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Research paper

Upholding te mana o te wā: Māori patients and their families' experiences of accessing care following an out-of-hospital cardiac event

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ABSTRACT

Objective: The purpose of this study was to explore the experiences of Māori patients and their families accessing care for an acute out-of-hospital cardiac event and to identify any barriers or enablers of timely access to care. **Design:** Eleven interviews with patients and their families were conducted either face-to-face or using online conferencing. Interviews were audio-recorded and transcribed for thematic analysis using Kaupapa Māori methodology.

Results: Data analysis identified three themes: (1) me and the event, (2) the people (3) upholding te mana o te wā or self-determined heart wellbeing. Knowledge of symptoms and a desire to maintain personal dignity at the time of the event affected emergency medical service initiation. Participants described relationships with health professionals, the importance of good quality information, having family support, and drawing on cultural practices as vital for their health care journey.

Conclusion: Systemic barriers including racism, discrimination, and inadequate resourcing exist for Māori journeying to and through care following an out of hospital cardiac event. Improving the cultural safety of health professionals, better access to community defibrillation, and improving understanding of the life-long impacts a cardiac event has on patients and whānau is recommended.

1. Introduction

Cardiovascular disease (CVD) is a major global health problem, with increasing CVD prevalence reported in low- and middle-income countries and plateauing of previously seen declines in high-income nations due to population growth and ageing [1–3]. Within nations, ethnic and racial disparities in CVD rates, outcomes and risk factors exist [4–6]. Further, CVD is a major contributor to reduced life expectancy for Indigenous peoples across the world and is a leading cause of death and disability for American Indians, Alaska Natives [7], First Nations people of Canada [8], Aboriginal and Torres Strait Islander Peoples in Australia [9], and Māori in Aotearoa New Zealand (NZ) [10].

In NZ, Māori experience higher rates in exposure to CVD risk factors such as low income, smoking and inadequately managed diabetes [6] as well as increased CVD mortality and hospitalisations [11]. Māori also

receive different treatments once diagnosed with CVD, being more likely to receive medication and less likely to receive revascularisation than non-Māori [12–14]. Māori males have the highest mortality rates from ischaemic heart disease, but comparatively lower rates of hospitalisation [15], suggesting important barriers to preventive interventions and acute care [16]. Attention to apparent inequities in CVD risks and outcomes among Māori females has received notably limited attention [17].

One potential reason for the ethnic disparities in CVD hospitalisations in NZ is differential access to pre-hospital care or transport. As a result, people may be dying in the community before they receive care, or not receiving an accurate diagnosis [18]. There are several well-established factors that increase the likelihood of a positive outcome following an out-of-hospital cardiac arrest. Faster ambulance response times [19,20], timely access to cardiopulmonary resuscitation (CPR) and automated external defibrillation (AED) [21,22] all increase the

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likelihood of survival. In cases of ST-Elevation Myocardial Infarction (STEMI) the optimum time for first medical contact from symptom onset is less than 90 min [23]. However Māori experience longer delays to acute reperfusion [24], are less likely to be directly transported to a percutaneous coronary intervention (PCI) capable hospital [25] and despite having higher rates of bystander CPR, experience poorer survival rates compared with New Zealand European people [26]. Māori are also affected by the distribution of public access AED, as there is an inverse relationship between area-level deprivation and availability of devices [27]. A higher proportion of Māori live rurally [28] and experience excess amenable mortality [29] which indicate that additional barriers to care exist by geography.

In NZ, there are various pathways to hospital care for people having an acute cardiac event in the community. People can call a first response team, or ambulance, via an emergency phone number (111), or self-transport to a health service. Previous research has demonstrated that Māori are less likely to receive timely access to pre-hospital emergency care compared with non-Māori, non-Pacific people [30]; and calls to investigate this first step in care – from symptom onset to hospital arrival – have been made [31]. The lived experiences of Māori who have had an acute cardiac event in the community has not been explored and may provide critical information to better understand, and potentially address, access and outcome inequities. Therefore, this research aimed to explore Māori experiences during an acute cardiac event in the community. A key objective was to investigate how existing systems and structures affected people's experiences, from symptom onset to arrival at hospital. This research was done as part of a larger research programme, Manawataki Fatu Fatu (Hearts Beating in Unison) to Achieve Cardiovascular Care in Equity StudieS (ACCESS) for Māori and Pacific people in New Zealand [32].

