire for more information (Flanagan et al., 2010). Canadian and Australian patients experienced emotional reactions to classification of their genetic variant, which changed their treatment and lifestyle decisions (Wong et al., 2019).

Cultural differences in understanding CID

Most research into patient understanding of CID, as well as other genetics-based illnesses, has been conducted in western cultures (Walter et al., 2004). The results may not generalise to other cultures, and so more research is needed to investigate

how patients from other cultures perceive and experience CID. Culture encompasses beliefs and behaviours that are shared by a group and can influence how an individual perceives and shapes his or her world (Turner, 1996). If a patient and healthcare provider are from different cultures, they may have different understandings of illness that can lead to misunderstandings and inhibit proper treatment. The importance of cultural awareness in genetic counselling has recently been highlighted in Hong Kong, where there are differences between Western individualist and Asian collectivist cultures (Zayts et al., 2019). Research in this area may help inform healthcare providers of the perspectives and experiences of patients from other cultures and help bridge cultural divides.

There is a gap between the cultural beliefs of Māori and Pasifika peoples in New Zealand and western biomedical approaches to CID. Māori and Pasifika peoples hold conceptualisations of health that are broader than those endorsed by mainstream medicine. Both Māori and Pasifika models of health propose that connections with ancestors, the spiritual world, family and the community, are major sources of health and wellbeing (Durie, 1985), and that transgressions to these relationships can cause illness. For example, in the Pacific, the death of a child may be seen as due to a father's infidelity (Capstick et al., 2009). This is very different to the biomedical approach which seeks to provide a physiological explanation. Another example is that having a large body in Pacific culture is a sign of beauty and status and so Western instructions to eat less may not align with these beliefs (Capstick et al., 2009). A third example is that Māori traditionally see *Taha Wairua* (the capacity for faith and to understand links between humans and the environment) as essential for health, and explanations for poor health are often made in regards to the external environment rather than looking inwards (Durie, 1998). As CID has a genetic cause, such cultural beliefs may make it difficult to apply a biomedical and physiological model of CID for some Māori and Pasifika patients.

The influence of cultural differences on health behaviours

Perceptions of health and illness can influence behaviours and, by extension, health outcomes for patients with CID. This may be problematic when biomedical treatment recommendations clash with cultural practices and beliefs. For example, medication non-adherence behaviours can be influenced by familial responsibilities and perceived damage to the tapu (sacred) body (Bassett-Clarke et al., 2012; Nikora et al., 2011). While Western medications are seen as valuable, traditional healing practices are often used concurrently and are held in the same regard (Durie, 1985). Investigating how Māori and Pasifika peoples conceptualise CID provides an opportunity to explore motivations and perceptions that may promote and constrain accessibility to healthcare, testing and medication use. This may inform changes to healthcare provision to support Māori and Pasifika patients and their families (whānau/āiga) through particularly stressful periods including genetic testing, diagnosis and long-term treatment. However, to date, there is no published qualitative research that explores how Māori and Pasifika patients are impacted by CID. Research is needed to explore how Māori and Pasifika patients perceive CID to help achieve culturally informed clinical practice.

This qualitative study used semi-structured interviews, conducted through Kaupapa Māori and Talanoa methodologies, to explore experiences and perspectives of Māori and Pasifika peoples and whānau/āiga living with CID. In particular this study aimed to explore understandings of CID, CID-related psychosocial impacts, perceptions of medications and Implantable Cardioverter Defibrillators (ICD) and experiences with clinical and/or genetic testing in Māori and Pasifika patients with CID.

Methods

Research framework

This research was situated within a phenomenological approach (Smith & Osborn, 2015) and informed by Kaupapa Māori Theory (Bishop, 1999) and Talanoa methodologies (Vaioleti, 2016) to ensure that Māori and Pasifika voices, worldviews and culture were validated and protected. Kaupapa Māori research recognises Māori cultural values and is a philosophy that ensures that Māori protocol is followed during research procedures (Walker et al., 2006). Qualitative methods, such as interviews fit well with the Kaupapa Māori approach. Talanoa means to talk or an exchange of ideas, and the researcher is involved in the research experience rather than standing back and observing (Vaioleti, 2016). Talanoa belongs to the phenomenological research family, which focuses on the meanings that events have for participants. Māori and Pasifika researchers were consulted throughout the research to ensure that the researcher was culturally aware, sensitive and safe, as well as to inform the researcher on appropriate forms of qualitative data analysis, interpretation and results dissemination.

Researcher's positionality and reflexivity

The primary researcher was a Sāmoan male, born and raised in Tāmaki Makaurau (Auckland), Aotearoa New Zealand and was a student in Health Psychology. He was raised in a multicultural environment and in the Christian faith. He has extensive experience in the medical health system having been diagnosed with a life-threatening heart condition in his youth and now lives having to deal with lifelong treatment and continual interactions with the medical health system. Further, family hospitalisations and later employment in the hospital context helped him to garner an appreciation of the difficulties experienced on both the providing and receiving ends of care. The shared commonalities in culture, beliefs and experience gave the researcher an empathetic understanding of the experiences of his participants which fostered rapport building and enabled discussion of sensitive topics openly. However, there were subcultures that the researcher did not have experience of; for example, Māori and other Pasifika worldviews, life with a CID and/or ICD, the experiences of women and parenthood (Dwyer & Buckle, 2009).

Ethics

Ethical Approval was granted by the New Zealand Health and Disability Ethics Committee (17/NTB/29/AM01) and the Auckland District Health Board (ADHB) research

review committee. The ADHB facilitated review by a Kaupapa Māori Research Analyst as part of its review procedures, who considered both Māori and Pasifika research principles. Senior Māori and Pasifika researchers were consulted during the development phase of this research.

Participants

Purposive sampling was used to recruit participants between May and December 2017. Participants who were eligible for the study if they were registered on the New Zealand Cardiac Inherited Diseases Group (CIDG) registry had been given a 'definitely affected' or 'probably affected' clinical status for CID, self-identified as Māori or Pasifika, were over the age of 18, and were living in Auckland. Initially, a language ability criterion was imposed on this study; however, this was later removed to give those who could not speak English a platform to participate and have their stories voiced. Research assistants fluent in other languages provided assistance as required (see below).

Information was sent to potential participants via email or post, or they were approached by staff during clinical appointments. Two Sāmoan and three Tongan participants were recruited over the phone by research assistants fluent in the respective languages. For those who expressed an interest, a suitable time, date and location was organised for an interview. This resulted in an initial participation rate of 33 primary participants. However, five were either unreachable or withdrew before the organised interview date, resulting in 28 final primary (patient) participants.

