

Title: Whānau Māori explain how the Harti Hauora Tamariki tool assists better access to health services

Abstract

In this paper whānau Māori highlight how a Kaupapa Māori centred intervention (the Harti Hauora Tamariki tool) has improved interactions with health services. The Harti tool is undergoing a Randomised Control Trial at Waikato Hospital in New Zealand. As part of the RCT, the authors engaged in a series of qualitative interviews with whānau members of tamariki Māori (children aged 0-5years) admitted to Waikato Hospital's paediatric ward. Whānau who met at least one criteria for New Zealand's domains of deprivation were included. Using a Kaupapa Māori approach to the study, participants shared their views on barriers and facilitators to accessing health resources and primary care services. Our interviews highlight how the Harti tool, when administered in a culturally appropriate and respectful manner that prioritised relationship-building, enabled better connection to healthcare services. Prevalent in our analysis were connections to wider determinants of health and ways to reduce existing health inequities. To conclude the paper, we highlight how the tool has enhanced feelings of being in control of health with the potential to reduce the likelihood of a hospital readmission.

Keywords: Indigenous health; tertiary healthcare; social determinants of health; New Zealand

Introduction

The impact of colonisation on Māori, the Indigenous people of New Zealand, and subsequent colonial-driven approaches to health has been significant and is well documented elsewhere (Reinfeld and Pihama 2007). Health inequities are exacerbated by the unjust distribution of social determinants of health (Chin *et al.* 2018) and by experiences of racism (Harris *et al.* 2012). This legacy of colonisation in public health policy (Cram *et al.* 2003), combined with past negative interactions with health workers (Pitama *et al.* 2011), results in whānau receiving sub-optimal care at a primary health level. Additionally, insufficient access to adequate resources (Hodgetts and Stolte 2017), deepens reduced access to primary health care. Subsequently, Māori patients and whānau find themselves having to engage with tertiary health services in order to receive healthcare in a timely manner (Jansen *et al.* 2011).

In New Zealand, public health service design and delivery has been established in ways that privilege individualistic, clinical discourses and acute need (Gifford *et al.* 2017). By their very design, this type of public health service delivery disadvantages Māori (Came 2014). Westbrooke and colleagues (2001) note that Māori patients receive inequitable access to interventions and reduced quality of care, resulting in unmet Māori health needs. Māori families accessing hospital care for a child encounter systemic barriers (Bolitho and Huntington 2006), and Māori patients themselves report negative hospital experiences (McKinny 2006). Medical understandings of health, which privilege biomedical and reductionist models, dominate health research approaches (Masters-Awatere 2017; Masters-Awatere and Nikora 2017). This acts to subsume the experiences of marginalised groups into the dominant colonial narratives, which approach health issues from an individual perspective.

This article draws on Kaupapa Māori (KM) theory to explore the health-related experiences of whānau Māori with a child aged 0-5years admitted to hospital during the research period (July–November 2018). Specifically, we report findings from qualitative interviews of participants from the mixed-methods Randomised Control Trial (RCT) of the Harti Hauora Tamariki tool. The wider project seeks to evaluate the effectiveness of the Harti tool (a whānau ora-based assessment instrument designed to reduce health inequities) as delivered by Research Assistants (RA's) utilising a KM approach. Overall, 1100 tamariki Māori aged 0-5years admitted to Waikato Hospital under a paediatric medical team will be recruited for the RCT. The intervention (utilisation of the Harti tool during inpatient care and delivered by the RA) is randomly assigned, with the control group receiving usual care; that is, hospital-based care as per usual (no Harti tool).

Methodology and methods

A series of in-depth qualitative interviews were undertaken with whānau (n=15) of tamariki Māori admitted to hospital regarding their experience of hospital care. Interviews (n=24) are with whānau who received a Harti (n=7) and whānau who experienced usual care (n=8). Interview participants were purposively selected from the wider group of participants who had consented to the RCT. We intentionally set our inclusion criteria to prioritise the experiences of whānau Māori living with poverty

and marginalisation. Whānau members of tamariki Māori who met at least one criteria for New Zealand's domains of deprivation (Salmond *et al.* 2006) were invited via telephone contact to participate in a face-to-face interview regarding their experiences of their child's hospital admission and subsequent healthcare provision. Pseudonyms were assigned using a random name generator and are used throughout.