2. Methodology and methods

Kaupapa Māori theory informed the study design and analysis. Kaupapa Māori is borne from mātauranga Māori (epistemologies, knowledge and understanding) and provides a “culturally defined theoretical space” [33] for research to be undertaken. Kaupapa Māori research is decolonising in its approach, grounded in Māori ways of knowing and being, representing Māori realities, producing evidence that informs transformational change and supporting Māori aspirations [34–36]. Kaupapa Māori research is not prescriptive, but can sit alongside other research methods that support the realisation of an Indigenous research agenda [36].

2.1. Eligibility criteria

There were two inclusion criteria. 1: Māori adults aged 18 years and older who had experienced an acute out-of-hospital cardiac event (OHCE). 2: Non-Māori whānau members of a Māori patient who had experienced an OHCE. Whānau is commonly translated to mean “family” however, this definition is overly simplified if viewed through the western lens of the nuclear family. Whānau, as is used in this study, is those connected by whakapapa (kinship) as well as those connected by non-biological ties to community [37]. An OHCE included (but was not limited to) a wide range of cardiac-related outcomes including myocardial infarction, acute chest pain, STEMI, and non-STEMI. Participants were excluded if their OHCE was a result of trauma.

2.2. Recruitment

Participants were recruited through a variety of methods. A recruitment poster was disseminated through the researchers' networks and on social media. Hato Hone St John (*Emergency Medical Service provider who deliver care across most of New Zealand*) used ethnicity and clinical impression data to identify a group of potential participants. An invitation to participate was sent through the mail by Hato Hone on

behalf of the researchers. Participants were also recruited via word of mouth. In cases where a potential participant was referred by another participant/person, the referrer obtained permission to pass on the contact information of the potential participant before the research team approached them.

2.3. Data collection

The data was collected during a period of COVID lockdowns and restrictions between 01 January 2022 and 01 December 2022. Up to one hour long, face-to-face, phone and online semi-structured interviews were conducted depending on the location of the participant, the level of COVID restriction in place, and the preference of the participant. The interview schedule was adapted from one previously tested that was used in the Manawataki Fatu Fatu project. The adapted questions were piloted and refined before use. Open questions addressed the experience of getting care for an acute event, the perceptions of the care received and identifying the type of care they would like to receive. Participants were prompted to talk about the dimensions of care that affected their experience positively and negatively. Informed consent was obtained from all participants prior to interviews commencing. Interviews were conducted by Māori researchers who speak Te Reo Māori (Māori language). The choice to use Te Reo Māori was at the discretion of the participant and most spoke primarily in English with Te Reo Māori being used throughout. This ensured no assumptions were made about the preferences or fluency of participants. Te Reo Māori was often used to describe concepts or perspectives that have specific meaning in Te Ao Māori (Māori world view). Interviews started with whakawhānau (relationship building) and karakia (blessing). Open ended questions in a conversational style were used to enable participants to describe their experiences in their own way and thus allowing a richer conversation. Interviews were digitally recorded using either a mobile device or the recording function of the online meeting tool. Each interview was ended with another karakia. The audio recordings were professionally transcribed then de-identified.

2.4. Analysis

Interview transcripts were imported into NVivo 12 [38] for analysis. Transcripts were analysed using an approach where constant comparative analysis of the transcripts was performed in an iterative process of close reading, and coding, of transcripts as they were completed. Successively coded transcripts were compared to previous transcripts and clusters of interview fragments that were coded to similar overarching themes were created. The thematic clusters were analysed for patterns and outliers. Themes and codes were refined where appropriate. Themes were presented at a whānau hui (gathering) for feedback and notes were made by the lead author during discussions which informed further refinement of the themes.