Whānau/`āiga participation

Both Māori and Pasifika health models highlight the importance of family in the health and well-being of an individual. Therefore, primary participants were encouraged to invite whānau or `āiga to participate alongside them. In the Pacific context, `āiga means family and can include not only immediate family but also extended family and inter-related families. For Māori, the concept of whānau means an extended family or a group of family members who live together in the same area. In the context of this study, we use whānau/`āiga to refer to family members for Māori/Pasifika patients respectively, and participants could bring their own meanings to these terms. Aside from being over the age of 18, there were no other eligibility criteria for family, and primary participants could invite as many whānau/`āiga as they wanted.

Participant information

In total, 35 participants (17 Māori and 18 Pasifika) participated in the interviews. This included 14 Māori primary participants and three whānau members and 14 Pasifika patients and four `āiga members. The 14 Pasifika primary participants included individuals of Sāmoan (n=4), Tongan (n=9) and iTaukei Fijian (n=1) descent. As shown in [Table 1](#), all 14 of the Pasifika and 11 of the 14 Māori primary patients had received a definite clinical CID diagnosis with the remaining three probably affected. All patients

Table 1. Demographic information, clinical characteristics and genetic status of patient participants by ethnic group. Note, seven family members also participated.

	Ethnic groups		
	Māori (n = 14)	Pasifika (n = 14)	Total (N = 28)
Age, range (mean)	18–63 (42.7)	23–69 (43.3)	18–69 (43.0)
Gender, n (%)			
Male	3 (21)	6 (43)	9 (32)
Female	11 (79)	8 (57)	19 (69)
Education, n (%)			
Tertiary	7 (50)	7 (50)	14(50)
Secondary	5 (36)	6 (43)	11 (39)
Missing	2 (14)	1 (7)	3 (11)
Employment status, n (%)			
Employed	10 (71)	11 (79)	21 (75)
Unemployed	2 (14)	3 (21)	5 (18)
Sickness beneficiary	2 (14)	0 (0)	2 (7)
Clinical diagnosis, n (%)			
LQTS	8 (57)	1 (7)	9 (32)
DCM	1 (7)	7 (50)	8 (29)
HCM	3 (21)	4 (29)	7 (25)
ARVC	2 (14)	1 (7)	3 (11)
BrS	0 (0)	1 (7)	1 (4)
Clinical status, n (%)			
Definitely affected	11 (79)	14 (100)	25 (89)
Probably affected	3 (21)	0 (0)	3 (11)
Genetic status, n (%)			
Positive	8 (57)	6 (43)	14 (50)
Unclassified	1 (7)	4 (29)	5 (18)
Uninformative	3 (21)	1 (7)	4 (14)
In progress	2 (14)	3 (21)	5 (18)
Beta-blocker use, n (%)			
Yes	10 (71)	10 (71)	20 (71)
No	4 (29)	4 (29)	8 (29)
ICD, n (%)			
Yes	4 (29)	6 (43)	11 (39)
No	10 (71)	8 (57)	17 (61)
CID Present in other family members, n (%)			
Yes	13 (93)	10 (71)	23 (82)
No	1 (7)	4 (29)	5 (18)

Note: LQTS: Long QT Syndrome, DCM: Dilated Cardiomyopathy, HCM: Hypertrophic Cardiomyopathy, ARVC: Arrhythmogenic Right Ventricular Cardiomyopathy, BrS: Brugada Syndrome, ICD: Implantable Cardioverter Defibrillator, CID: Cardiac Inherited Disease.

had undergone genetic testing prior to the interviews; however, five patients were still awaiting their results as they had undergone genetic testing the week prior to the interview.

Data collection

Overall, 21 semi-structured interviews were conducted, 14 of which were one-on-one with primary participants and the other seven were whānau/āiga interviews. Of these whānau/āiga interviews, three were pairs of primary participants (both with CID), three involved one primary participant and one family member and the last whānau/āiga interview included four primary participants and four whānau/āiga members (all related). The interview lengths ranged from 40 to 75 minutes. The majority of interviews were conducted in participants' homes (n = 17), while two chose their place of work, and the other three elected the university, the hospital and a local

café, respectively. Two interviews were conducted in Sāmoan by a Sāmoan community member and three in Tongan by a Tongan mental health researcher.

All interviews were informed by Kaupapa Māori Theory and Talanoa methodology. According to Vaoleti (2016), the beginning of each interview is an important space for the researcher to build rapport. Specifically, rushing straight into research formalities transgresses 'anga faka-Tonga' (the Tongan way or Tongan custom), where the researcher is perceived as disrespectful and uninterested in the participant's life/story; undermining the relationship. Thus, the researcher took a small parcel of food to each interview and engaged in discussions about the current occurrences in the participant's lives or offering to help with chores in cases where interviews were held in the home.

Formalities began with reviewing the participant whānau/āiga information and consent forms. Following this, the participants were offered a chance to say karakia/lotu (prayer) before commencement of the interview. Patients and whānau/āiga were then asked to complete a demographic questionnaire, which included the type of CID they had been diagnosed with, gender, age, ethnicity, highest education qualification, employment status, current treatment and whether the condition is present in other family members. Clinical and genetic statuses were collated and matched from the national CIDG registry.

An interview schedule provided guidance on topics to be discussed. This included; the personal impacts of CID, whānau/āiga impacts, perceptions of treatment and experiences with the CID clinics. Given the differences between participants, the interviews allowed for a flexibility in being able to explore diverse perceptions and experiences.

As per the Talanoa methodology, the interview ended when no new discussion points were raised by the participants (Vaoleti, 2016). It was at this point that a koha/meaalofa (gift) of a shopping voucher was presented to participants as a token of appreciation. Gift giving is a culturally significant practice in the Pacific region that nurtures relationships and bolsters trust (Tamasese et al., 2010). Good practice guidelines for working with Māori also suggest koha may be given to participants in recognition of the contribution they have made (Sporle & Koea, 2004). Promoting Māori voice is an important principle in achieving health equity in New Zealand and we aimed to recruit equal numbers of Māori and Pasifika participants (Reid et al., 2017).

Data analysis

Transcriptions

The audio recorded interviews were transcribed by the researcher verbatim. Interviews conducted in Sāmoan were transcribed by the researcher and reviewed by the interviewer for validity. Those conducted in Tongan were transcribed by an independent member of the Tongan community and reviewed by the interviewer.

Interpretative phenomenological analysis (IPA)

The qualitative data were analysed by the first author and followed the six steps outline by Smith et al. (Smith & Osborn, 2015). These steps complement Māori and Pacific peoples' rich narratives.

Step 1: Reading and re-reading: to help the researcher become familiar with each transcription and the world context of the participant.

Step 2: Initial noting: making notations of repeated ideas, statements and words, how phenomena were described and potential links to wider underlying psychological concepts.