Quantitative research, with its focus on numerical frequency to argue generalisability, has not appreciated the ways that generalisation can occur within qualitative research (Hodgetts *et al.* in press). Imbued with culturally cognisant iterative and reflexive research processes (Hodgetts *et al.* 2018), we posit that this paper lays a strong foundation for arguing the current experience of hospital care for Māori whānau. As such the authors take an active position in supporting the importance and relevance of previously argued culturally appropriate care in health services. Drawing on Kaupapa Māori methodologies (Pihama *et al.* 2014; Masters-Awatere and Nikora 2017), we employed a participant-centred approach (Jones *et al.* 2013; Nikora *et al.* 2012). Specifically, interviews were held with participants in their homes, koha of food and a NZ\$100 supermarket voucher was given to participants in recognition of their time and knowledge. We intentionally engaged in a manner that communicated the value and worth of participants' experiences. The interview questions were embedded into conversation so that the interview progressed in a way that felt comfortable, non-intrusive, and enjoyable. Where possible, repeat interviews were conducted to further extend the conversation. These embedded practices reflect our Kaupapa Māori orientation to research engagements.

After every interview extensive field notes, including reflexive notes, descriptions of interactions, observations and remembered conversations, were taken. This information was utilised along with quotes generated during the research process. Each participant gave insights into healthcare, access, poverty and marginalisation that is of significance beyond their individual lifeworlds (Flyvbjerg 2006; Ruddin 2006). Our interpretative processes involved 'looking at' and 'looking behind' the words participants used in the construction of health narratives (Chamberlain 2000; Hodgetts *et al.* 2014; Kirkeby 2011). It also involved being aware of our positionality as researchers and the way in which this influences narratives told during research interviews (Radley and Billig 1996). Analytically, we drew on the notion of "researcher as bricoleur" (Denzin and Lincoln 2000), whereby knowledge creators draw together artefacts, narratives, and cultural contexts in the construction of meaning and new understandings (Hodgetts *et al.* 2018; Radley and Chamberlain 2001; Rogers 2012).

Results

Whānau members in the intervention group (i.e. who received the Harti tool as administered by the RA) reported positively on their experience. Participants' specifically mentioned the ability of the RA to engage with them as Māori. Subsequently, they felt treated with value, dignity, and respect. This experience contrasts with previous health-related interactions. For example, Mere is the primary

caregiver for her grandchild, who has a chronic illness. She is highly familiar with the hospital environment. In the quote below she comments on her Harti experience:

I found it really relaxing. Questions I could relate to [the RA] ... It was so refreshing to talk to somebody that knew where you were coming from ... It was really awesome that [the RA] took that time to explain. My partner, he is more understanding in Māori than he is in English, so for her to take that length of time was good for him. – Mere

Mere particularly enjoyed the in-depth conversations regarding health-related matters without having to translate for her husband (partner). His first language is te reo Māori, and Mere often found herself needing to act as his interpreter. Being able to converse naturally provided much-needed respite (Pitama *et al.* 2011). Overall, participants appreciated receiving culturally appropriate, respectful interactions, despite the personal nature of questions asked:

It was pretty cool. I liked it because it was someone to help me get it off my chest sort of thing, but wasn't going to judge me for what I was saying, so it was cool. I liked it. It wasn't a nurse that would write down notes and then the next nurse reads it and then asks you. So that is what made it easier for me. – Anahera

I think the questions are a bit too personal, but [the RA] made me feel comfortable answering them. I suppose it depends on who is delivering it. – Penny

She [the RA] did tell me that...some people think they are intrusive questions before she asked them and stuff. She made me feel comfortable. – Astra

Key to “making people feel comfortable” were everyday Kaupapa Māori practices such as whakawhanaungatanga (establishing shared connections), being conversant in te reo Māori, and taking the time necessary to cover questions and comments thoroughly instead of rushing tool delivery (Pitama *et al.* 2011; Jones *et al.* 2013).