2.5. Ethics

Ethics for this project was obtained from Auckland Health Regional Ethics Committee (AHREC), reference AH22609.

3. Results

Eleven participants (six female and five male) were interviewed. Ten self-identified their ethnicity as Māori and one as Samoan (whānau member). Participants' ages ranged from 35 to 75 years. Seven were of working age at the time of their OHCE and two of those had an OHCE at work. Nine lived in an urban community and two lived rurally. Of the Māori participants interviewed, nine had an OHCE, five also had family who had an OHCE, and seven had no heart health concerns prior to their OHCE. Of those who had experienced an OHCE, six had multiple acute events.

Qualitative analysis of the interviews identified three themes: Me and the event; the people; and a journey to uphold “te mana o te wā.”

3.1. Me and the event

3.1.1. My context

Most participants were under 45 years at the time of their first acute cardiac event, were working and had caregiving responsibilities. The decision to call an ambulance was often made in the context of competing responsibilities to work, family and finances.

“[When I had the cardiac event] I, again, had to organise kids, work, life – everything.”

3.1.2. Previous knowledge and experience

Participants had preconceived ideas about cardiac symptoms and how to manage these, including the appropriateness of calling an ambulance. Several participants self-transported to a medical clinic rather than call an ambulance because they didn't realise that they were having acute cardiac symptoms. Their expectation was that heart attacks were crushing pain followed by collapse.

“He wasn't going, ‘Ooh-ooh-ooh...’, and rolling around the floor”.

Others mistook the symptoms for more common, and less severe, conditions.

“We drove from work, ... to urgent care because we didn't even know it was a heart attack. I just thought it was an anxiety attack because he couldn't breathe out very well and he was breathing shallow ... which is similar to anxiety.”

Participants' perceptions of ambulance services informed their decision making.

“I've never used an ambulance service. For me, it is something that's really expensive and it's something I guess in the back of my mind that you use for someone who's collapsed, or in a severe state that they can't get [there] themselves.”

3.1.3. Maintaining self-dignity

Fear of judgement from ambulance staff and a desire to maintain their dignity discouraged some participants from calling an ambulance.

“Some people can make judgments in the first three seconds of meeting you and you can feel it. It's a feeling you get. I guess rescuers if they just come in to do their job rather than sit there and judge, start asking questions like, “What have you been doing?”

3.2. The people

Participants described key people involved in the event including witnesses, whānau, ambulance staff and other health professionals.

3.2.1. Witnesses

Witnesses provided various types of care during the event from accessing care, delivering CPR and, when the witness was whānau, giving emotional support during a time fraught with pain and fear.

“Thank goodness she [their work colleague] had the peace of mind, ‘cause she looked at him ... ‘Nah, you're going straight to Urgent Care’.”

3.2.2. Whānau

Whānau played active roles in successfully navigating care, advocacy, emotional support, and liaison with services.

“If you don't have people like the [his wife] in the world you're too tired, you're too sick to fight.”

“If you haven't got a family that's with you on that journey for whatever reason, then you become really isolated really quickly.”

3.2.3. Health professionals

Participants described both positive and negative experiences with health professionals after their cardiac event. Interpersonal relationships with general practitioners were described in a positive light, although participants experienced barriers to seeing their general practitioner when needed. They described feeling safe with GPs, dropping in for an electrocardiogram if feeling unwell and being prioritised for appointments. For others, a regular doctor helped them feel confident to ask questions and share concerns about their health.

“there's some doctors that you can engage with, [our] GP [is] one of them; you know she just opens up.”

“[I wish I could easily get] an appointment. There's a lot of karakia involved. Because they're [GP] so busy and it might take a week or two to get an appointment; so when it comes to your heart, you haven't got a week or two.”