Step 3: Developing emergent themes: the initial notes from step 2 were organised into themes.

Step 4: Searching for connections between emergent themes: this involved processes of abstraction (making connections), subsumption (developing superordinate themes) and polarisation (identifying differences) across emergent themes. The goal of this step was to produce a framework/structure to make sense of the emergent themes.

Step 5: Moving onto the next case: once this structure was created for the first case, steps 1–4 were repeated on another transcription.

Step 6: Looking for patterns across cases: similar to step 4, a framework of connections, levels and divergences of themes across cases is created to make sense of how Māori and Pasifika peoples as groups make sense of life with a CID.

In order to make sure the themes generated were valid and reliable, an independent Pasifika Health researcher also conducted IPA on five of the transcripts. Discussions were undertaken between the first author and the independent Pasifika Health researcher to explore and resolve discrepancies. We used a Kaupapa Māori approach to avoid victim blaming or deficit theories being applied and to respect matauranga Māori (Māori way of knowing) (Reid et al., 2017).

Results

Three themes were identified which reflect important and prominent patterns of interpretations, experiences and meaning-making expressed by participants across the interviews. In the quotations, participants are referred to by a code indicating ethnicity grouping and participant number; M refers to Māori participants and P refers to Pasifika participants.

Theme 1: Difficulty in understanding the disease as separate from symptoms

The first theme describes how Māori and Pacific patients had difficulties making sense of their illness as separate to their experiences of symptoms and their general health. Patients only have access to their symptoms and not to the disease itself. Therefore, they infer information about the disease from these symptoms and this has implications for their medication adherence and health behaviours. Participants' experience of symptoms drove their ideas about their disease, including its cause, its identity, their management of activities and adherence to treatment.

Symptoms were sometimes perceived as being due to stress or physical exertion and sometimes interpreted as 'normal' and transient, like experiencing an acute illness. Because symptoms were not present all the time, some patients thought that they only had CID when their symptoms were present. Symptoms guided their decisions around sporting activities, rest and decisions to take medications. Patients also relied

on their age and physical strength to infer the severity of their illness and subsequent need for treatment, which makes sense for many illnesses but not in the context of CID. Māori participants, in particular, often discussed changing medication regimes according to how efficacious they felt their medications were and the symptoms they experienced. This may be reflective of a form of Tino rangatiratanga (right to autonomy), in which participants' expressed control and self-autonomy over the care of their own bodies. In the following paragraphs, this theme is presented in two subsections, with illustrative quotes.

Symptoms and illness understanding

Participants made links between the experience of stress and the onset of symptoms and severe cardiac events such as fainting, chest pain and breathlessness:

'My work at the time had a contribution as well. It was quite a hard time... there's quite a lot of work I needed to [do].' (P13)

For others, physical exertion related to seemingly innocuous activities, including household chores and sports, were seen as a triggering factor:

'I was actually cleaning and I was pushing back the fridge to sweep out whatever was behind. So, I think I actually like over-worked myself.' (P12)

Two participants perceived their symptoms to be common experiences, which did not warrant concern. By virtue of experiencing these symptoms for the majority of their lives, it is possible that there were no opportunities with which to compare the cardiac events against:

'I thought it happened to everyone. I thought 'oh, it'll go away, it's like the flu or something' but obviously from that first time it just slowly crept up on me worse and worse.' (M10)

The conceptualisations Māori and Pasifika participants held regarding CID were often discussed in a context where medical knowledge of CID was lacking. Many participants inferred important characteristics of their CID such as relative severity, chronicity and risk of their CID, from their physical condition, age or symptoms.

'I'm not like you know, very sick. I'm very strong, you know? Doesn't matter I have a heart problem, I still strong.' (P2)

An important way that participants made inferences about their condition was by monitoring their symptoms. Some participants perceived their condition to only be present when they had symptoms, and thus were more likely to view their CID as having a cyclical timeline, rather than chronic:

'The doctor sent me to the hospital straight away, and the doctor say I got a heart, it's growing like bigger, sometimes it close, sometime it's like open like a rose.' (P2)

Others expressed an uncertainty about the causes of symptoms they experienced, often attributing symptoms of other conditions to their CID, including swelling in the face (P2), migraines and excessive sweating (M11 and P14).

Symptoms as driving health behaviours/treatment

Some patients used symptoms as a guide to become aware of their limits and slow down, whilst maintaining their sense of independence:

'The doctor say you can't go lifting, or you can't go do heavy stuff or, for me, my heart. I always like doing my own lifting stuff, making me more strong... Sometimes I'm very, uh, dizzy. If I feel if I'm dizzy I come sit down for a little while, or I sleep.' (P2)

The perceived purpose of medications (to treat specific symptoms) influenced the way some patients made sense of their condition(s):

'I don't have one [medication] for my heart; just my water, my sugar and the one for my blood pressure, that's it. I'm telling you that I don't have a heart condition because I don't have tablets to take.' (P3)

Many participants discussed their concerns about the side-effects of beta-blockers, including the impact on their physical health:

'I had to stop because it made me more tired... We all have specific different conditions so mine [heart rate] was extra slow, so when I took the beta blockers it was even more slow.' (P10)

Other participants commented how they felt their medications caused cognitive and emotional side-effects:

'I feel my body is turning to tiredness and I get quite moody and I know it's the medication because I've never really struggled with those things.' (M14)

'I think the only time I started worrying was when they gave me the pills that just made me tired, you know?... So, I just said to my doctor "well sorry, I'm not taking them during the day, I'm gonna have them at night."' (M4)

Participants often found it difficult to perceive beta-blocker medications as necessary without experiencing symptoms, or if they did not know the function it served in their bodies:

'I do forget to take them [beta-blockers] sometimes if I've had a long day, but I just pick it up the next day... I have no idea because I've never known what the feeling [symptoms] is.' (P4)

Some participants' perceptions of the necessity of taking beta-blockers reduced when their symptoms abated, and it was only through repeated cardiac events that they understood the importance of medication:

'Initially I hated it [beta-blockers]. I wanted nothing to do with it and I learnt the hard way. As soon as I feel better, I go "nah I don't need those pills." I'm starting to run around. I was so stubborn I wouldn't give up playing rugby and um cos you'd feel great and then BOOM! I'm down on the field again. I think it happened four times before it got through to me.' (M10)

Further, others perceived their CID to be healed after being on medication:

'I thought I was healed you know. At one stage I stopped taking my medication.' (M12)

The most common way participants judged the necessity of ICDs was by measuring it against their perceived severity and mortality. Specifically, ICDs were only deemed necessary for those whose conditions were severe:

'To be honest I think I'll probably end up needing one [ICD] when I turn 60 – when I'm older and my heart will be weaker and vulnerable to that kind of thing... For now, as a relatively young and healthy adult I don't really need it.' (M13)

Treatments for CID were perceived to be important as protective measures against the experience of symptoms and severe cardiac events. Beta-blockers and ICDs allowed the broadening of activities and were important in negotiating life limits and restrictions:

'I don't want [LQTS] to change my lifestyle... Obviously I've got the diagnosis and I know what to do. I have to take these beta-blockers and get checked on.' (P4)

Theme 2: Ancestors and future generations

The second theme was the experience of CID across the generations, from ancestors to present and future generations. The experiences of previous generations were drawn on when interpreting the cause and severity of illness, as well as the benefits of testing and treatment. There was a strong sense of duty to family to get tested and to look after family members. This was especially salient in the narratives of Māori participants, who often cited implications for their family.