Across both groups, participants mentioned their reluctance to intrude on busy, rushed staff with their concerns and questions. Even where participants did request assistance, they often had to wait some time before a health professional arrived. This sense of “not wanting to disturb staff” left participants feeling isolated and alone. Having an RA spend time with whānau in a calm and relaxed manner while they engaged with the Harti tool was a welcome change. Participants repeatedly commented on their appreciation for such an approach:

[The RA] even brought me lunch the next day. I felt like I really just had a friend to talk to. I was up there by myself and going crazy in that little room ... it [the Harti] was real good. Yeah. Like they actually cared. When you have kids in there you don't get fed at the hospital, so it was good having someone come in – especially if you don't have anybody up there and you are just stuck. I thought it was quite good. – Jodie

She [The RA] went through a lot of things with us, it was really good too. Like the house is one of them she went through. She made sure that we were up to date with everything that

had to do with her, like assistance from everybody. Yeah ... So we are really interested in that Tamariki Ora, and the Whare Ora. Yeah, she referred us to Quit Smoking ... She was awesome. Really. I mean what took maybe was supposed to have been half an hour took us maybe two hours. It was awesome. Yeah, it was just cool. Made sure that we knew about this, we knew about that or if we were hooked onto this – right down to Work & Income, if we were getting that and if we knew that it was there. It was awesome. She was good. – Mere

The combination of listening work, self-autonomy, and genuine care for their well-being as Māori left participants feeling valued with a renewed sense of confidence for navigating additional services.

As well as relational skills, the immediate practical support offered to those in receipt of the Harti tool was also valued. One such example is the provision of children's car restraints and booster seats (colloquially referred to car-seats) to whānau whose current car-seats were broken, out-of-date, or otherwise unsafe. For low-income whānau in particular, not being able to afford important items such as car-seats leaves a sense of shame and of being a "bad mum". Aroha comments:

I really can't afford to get a brand new one and I've been asking on PIF [Pay It Forward, a Facebook page] and I was telling [name] about it, and the next minute she walks in with a car seat for me. I was gob smacked man. Not very many good things like that happen to us. It was awesome. – Aroha

The provision of a safe, new car-seat was highlighted as significant positive. Jodie had been using an old (and unsafe) car-seat she had found in her in-law's garage. Receiving a new car-seat was also significant for her:

I have told everyone – holy shit, when I went to hospital I got this and I got that. I got hooked up with all this! I have messaged my Mum and my cousin. Holy shit cuz, you know I got a free car seat when I was at hospital! – Jodie

Having a brand-new, safety regulation-meeting car-seat eased both Aroha and Jodie's worries, supported their parenting practices, and was a tangible reminder of care for their families' well-being. In general, having a tool delivered in a culturally enhancing and affirming manner concurrently with practical support (and referrals to appropriate services), left whānau members feeling cared for, confident, and better able to navigate health services.

During conversations with usual care participants it became clear that whānau were content with the bare minimum of care; i.e. that their child received clinical treatment. Celia's experiences starkly exemplify this: her first daughter died in hospital 4 years prior and Celia still carries a sense of receiving second-rate treatment. Celia explains:

They [medical staff] weren't actually listening to our point of view on what we wanted, but doctors were saying there is no chance of her actually surviving because she is only young, otherwise they would drill in her thing to make the blood flow. It was not what we wanted to hear and it was not what we wanted, we had a choice of switching her life support off and letting her go. Us as parents we didn't want to. After all that happened we kind of blamed the hospital ... The care was OK, but we thought that they could have done something more to

actually help her stay alive. The risk was 50/50 and so we just decided to pull the plug and kind of hated hospitals ever since then. – Celia

Despite not yet having a diagnosis for her son's condition, no treatment plan, and being denied access to the child's playroom at hospital, Celia was pleased with the healthcare her son received. She was grateful that her son was alive and that staff were taking her concerns seriously. Her bar for successful healthcare provision is based on answering the question; "Did my baby die?" Celia alludes to this below:

Then in the back of our minds we were like if we end up staying here [mouldy apartment] we are going to lose him like we lost our daughter. Everything in the back of our mind was we really need to get out of here otherwise he is going to get sick. Eventually we moved and now he is getting sick. He has his seizures now and again. But he hasn't had one since he has come out of hospital, so hopefully we are doing it right this time. Doing his health and eating a bit right this time. – Celia

Such comments reflect the individualisation of healthcare and the historical poor treatment of Indigenous women and children within New Zealand's public health system (Blakely *et al.* 2004; Pihama *et al.* 2014). Underlying bias and deeply entrenched racialized beliefs lead to second-rate treatment and increased health inequities (Harris *et al.* 2012). Ensuring equitable health service provision services requires creating new, overwhelmingly positive experiences that erase the cumulative negative impact of past ones and raise the bar of expectation (Arlidge *et al.* 2009; Pihama *et al.* 2014).