Participants also presented a range of interpersonal experiences with health care providers that left them feeling disempowered or vulnerable. They felt that they were being discriminated in their care because they were Māori. As a result, there was a reluctance to see a clinician again.

“All those feelings of ‘why am I not being treated fairly here?’ If there was somebody down the hallway, Pākehā or whoever, would they have got [care]? You just don't know these things. Once that sets off in my head, I just get really tired and I just want it to end so I'll stop it and discharge myself.”

Others described sensing discrimination based on body weight/habitus, with similar hesitancy to present again.

“There's all that layer of just getting to the doctor and then feeling whakamā [embarrassed] when you get there. The first thing he does is, “Get on the scales.” You're like, “Here we go.”

3.3. A journey to uphold “the mana of the wā”

3.3.1. Consistency of care across the journey

Participants linked variables in their first healthcare response to outcomes which left them with lasting impressions about care for acute cardiac events. This is best illustrated through two experiences. One person described a seamless process from immediately receiving CPR, AED being performed by bystanders, ambulances arriving quickly and then dispatched to hospital where they received timely treatment. In contrast, another participant described the following experience where a whānau member had died, highlighting significant failings in the distribution of resources as well as personal anguish of what could have been.

“...he collapsed and of all the services that came, the fire brigade came. They didn't have the defibrillator on their truck. The crash team came with the doctor. They had no defibrillator on their vehicle. They didn't have intubation for oxygen which is what he needed because he was without oxygen for some time. They went down ... the road where he collapsed, it's only just down the road from the rest home. They had no defibrillator there either.”

3.3.2. Feeling fortunate

All participants described feeling grateful to be alive and for the good care in their journey. However, access to timely care and survival was often perceived as ‘being lucky’ rather than what people should receive.

One whānau member said about their father.

“He was in the right place at the right time, with the right sort of person, to have the sound of mind to take him in.”

3.3.3. Care not sustained across the journey

Participants also described a desire for more care and support as part of their ongoing journey. These were plentiful at the acute phase but often dropped off over time.

“I think the biggest journey was post the arrest. You get all the support while you're in the system, it's once you leave the system then you've got no support.”

3.3.4. Feeling informed

One key area that participants felt could support the journey was having high quality, accessible and timely information throughout. People sought more clarity about the seriousness and ongoing treatment of the event, in addition to adequate time for education.

“I know people get a little bit of education around that when they leave hospital but it's not always clear. Sometimes it's a little bit too quick.”

“They told us that he had a heart incident, but until we actually got home and read it, it was like more than an incident.”

Others highlighted that there needed to be more education on the location of AED in the community and how to perform CPR.

“There are a few defibrillators around town but not everybody knows where they are. We've only just got one at the marae just in the last month. The marae had to pay for it.”

“About getting defibs into our communities, onto our maraes, and all those different spaces. Then backing that up with the background stuff, with training with community CPR. These are lifesaving tools. Fundamental tools. Gotta teach it.”

Group sessions for patients and their whānau, when offered, received mixed responses from participants. When people with lived experience of OHCE were able to share their stories, participants found this incredibly useful. Clinician-led sessions were criticised for being unwelcoming and unsafe.

“I looked at this group that came to [town where they live], and it was quite draining really, because you come in and you listen to another lecture and that's it; there's no kai and you didn't really have time to talk to people, and you could see that people were wanting to talk.”

“It was obvious from the nods around the room and the questioning around the room that other people got [referral for treatment]. Other white middle-aged older people got them and the only brown person in the room didn't get any of them. It was extremely distressing.”

3.3.5. Hauora: holistic wellbeing

The impact on their mental, social, and physical health were important considerations for all participants. One described the journey for a cardiac event as being:

“more than the medication. It's about adjusting your whole lifestyle, your mental state and your emotional state I think is just as important as changing all the physical stuff around you.”

Mental wellbeing focussed on balancing one's internal fears of a cardiac event recurrence with external pressures to exercise as part of the recovery.