Ancestors

Past generations were referred to in making sense of the illness cause and severity and a cause of distress.

'My Mums had her condition for her entire life... I was a regular kid and then they were like 'hang on we should probably get you tested to see if you have it' and then turns out I did.' (M13)

'Our Uncle's dead at the age of sixty and we're all hitting that fifty stage now... I've got nieces and nephews that are more serious than I am um at very young ages... So, it's getting younger and younger.' (M6)

'We just (pause) - it was hard when she passed. It was hard as. I found her when she passed and that was the hardest thing ever, and I just- I lost it.' (M5)

Reflecting on the past, participants often queried whether lives could have been saved had the same resources available today existed then:

'I think even for those like in memory of those who have passed on because if they knew about it and got tested, they could still be alive.' (P4's brother)

'Back then, they probably didn't have the services to do all of that and yeah she was like, "nah, I wanna get tested", and when it came back, that's why she took medication.' (M3)

Future generations

Genetic testing was seen as granting important information that allowed participants to prepare themselves and their families:

'You have to start planning how to safeguard these guys. She's [daughter] heavily into sports too and you know you'll constantly sort of searching for defibs in the area although you know the chances of it [cardiac event] happening vary.' (M10)

Engaging in genetic testing was seen as an important way to fulfil responsibilities to protect future generations. Participants readily understood the implications of having a genetic condition within the family and also having the opportunity to intervene through testing:

'You mention generations to Māori, and the fear goes [away] and it's like, whoa, we better get this done... Māori are quite tight on generational Māori things... genealogy in particular, so absolutely let them know "Hey, you know, we've found that there's a high chance in Māori families that have this and it's only been discovered. I want you guys tested."' (M6)

Others derived a sense of advocacy from their experience and felt they were obligated to increase awareness about CID to other Māori and Pasifika families to reduce fatalities:

'It was important that I raise that awareness, because, like I said, so many people are dead and you know it could have been prevented. So, I just feel like from this experience I really wanna encourage some sort of focus evenings they could put on or even get into the churches and just talk about it.' (P4)

Participants experienced anxiety when awaiting test results, especially those of their children. Here, the anxiety reflected concerns about their child's mortality, as well as potentially feeling guilty for passing it on:

'I wasn't prepared to tell them [sons] if it wasn't good news. I never prepared myself for that... So, I was living in denial that I don't want my kids to have this... cos of course, I would blame myself for it.' (M6)

The potential to pass on the condition to future generations was a serious concern for many:

'A couple of years ago I did fall pregnant but had a miscarriage [pause]. On the positive side it was kinda like, well at least they're not going to have to go through what I had to.' (M9).

However, in the younger participants, having children was an important point of discussion and they felt well supported with medical technology and the knowledge available to be able to safely carry and raise a child:

'I'm pregnant now... they put me in the high-risk pregnancy category which is pregnant women who have other conditions, so I feel pretty well looked after.' (P10)

However, many participants stated that they held no animosity towards their parents for passing it on.

Concern over further CID diagnoses in family members was present in the majority of participants, and one participant relayed how her parents became increasingly hypervigilant:

'Both my parents, they take them [symptoms] like real serious now. Like, if anyone has a cough and they're like "oh let's go to the doctors now."' (P12)

ICDs were also seen as an important way to abate family concerns:

'Sometimes my children say things to me, you know, 'Dad, you should slow down' but I don't see the reason to do that. I mean I've got the defibrillator, so if my heart misses a beat it will kick it in.' (P1)

Other participants reflected on how fear played a role in the decision to not undertake genetic testing in family members:

'They don't wanna do it because they are living in denial, and they don't think that they've got it... very much a fear thing.' (M6)

Participants found that clinical staff who took the initiative to include whānau/āiga were more compassionate and caring:.

'They actually wanted me to make sure that I get the rest of my family um checked too as well which I thought 'this is why we've got people around like them'; I thought that was pretty awesome for them to wanna you know.' (M7)

Participants also expressed valuing family input in the decision to have an ICD implanted:

'My oldest son said 'Mum, if it's something for you to be here with us then why not?' (P14)

Theme 3: Spirituality and religion

The third theme concerned spirituality and religion, which was especially strong in Pasifika interviews. For some Pasifika, family transgressions were seen as possible causes, and the illness seen as part of God's plan. There was some reluctance to have a ICD in the body which would interfere with returning to God. For Māori, spirituality was more apparent in terms of the sacredness of the body and its tissues.

Pasifika spirituality

Spirituality was a prominent point of discussion in one āiga interview regarding causation:

'They think it was something to do with my grandma... They did something back in the day and some curse had been put on the family and they thought that could be one of the reasons why all his family has died.' (P8)

For many Pasifika, CID was seen as a part of God's divine plan, a view not expressed by Māori participants:

'That's why I feel strong now. Maybe God gave me more life and more day for me to survive.' (P2)

Many Pasifika participants expressed finding solace in religion, and they often turned to their faith in times of stress and anxiety for guidance:

'When I was told I might have it [LQTS] fear crept in. But then my faith in God sorta took it away because we have something spiritual we can fall back on.' (P4's Brother)

Participants found it helpful to consider their diagnosis and life thereafter as a part of a larger and purposeful plan:

'I thank [God] for giving me the opportunity to be alive... He's the one who gives it and I know that if he happen to keep me living up until now then that means I've got a purpose here.' (P14)

However, some participants explained how their symptoms prevented them from fulfilling valued social roles including in the church and family:

'I use to be a church leader for the choir. At times people tell me to stop before I get sick but they don't know it's part of my exercise.' (P6)

Some were resistant to an ICD on spiritual grounds; they were not comfortable with having a foreign object put into their God-given, and therefore sacred, body:

'I can't put my body through that because the Lord made me and I will return to him...if this is how He's coming to get me then so be it.' (P3)

Māori spirituality

Some Māori participants discussed ownership and cultural practices related to genetic material, specifically alluding to the inherent spirituality and presence of *mauri* in blood samples, which needed to be respected:

'I felt it was kinda queer because "hey it's mine' not theirs you know... Like being Māori when we have baby, we bury the placenta. It's our thing, its tapu; even our hair and nail cuttings. We do things that other people will think 'ewwww superstitious.'" (M8)

This quote demonstrates how easily others, unaware of Māori culture, might disregard culture, which may lead to inadvertent unethical and culturally unsafe practice.