Another example of health inequities and the importance of taking a culturally supportive approach are referrals to the Quit Smoking programme, a nationally-funded initiative that aims to reduce the incidence of tobacco smoking for whānau Māori. Tobacco-smoking participants in the usual care group were not always referred, while others were treated in an alienating manner:

We'd both love to quit smoking but smoking so long it is just hard. We have tried to go cold turkey and it doesn't work. To be honest, it doesn't work. Especially when we are both trying to give up and we both are at each other and then...it is not a good look. We are still smoking. Maybe one of us will have to do it first and then the next one. – Celia

Celia and her partner are ideal candidates for Quit Smoking and, with support, would likely achieve their goal of being smoke-free. Celia was not referred while in hospital with her son, and was unaware she could access the Quit Smoking programme. Taryn felt badgered by a health professional, leaving her reluctant to engage with services:

[Doctor] wasn't worried about our son, he was just more worried about us. He was even saying how much do you earn? He was even talking about how much do you spend a week on cigarettes. I didn't even get to tell him that we're not heavy smokers, and then he was like – I bet you it is like \$70 a week. \$70 a week you could have been saving that for your family. Do you¹ want to go on holidays, do you want to eat? I was just like... we've just finished a

¹ You is a colloquial term in New Zealand, used to refer to more than one person

date night. My Mum was fuming. I thought maybe this is what it is at the hospital, this is normal. My Mum was like – this is not right! I feel like us being Māori and we're smokers, I feel it was kind of an aggressive thing, I have to have this conversation with everyone, so I'm just going to be an arsehole. – Taryn

While well-intentioned, shaming people is a misguided method that achieves little (Walker 2014) and contrasts strongly with the approach undertaken by the RA's. Aroha, whose child had been hospitalised 3 times this year and who received a Harti during the third hospital admission, comments on her success at reducing her cigarette use:

I have been thinking about it for a while but I've always been putting it off – man, I'm going to start going crazy and I've got the kids to look after by myself. No! But it has actually been really good, and I'm glad that she [the RA] gave me the push to do it [and] referred me to the Quit Smoking coach, so she comes around every week to talk to me as well, so that is cool for support ... I mean, if you were around at the first ... I might be smoke free already. – Aroha

As a result of engaging with the Quit Smoking programme, Aroha has reduced her cigarette use from 10 cigarettes a day to 4. While not all whānau who received a Harti also engaged with Quit Smoking, for those, like Aroha, who are ready to address their tobacco use, being treated in a culturally supportive and encouraging manner resulted in a positive uptake of services.

Discussion

While each of these interviews were the result of a child's admission to hospital, the interactions with staff delivering the Harti tool highlight the ways in which access to primary health care was improved for these whānau Māori. Three key interconnected strategies were identified: relationship, matching, and connections. Each of these are explained below.

Firstly, tool delivery prioritised relationship-building with whānau over accomplishing tool protocols. This KM-based approach is in direct contrast to the individualistic clinical focus dominating New Zealand healthcare provision (Came 2014; Gifford *et al.* 2017). Perceptions of “busy” clinical staff contribute to whānau reluctance to request assistance (Arlidge *et al.* 2009). The absence of relational connection with hospital staff exacerbates their sense of discomfort and isolation (Stewart *et al.* 2014). For whānau who had experienced hospital admissions prior to receiving the Harti tool, the difference was like a ray of sunshine on a cloudy day. The example shared by Mere, of an RA who took the time to thoroughly go through the Harti tool, reflects the care given by RA's to patients and their whānau, contrasts markedly with the approach of clinical staff charged with hospital service delivery. Despite the personal nature of questions within the Harti tool, participant's repeatedly commented that the respectful and culturally appropriate practice of RA interactions resulted in open and honest answers to what would otherwise be perceived as challenging and alienating questions. It was clear that a high level of trust had been established by the RA's. Our findings are congruent with previous research (Jones *et al.* 2013; Kerr *et al.* 2010; Kidd *et al.* 2013) that highlights engaging in KM

processes such as whakawhanaungatanga, koha, conversing in te reo and, taking time to fully answer questions results in increased patient engagement and higher quality interactions.