“When you've had a heart attack it's really hard to try and explain to somebody that the fear is if I do overexert myself and fall over and

have a heart attack on the ground it's because you've told me that I needed to do some exercise.”

Whānau wellbeing was also a balancing act and participants described the tensions in ‘self-management’ compared with whānau ‘taking over’ in order to prevent further events. One participant described how his whānau would send him away rather letting him help with the yard work.

“I try to but I'm always out there trying to, ‘Do this properly, do that, do that.’ I like to be the director, but the kids tell me, ‘Go and sit down. Go inside.’ Oh well. So I disappear inside.”

Participants described how the experience contributed to their new identity, building on their life-story in positive ways:

“I've had the event, but that event is not going to determine who I am, it's going to be an addition to the journey of who I've always been.”

3.3.6. Supporting wellbeing through rongoā

All participants described aspects of Te Ao Māori that underpinned their experience and response to their OHCE. They described the rongoā (traditional wellbeing practices) utilised in their journeys, such as the taiao (environment), karakia (ritual chant/prayer) and whakapapa (kinship) and acknowledged how these linked the body, spirit, mind within themselves and with whānau:

“I've had to really listen to my body, my tinana (body), and there's good dialogue going now between that and my wairua (spirit). And the hinengaro (mind), I understand that's something that's impacted on my life and I just want to make sure that I'm here in the lifetime space, you know with our mokos[sic] (grandchildren) and loved ones.”

One participant described the importance of the manawa (*heart*) which motivated them to improve their heart health.

“Do you see what it means eh? The mana (spiritual power) of the wā (time); it keeps you going right from the time you start life, ‘til it's time you move on to the other life, to the afterlife.”

In describing whakapapa in their journey, participants recognised that there were familial links to heart disease, but also skills passed down from tīpuna (*ancestors*).

“We discovered near the end of her life, there was something to do with her heart, and then my grandfather – so you know you can see the whakapapa lines there eh. But even with that, it still shouldn't stop us from also looking at what other characteristics are passed down”.

Although there was a collective desire to use mātauranga Māori, including rongoā, in their healing journey, participants had to make their own arrangements and often felt marginalised when they couldn't or were denied access to this:

“If you wanted a more Māori lens normally you've got to do that yourself. The whānau reaches out to somebody that can carry that for you. If you're not in the know then you're not in the know”

4. Discussion

This qualitative study explored the experiences of Māori in accessing care during an acute cardiac event in the community. Interviews with eleven participants across NZ, analysed using a de-colonising methodology, identified three themes which influenced the experience and decision making: their own personal context, knowledge and experience; the people involved in the experience; and how this was a journey to uphold the “mana of the wā”, which was holistic, included their own cultural worldview and didn't end when they arrived at hospital.

To our knowledge this is the first study to explore the influences in the pre-hospital, and particularly ambulance, pathway for Māori. Our findings reflect participants kōrero (stories) that frames their pre-hospital experience within their journey to uphold their manawa/mana o te wā (heart). Participants described several key areas to effect change, and potentially contribute to equity in acute cardiac care access and outcomes.

At the time of the event participants identified how decisions to obtain care were influenced by perceptions of need and understanding of cardiac emergencies within the context of financial, family, and work commitments. Where witnessed cardiac arrests prompted immediate calls for an ambulance, other symptoms were interpreted less urgently, and participants chose to self-transport to a community clinic rather than call an ambulance. Unfortunately, this confusion can lead to significant delays in the receipt of life- and heart-saving care [31,39]. Symptom recognition is important for timely access yet, internationally, research has identified ethnic differences, with minoritised populations less likely to recognise serious cardiac symptoms [40,41]. Further there may be different cardiac symptoms for some ethnic groups based on comorbidities (e.g. higher rates of diabetes for Māori [42], and diabetes associated with 'silent heart attacks' [43]). Further research to better understand this phenomenon, and develop and implement strategies, is strongly warranted.