Discussion

The experiences of Māori and Pacific patients with CID are in some ways similar to experiences reported by patients with CID from other cultures but in other ways new experiences were detected. For example, previous studies have shown that patients report concerns about family and children, testing, guilt for passing on the condition, lifestyle limitations in work and sport, as well appreciation of treatment (Janney, 2011; Weil, 2000). These experiences were also apparent in the stories of Māori and Pacific patients, but the analysis in this paper presents a more holistic perspective that is not present in earlier work on CID. First, patients only have access to their symptoms, and these drove their understanding of illness and health behaviours, including treatment adherence. Second, patients reported stories of ancestors and feelings of responsibility towards future generations, which encouraged testing and treatment adherence. Third, spirituality was important in making sense of causality, finding solace, and in making treatment decisions.

General support for these themes can be found in other Māori literature. The first theme can be linked to *taha tinana* (physical health), the second theme can be linked to *taha whanau* (family health) and the third theme linked to *taha wairua* (spiritual health). In Māori health models, damage to these dimensions can cause a person or a collective to become unbalanced and unwell (Durie, 1998). Support for theme 1 can also be found in previous studies with Pasifika, in which Pasifika patients found it difficult to accept a diagnosis without the presence of salient symptoms (Bailey et al., 2010). Other studies in Pasifika populations have demonstrated that the presence of persistent and salient symptoms influenced perceived medication necessity

(Barnes et al., 2004; Bassett & Holt, 2002; Bean et al., 2007; Norris et al., 2011). In support of theme 2, previous work states that chronic conditions can produce psychological distress throughout the family, especially in collectivist cultures (Mokuau, 1991). In this study, genetic testing was largely seen as a way to fulfil family responsibilities, which mirrors findings in other research in patients with CID and other chronic conditions (Evans, 2012). According to Te Momo (2007), it is now more common for Māori to supportive of biotechnology. In accord with theme three, spiritual and religious causes for illness have been found in other Māori and Pasifika research (Kaholokula et al., 2008; Sanders et al., 2011). Although diverse, Māori and Pasifika knowledge often surmises that illnesses can be seen as retributory of past social transgressions (Mark & Lyons, 2010).

These findings highlight a gap in understanding of CID and its treatment between medical professionals and indigenous ethnic groups, which has implications for clinical care. First, further efforts must be made to communicate the meaning of symptoms with Māori and Pasifika with CID to help them better understand their condition. This also applies to explanations of treatment. Beta-blocker therapy greatly reduces the risk of syncope and sudden cardiac death in patients with LQTS, yet medication adherence is suboptimal in approximately 50% of patients (Waddell-Smith et al., 2016). Medical practitioners need to be cognisant of the ways in which culture can inform and shape health behaviours. For example, the practice of altering medication doses as a form of Tino rangatiratanga contrasts with medical definitions of adherence (Hugtenburg et al., 2013).

Second, physicians need to be aware that spiritual and religious guidance can be an important avenue of support within the medical care of Māori and Pasifika patients (Kaholokula et al., 2008). Recommendations to take medications that are perceived to have detrimental impacts on other aspects of health and spirituality may not be well received. Concerns about the spirituality of the body can prompt the pursuit of alternative and complementary treatment perceived to have fewer side-effects and better attend to the perceived causes of their CID (Watkins et al., 2011). In this study, belief in God's plan was especially apparent in Pasifika, highlighting the strong role of the church in Pasifika culture.

Third, the results indicate a preference for person-focused care over patient-centred care. The patient-centred orientation is narrow in its scope, often viewing changes in the physical disease in isolation (Starfield, 2011). This ignores the wider cultural, social, spiritual, mental and lifestyle factors which are also important for health and well-being. For this reason, person-focused care, which holds the position of disease as part of a wider interrelated phenomenon, may be better suited in providing comprehensive and compassionate care for Māori and Pasifika peoples.

Fourth, in terms of health screening and testing, cultural differences in practice and policy have made engagement difficult for Māori and Pasifika (Puaina et al., 2008). In this study, participants expressed apprehension around the inappropriate use of their samples and potential exploitation of the knowledge that may be garnered from them. This shared cynicism across ethnic minority groups is a legacy of longstanding histories of exploitative research and unsustainable resource use by non-indigenous groups (Riley, 2004). However, making these concerns known can be difficult within the medical context (Satterfield et al., 2005). As a contentious issue for both Māori

and Pasifika peoples, transparency of information surrounding the collection, storage, testing and disposal of samples is important (Hudson et al., 2008).

Finally, this study emphasises the importance of cultural competency and cultural safety training for healthcare providers. According to Tiatia-Seath (2008), cultural competency is a reflective practice in healthcare whereby healthcare providers must acknowledge their own culture in order to begin to understand the culture of others. Cultural safety acknowledges the barriers to care that arise from power differences between the provider and the patient, and stresses awareness of the culture of the clinician and the clinical environment (Curtis et al., 2019). It is important to create an environment that affirms and values the cultural practices and beliefs held by Māori and Pasifika peoples and their family. These include, but are not limited to, enhancing the capacity for *whānau* involvement in care, using transparent, empathetic and open communication styles, engaging in *whakawhanaungatanga*, respecting *tino rangatiratanga* and being mindful of power imbalances. Valuing these in the clinical setting strengthens rapport and bolsters resilience and protection from psychological distress (Muriwai et al., 2015; Ratima et al., 1999).

The wider implications are that these findings may help to inform ways to reduce health inequities. In Aotearoa New Zealand, Māori and Pasifika peoples with chronic illness face poorer health outcomes compared to other ethnic groups (Statistics New Zealand, 2013). Māori and Pasifika also have lower rates of health service engagement and medication adherence, and those who do attend primary health care services are more likely not to have their health needs adequately addressed (Baxter et al., 2006).

Limitations

A limitation of this study is that the sample who agreed to be interviewed may have been those who were able to better cope with their condition and therefore in a better position to discuss sensitive details. Thus, the concerns and experiences of other Māori and Pasifika peoples, which could potentially be more negative, may not have been captured. Additionally, it is important to understand the diversity within and between Pasifika and Māori peoples. A strength of the study was that it was able to provide an in-depth exploration of 17 Māori participants, which generated similar cultural nuances. However, although 18 Pasifika peoples were included, this study was not able to explore cultural nuances between the Pacific nations. As well as this, the investigation was limited to the Auckland region of Aotearoa New Zealand, and the quality and access to CID healthcare services may differ drastically across New Zealand. Further, the current research did not explore differences across CIDs. Future research could address these limitations.

Conclusion

This is the first study to explore the perspectives and lived experiences of Māori and Pasifika with CID and highlights the gap in understandings of CID and its treatment between medical professionals and indigenous ethnic groups. Patients face difficulties in understanding how symptoms are linked to CID, feel strong familial responsibilities and often have spiritual beliefs linked to health. These factors play a role in shaping

perceptions and guiding healthcare behaviours. Members of indigenous communities are often at higher risk of experiencing worse health outcomes and face more barriers to engaging in mainstream research. Thus, their concerns, needs and voices are often not recognised and addressed. These findings help to guide healthcare providers to understand the best ways to communicate with patients about their CID and tailor healthcare to be more culturally appropriate.

Data deposition

Not applicable.

Disclosure statement

The authors report no conflicts of interest.

Funding details

No funding was acquired for this study.

ORCID

Mikaela Law  <http://orcid.org/0000-0002-6667-6076>

Claire O'Donovan  <http://orcid.org/0000-0002-6272-7606>

Elizabeth Broadbent  <http://orcid.org/0000-0003-3626-9100>

Data availability statement

Due to the nature of this research, participants of this study did not agree for their data to be shared publicly, so supporting data are not available.

References

- Andersen, J., Øyen, N., Bjorvatn, C., & Gjengedal, E. (2008). Living with long QT syndrome: A qualitative study of coping with increased risk of sudden cardiac death. *Journal of Genetic Counseling*, 17(5), 489–498. <https://doi.org/10.1007/s10897-008-9167-y>
- Arora, J. (2016). Living with dilated cardiomyopathy. *BMJ (Clinical Research ed.)*, 355, i4063. <https://doi.org/10.1136/sbmj.i4063>
- Bailey, A., Fuatai, S., Funaki-Tahifote, M., Sua, T., Teevale, T., & Tuitahi, S. (2010). Promoting healthy lifestyles for Pacific peoples. *Best Practice Journal*, 32, 32–40. <https://bpac.org.nz/bpj/2010/november/promoting.aspx>
- Barnes, L., Moss-Morris, R., & Kaufusi, M. (2004). Illness beliefs and adherence in diabetes mellitus: A comparison between Tongan and European patients. *The New Zealand Medical Journal*, 117(1188), U743. <https://www.nzma.org.nz/journal/117-1188/743/>
- Bassett, S. F., & Holt, E. A. (2002). New Zealand resident Tongan peoples' health and illness beliefs and utilisation of the health care system. *Pacific Health Dialog*, 9(1), 40–47. <https://pubmed.ncbi.nlm.nih.gov/12737416/>
- Bassett-Clarke, D., Krass, I., & Bajorek, B. (2012). Ethnic differences of medicines-taking in older adults: A cross cultural study in New Zealand. *The International Journal of Pharmacy Practice*, 20(2), 90–98. <https://doi.org/10.1111/j.2042-7174.2011.00169.x>

- Baxter, J., Kokaua, J., Wells, J. E., McGee, M. A., Oakley Browne, M. A., & New Zealand Mental Health Survey Research Team. (2006). Ethnic comparisons of the 12 month prevalence of mental disorders and treatment contact in Te Rau Hinengaro: The New Zealand mental health survey. *The Australian and New Zealand Journal of Psychiatry*, 40(10), 905–913. <https://doi.org/10.1080/j.1440-1614.2006.01910.x>
- Bean, D., Cundy, T., & Petrie, K. J. (2007). Ethnic differences in illness perceptions, self-efficacy and diabetes self-care. *Psychology & Health*, 22(7), 787–811. <https://doi.org/10.1080/14768320600976240>
- Bishop, R. (1999). Kaupapa Maori Research: An indigenous approach to creating knowledge [Paper presentation]. Maori and Psychology: Research and Practice. Proceedings of a Symposium Sponsored by the Maori & Psychology Research Unit, Hamilton. In N. Robertson (Ed.), Department of Psychology, University of Waikato (pp. 1–6). <https://hdl.handle.net/10289/874>
- Capstick, S., Norris, P., Sopoaga, F., & Tobata, W. (2009). Relationships between health and culture in Polynesia – A review. *Social Science & Medicine* (1982), 68(7), 1341–1348. <https://doi.org/10.1016/j.socscimed.2009.01.002>
- Curtis, E., Jones, R., Tipene-Leach, D., Walker, C., Loring, B., Paine, S. J., & Reid, P. (2019). Why cultural safety rather than cultural competency is required to achieve health equity: A literature review and recommended definition. *International Journal for Equity in Health*, 18(1), 1–17. <https://doi.org/10.1186/s12939-019-1082-3>
- Durie, M. H. (1985). A Māori perspective of health. *Social Science & Medicine* (1982), 20(5), 483–486. [https://doi.org/10.1016/0277-9536\(85\)90363-6](https://doi.org/10.1016/0277-9536(85)90363-6)
- Durie, M. (1998). *Whaiora Māori health development* (2nd ed.). Oxford University Press.
- Dwyer, S. C., & Buckle, J. L. (2009). The space between: On being an insider-outsider in qualitative research. *International Journal of Qualitative Methods*, 8(1), 54–63. <https://doi.org/10.1177/160940690900800105>
- Elliott, P., Lambiase, P. D., & Kumar, D. (2020). *Inherited cardiac disease*. Oxford University Press.
- Evans, D. (2012). Whakapapa, genealogy and genetics. *Bioethics*, 26(4), 182–190. <https://doi.org/10.1111/j.1467-8519.2010.01850.x>
- Flanagan, J. M., Carroll, D. L., & Hamilton, G. A. (2010). The long-term lived experience of patients with implantable cardioverter defibrillators. *MEDSURG Nursing*, 19(2), 113–119. <http://samples.jbpub.com/9780763794675/JournalArticles/Flanagan.pdf>
- Hamang, A., Eide, G. E., Rokne, B., Nordin, K., & Øyen, N. (2011). General anxiety, depression, and physical health in relation to symptoms of heart-focused anxiety: A cross sectional study among patients living with the risk of serious arrhythmias and sudden cardiac death. *Health and Quality of Life Outcomes*, 9(1), 100–110. <https://doi.org/10.1186/1477-7525-9-100>
- Hamang, A., Eide, G. E., Nordin, K., Rokne, B., Bjorvatn, C., & Øyen, N. (2010). Health status in patients at risk of inherited arrhythmias and sudden unexpected death compared to the general population. *BMC Medical Genetics*, 11(1), 1–10. <https://doi.org/10.1186/1471-2350-11-27>
- Hudson, M. L., Allan, C. A., Bedford, K. R., Buckleton, J. S., & Stuart, K. (2008). The impact of Māori cultural values on forensic science practice in New Zealand. *Journal of Forensic Sciences*, 53(2), 380–383. <https://doi.org/10.1111/j.1556-4029.2008.00661.x>
- Hugtenburg, J. G., Timmers, L., Elders, P. J., Vervloet, M., & van Dijk, L. (2013). Definitions, variants, and causes of nonadherence with medication: A challenge for tailored interventions. *Patient Preference and Adherence*, 7, 675–682. <https://doi.org/10.2147/PPA.S29549>
- Ingles, J., Lind, J. M., Phongsavan, P., & Semsarian, C. (2008). Psychosocial impact of specialized cardiac genetic clinics for hypertrophic cardiomyopathy. *Genetics in Medicine: Official Journal of the American College of Medical Genetics*, 10(2), 117–120. <https://doi.org/10.1097/GIM.0b013e3181612cc7>
- Janney, A. (2011). *Anxiety in individuals affected by long QT syndrome as experienced by members of an online user group PCOM Psychology Dissertations*, Paper 190. https://digitalcommons.pcom.edu/cgi/viewcontent.cgi?article=1186&context=psychology_dissertations
- Johnson, J. N., & Ackerman, M. J. (2013). Return to play? Athletes with congenital long QT syndrome. *British Journal of Sports Medicine*, 47(1), 28–33. <https://doi.org/10.1136/bjsports-2012-091751>