Increased symptom knowledge or health literacy, however, does not always translate into timely access. Witnesses, whānau, and health professionals play an important role in how participants respond to an acute event. Several participants reported interactions with a health provider that was assumptive, discriminatory, or racist that made them hesitant to engage with health services. The experience of racism and discrimination are well documented barriers to care in Aotearoa [44–46]. Similarly, inter-personal discrimination based on ethnicity and weight contributes to delays in seeking care [47,48] and to poor CVD outcomes [49–51]. Also consistent with other research, whānau support was often drawn upon to mitigate these barriers, [52] this is often characterised as having to 'fight' to ensure care was sustained [53].

The impact of colonisation on the whānau in our study is reflected in structural barriers they identified, and the concerns raised about the loss of traditional knowledge and practices or limited access to these when required. The struggle for health equity is a common experience across indigenous populations globally [54]. In NZ, the alienation of land, disruption to social systems, as well as cultural and economic marginalisation caused by colonisation [55] have entrenched Māori health disparities over generations. Participants described structural racism which resulted in inadequate health literacy [56], cost-barriers [52], and lack of life-saving resource for Māori [14]. Participants also raised concerns about access to CPR/AEDs while waiting for the ambulance and expressed a desire to learn CPR, have more defibrillators in proximity, and know the locations.

One way to address structural and interpersonal barriers to care is through improving cultural safety within the health system and workforce [57], this must extend to the ambulance and first-response teams [58]. Work is beginning on this strategy across New Zealand. Te Aka Whai Ora, the Māori Health Authority, was recently established to support a whole of system approach to Māori wellbeing, including integration of Iwi (tribal) and traditional knowledge and practices. Participants' suggestions that whānau and other local experts are key to driving initiatives, accessing effective and timely care, and understanding who knows what, align with Te Aka Whai Ora's aspirations [59] and evidence from related Indigenous health research. A number of co-designed community awareness programmes to improve local knowledge of CPR and AEDs are also underway [60] including the funding of AED and provision of CPR in rural marae [61].

These results align with the findings from the qualitative component of the broader Manawataki Fatu Fatu project [62] in which Māori and Pacific people from across NZ were interviewed about their overall experience of heart healthcare, from cardiovascular risk assessment/

heart checks to heart failure.

A major strength of this research was its design as a Māori-led study using Māori methodologies and being strengths-based and solutions focussed. A major limitation was the under-representation (two of eleven) of rural participants. Quantitative evidence regarding reduced access to health, including CVD, care for rural Māori was recently reported [63]. It would have been useful to explore this qualitatively here. However, we believe that our research provides unique and important information for both rural and urban dwelling Māori communities. We did not specifically collect information about people who had died in the community from an out of hospital cardiac event, which would have enriched the data considerably. However, some participants described instances of whānau members who had died. Important evidence about barriers and facilitators for all outcomes was attained. Finally, we acknowledge that there are similar issues regarding pre-hospital care for Pacific people living in NZ, and other Indigenous peoples around the world. Further research with Pacific and Indigenous peoples is recommended.

5. Conclusion

Māori experience systemic barriers in their journey to and through care after an OHCE that require interventions which improve the cultural safety of health professionals and provide more access to necessary resources such as community defibrillators. Throughout the journey through care, mātauranga Māori and rongoā centred wellbeing strategies were widely used by whānau. The approaches used should inform interventions and practice going forward to improve the experience and outcomes for Māori who have had an OHCE. Achieving equity is essential if we are to uphold the mana of people and their hearts.

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CRedit authorship contribution statement

Author 1: conceptualization, methodology, investigation, data curation, validation, formal analysis, writing - original draft, writing - review and editing.

Author 2: writing - review and editing, supervision, funding acquisition.

Author 3: writing - review and editing, supervision.

Author 4: writing - review and editing.

Author 5: writing - review and editing.

Author 6: writing - review and editing.

Author 7: writing - review and editing.

Author 8: validation, writing - review and editing, supervision, funding acquisition.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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