- Kaholokula, J. K., Saito, E., Mau, M. K., Latimer, R., & Seto, T. B. (2008). Pacific Islanders' perspectives on heart failure management. *Patient Education and Counseling*, 70(2), 281–291. <https://doi.org/10.1016/j.pec.2007.10.015>
- MacIntyre, C., & Lakdawala, N. K. (2016). Management of atrial fibrillation in hypertrophic cardiomyopathy. *Circulation*, 133(19), 1901–1905. <https://doi.org/10.1161/CIRCULATIONAHA.115.015085>
- Mark, G. T., & Lyons, A. C. (2010). Māori healers' views on wellbeing: The importance of mind, body, spirit, family and land. *Social Science & Medicine* (1982), 70(11), 1756–1764. <https://doi.org/10.1016/j.socscimed.2010.02.001>
- Maron, B. J., Towbin, J. A., Thiene, G., Antzelevitch, C., Corrado, D., Arnett, D., Moss, A. J., Seidman, C. E., Young, J. B., & Council on Epidemiology and Prevention. (2006). Contemporary definitions and classification of the cardiomyopathies: An American Heart Association scientific statement from the council on clinical cardiology, heart failure and transplantation committee; quality of care and outcomes research and functional genomics and translational biology interdisciplinary working groups; and council on epidemiology and prevention. *Circulation*, 113(14), 1807–1816. <https://doi.org/10.1161/CIRCULATIONAHA.106.174287>
- Megari, K. (2013). Quality of life in chronic disease patients. *Health Psychology Research*, 1(3), e27. <https://doi.org/10.4081/hpr.2013.e27>
- Mokuau, N. (1991). *Handbook of social services for Asian and Pacific Islanders*. Greenwood Publishing Group.
- Muriwai, E. M., Houkamau, C. A., & Sibley, C. G. (2015). Culture as cure? The protective function of Māori cultural efficacy on psychological distress. *New Zealand Journal of Psychology*, 44(2), 14–24. <https://mro.massey.ac.nz/handle/10179/11792>
- Nikora, L. W., Hodgetts, D., Carlson, T., & Rua, M. (2011). Māori and medications: What happens when the pills go home? *AlterNative: An International Journal of Indigenous Peoples*, 7(2), 87–99. <https://hdl.handle.net/10289/6315> <https://doi.org/10.1177/117718011100700202>
- Norris, P., Va'ai, C., Fa'alau, F., Churchward, M., & Arroll, B. (2011). Pain, infection, and colds and flu: Samoan people's views about antibiotics. *Research in Social & Administrative Pharmacy: RSAP*, 7(1), 81–92. <https://doi.org/10.1016/j.sapharm.2010.01.002>
- Petrie, K., & Jones, A. (2019). Coping with chronic illness. In C. Llewellyn, S. Ayers, C. McManus, S. Newman, K. Petrie, & T. Revenson. (Eds.), *Cambridge Handbook of Psychology, Health and Medicine* (Cambridge Handbooks in Psychology (pp. 110–113). Cambridge University Press.
- Puaina, S., Aga, D. F., Pouesi, D., & Hubbell, F. A. (2008). Impact of traditional Samoan lifestyle (fa'aSamoa) on cancer screening practices. *Cancer Detection and Prevention*, 32(1), 23–28. <https://doi.org/10.1016/j.cdp.2007.04.012>
- Rasoul, D., Potluri, S., Wong, S. C., Gorantla, R. S., Aziz, A., Chandran, S., Uppal, H., & Potluri, R. (2015). Psychiatric co-morbidities in patients with dilated cardiomyopathy. *International Journal of Cardiology*, 191, 71–73. <https://doi.org/10.1016/j.ijcard.2015.04.271>
- Ratima, M. M., Fox, C., Fox, B., Te Karu, H., Gemmell, T., Slater, T., D'Souza, W. J., & Pearce, N. E. (1999). Long-term benefits for Māori of an asthma self-management program in a Māori community which takes a partnership approach. *Australian and New Zealand Journal of Public Health*, 23(6), 601–605. <https://doi.org/10.1111/j.1467-842x.1999.tb01544.x>
- Reid, P., Paine, S. J., Curtis, E., Jones, R., Anderson, A., Willing, E., & Harwood, M. (2017). Achieving health equity in Aotearoa: Strengthening responsiveness to Māori in health research. *The New Zealand Medical Journal*, 130(1465), 96–103. <https://journal.nzma.org.nz/journal-articles/achieving-health-equity-in-aotearoa-strengthening-responsiveness-to-maori-in-health-research>
- Riley, M. (2004). *Indigenous intellectual property rights: Legal obstacles and innovative solutions*. Rowman Altamira.
- Rucinski, C., Winbo, A., Marcondes, L., Earle, N., Stiles, M., Stiles, R., Hooks, D., Neas, K., Hayes, I., Crawford, J., Martin, A., & Skinner, J. R. (2020). A population-based registry of patients with inherited cardiac conditions and resuscitated cardiac arrest. *Journal of the American College of Cardiology*, 75(21), 2698–2707. <https://doi.org/10.1016/j.jacc.2020.04.004>
- Sanders, D., Kydd, R., Morunga, E., & Broadbent, E. (2011). Differences in patients' perceptions of schizophrenia between Māori and New Zealand Europeans. *The Australian and New Zealand Journal of Psychiatry*, 45(6), 483–488. <https://doi.org/10.3109/00048674.2011.561479>

- Satterfield, T., Roberts, M., Henare, M., Finucane, M., Benton, R., & Henare, M. (2005). Culture, risk, and the prospect of genetically modified organisms as viewed by Tāngata Whenua. <http://hdl.handle.net/1794/20637>
- Smith, J. A., & Osborn, M. (2015). Interpretative phenomenological analysis as a useful methodology for research on the lived experience of pain. *British Journal of Pain*, 9(1), 41–42. <https://doi.org/10.1177/2049463714541642>
- Sporle, A., & Koea, J. (2004). Maori responsiveness in health and medical research: Key issues for researchers (part 1). *The New Zealand Medical Journal (Online)*, 117(1199), U997. <https://www.proquest.com/docview/1033757961/abstract/E0E710C1CE5246EDPQ?accountid=8424>
- Starfield, B. (2011). Is patient-centered care the same as person-focused care? *The Permanente Journal*, 15(2), 63–69. <https://doi.org/10.7812/TPP/10-148>
- Statistics New Zealand. (2013). 2013 census QuickStats about Maori. <https://www.stats.govt.nz/assets/Uploads/Retirement-of-archive-website-project-files/Reports/2013-Census-QuickStats-about-Maori/qs-maori.pdf>
- Steptoe, A., Mohabir, A., Mahon, N. G., & McKenna, W. J. (2000). Health related quality of life and psychological wellbeing in patients with dilated cardiomyopathy. *Heart (British Cardiac Society)*, 83(6), 645–650. <https://doi.org/10.1136/heart.83.6.645>
- Subasic, K. (2013). Living with hypertrophic cardiomyopathy. *Journal of Nursing Scholarship: An Official Publication of Sigma Theta Tau International Honor Society of Nursing*, 45(4), 371–379. <https://doi.org/10.1111/jnu.12040>
- Tamasese, T. K., Parsons, T. L., Sullivan, G., & Waldegrave, C. (2010). *A qualitative study into Pacific perspectives on cultural obligations and volunteering*. Pacific Section and the Family Centre Social Policy Research Unit. <http://familycentre.org.nz/wp-content/uploads/2019/04/Cultural-Obligations-and-Volunteering-Main.pdf>
- Te Momo, O. F. (2007). Biotechnology: The language of multiple views in Māori communities. *Biotechnology Journal*, 2(9), 1179–1183. <https://doi.org/10.1002/biot.200700123>
- Tiatia-Seath, S. (2008). Pacific cultural competencies: A literature review. New Zealand Ministry of Health. <https://www.health.govt.nz/publication/pacific-cultural-competencies-literature-review>
- Turner, D. C. (1996). The role of culture in chronic illness. *American Behavioral Scientist*, 39(6), 717–728. <https://doi.org/10.1177/0002764296039006008>
- Vaiolenti, T. M. (2016). Talanoa research methodology: A developing position on Pacific research. *Waikato Journal of Education*, 12(1), 21–34. <https://hdl.handle.net/10289/6199> <https://doi.org/10.15663/wje.v12i1.296>
- Waddell-Smith, K. E., Li, J., Smith, W., Crawford, J., Skinner, J. R., & Cardiac Inherited Disease Group New Zealand (2016). β -Blocker adherence in familial long QT syndrome. *Circulation. Arrhythmia and Electrophysiology*, 9(8), e003591. <https://doi.org/10.1161/CIRCEP.115.003591>
- Walker, S., Eketone, A., & Gibbs, A. (2006). An exploration of kaupapa Maori research, its principles, processes and applications. *International Journal of Social Research Methodology*, 9(4), 331–344. <https://doi.org/10.1080/13645570600916049>
- Walter, F. M., Emery, J., Braithwaite, D., & Marteau, T. M. (2004). Lay understanding of familial risk of common chronic diseases: A systematic review and synthesis of qualitative research. *Annals of Family Medicine*, 2(6), 583–594. <https://doi.org/10.1370/afm.242>
- Ware, J. E., Jr, & Sherbourne, C. D. (1992). The MOS 36-item short-form health survey (SF-36): I. Conceptual framework and item selection. *Medical Care*, 30(6), 473–483. <https://www.jstor.org/stable/3765916> <https://doi.org/10.1097/00005650-199206000-00002>
- Watkins, C. L., Fernandez-Robles, C., Miller, K. M., Pine, A., & Stern, T. A. (2011). Use of complementary and alternative medicine by patients with cancer. *The Primary Care Companion to CNS Disorders*, 13(2). <https://doi.org/10.4088/PCC.10f01011>
- Weil, J. (2000). *Psychosocial genetic counseling*. Oxford University Press.
- Wilde, A. A., & Behr, E. R. (2013). Genetic testing for inherited cardiac disease. *Nature Reviews. Cardiology*, 10(10), 571–583. <https://doi.org/10.1038/nrcardio.2013.108>
- Winbo, A., Earle, N., Marcondes, L., Crawford, J., Prosser, D. O., Love, D. R., Merriman, T. R., Cadzow, M., Stiles, R., Donoghue, T., Stiles, M. K., Hayes, I., & Skinner, J. R. (2020). Genetic

testing in Polynesian long QT syndrome probands reveals a lower diagnostic yield and an increased prevalence of rare variants. *Heart Rhythm*, 17(8), 1304–1311. <https://doi.org/10.1016/j.hrthm.2020.03.015>

Wong, E. K., Bartels, K., Hathaway, J., Burns, C., Yeates, L., Semsarian, C., Krahn, A. D., Virani, A., & Ingles, J. (2019). Perceptions of genetic variant reclassification in patients with inherited cardiac disease. *European Journal of Human Genetics: EJHG*, 27(7), 1134–1142. <https://doi.org/10.1038/s41431-019-0377-6>

Zayts, O., Shipman, H., Fung, J. L.-F., Liu, A. P.-Y., Kwok, S.-Y., Tsai, A. C.-H., Yung, T.-C., & Chung, B. H.-Y. (2019). The different facets of “culture” in genetic counseling: A situated analysis of genetic counseling in Hong Kong. *American Journal of Medical Genetics. Part C, Seminars in Medical Genetics*, 181(2), 187–195. (Hoboken, USA: John Wiley & Sons, Inc.) <https://doi.org/10.1002/ajmg.c.31699>