The second key strategy relates to the matching of key indigenous worker (the RAs) with participating whānau. Matching refers to the purposeful selection of researchers to “match” variables such as ethnicity and gender with research participants (Patton 2002). Comments from whānau Māori in the results section of this paper highlight the benefits of cultural matching for reducing healthcare inequities. Consider Mere, who talked at length about how affirming she found her interactions with the RA. One of the most “refreshing” aspects for Mere was the ability of the RA to speak directly to her husband in te reo Māori. Subsequently, Mere was able to relax with the assurance that her husband could have matters explained directly to him. Our findings extend the work of Pitama *et al.* (2011). If more healthcare professionals were able to “match” their patients and converse in te reo Māori, which is an official language in New Zealand, this would relieve the additional burden faced by whānau members of needing to act as unpaid translators.

The final strategy is summarised as connection. Essential to creating and maintaining connections with whānau is an ability to listen (Stevenson *et al.* 2016), as well as the capacity to display genuine care for participant’s well-being (Walker *et al.* 2008), followed by action where need is identified. In the provision of car-seats, as articulated by Aroha and Jodie, we hear of their surprise and joy to receive items for their child’s safe transportation. The car-seats act as a tangible reminder of care and connection that remain long after their hospital visit (Olsen 2003). In Aroha’s quotes regarding her referral to the Quit Smoking campaign, we see an example of the ability of the RA’s to connect whānau with external services. Mere also mentions additional health services that the RA was instrumental in connecting her to.

There are multiple levels of connection presented in this paper: clinical staff, hospital and primary health services, external services. Here, the RA was essential in linking these levels together with patients and whānau with respect to their disclosed needs. The relationship established with the Research Assistant was an essential component to engagement with services. For whānau, having someone who: did not judge their specific situation; took time to understand their concerns; provided practical assistance (such as a car-seat) contributed to feelings of personal connection that enhanced participants’ sense of self-worth. The seed planted by these efforts built feelings of self-autonomy and gave confidence to whānau to navigate the additional health services.

In contrast to the highly connected nature of whānau who received the Harti tool, whānau randomised into the usual care group did not experience the same aspects of relationship-building, matching, and connection. Instead, they reported feelings of negative judgement by well-intentioned staff whose discourse shamed rather than assisted. Taryn’s experience exemplifies this. Additionally, the narratives provided by whānau who received usual care indicate that they were equally satisfied with their level of care to those who received the Harti – even though the provided care was very different.

When the bar is so low that a positive experience is determined on the basis of whether or not the child remains alive at the end of the admission, such as in the case of Celia, trust in the public health system is not very high (Harris *et al.* 2012). The experiences of the usual care group, and of the participants from cited studies, provide a clear contrast to the positive gains made through utilising the Harti tool in a KM manner.

Conclusion

This paper extends on Kaupapa Māori theory through embedding a Kaupapa Māori approach to an applied research project. We have purposefully engaged a Kaupapa Māori lens when designing the bigger Harti project. As such we applied the same lens when considering the experiences of whānau Māori shortly after the hospital admission of their tamaiti. Our core goal with the paper has been to evolve understanding of Kaupapa Māori as appropriate in both the health service delivery design of the study and its subsequent application in the research process. Central to our approach has been the recognised importance of contributing to previously articulated arguments for culturally appropriate and relevant processes in health research.

Cognisant of the individualistic nature of health service provision, this paper highlights strategies for mitigating unmet needs. Our findings highlight ways it is possible to provide high-quality care for Indigenous people within current healthcare environments. A key influence identified here were the staff who were willing to take the time necessary to establish a relationship that is centred on the needs of whānau (rather than the clinician). The willingness of whānau to engage with hospital staff had flow on effects when engaging with primary care services. Namely, that having a relationship with an Indigenous health worker who evaluated individual situations, took time to understand concerns, and provided a clear pathway for additional services and practical responses, contributed to a sense of autonomy and self-worth beyond the hospital setting. The resulting feelings of being in control of health enhanced wellbeing.

Indigenous health workers influenced the ways in which the administration of this tool is delivered and worked towards reducing negative hospital experiences for whānau Māori. As demonstrated here, positive interactions at tertiary level care facilitated better engagement with primary care services and have the potential to reduce the likelihood of a hospital readmission.

Glossary of Māori words

To assist the reader, we include here a brief definition of relevant Māori terms. Unless otherwise indicated (by an asterisk) all definitions were taken from the noted citation (Moorfield, 2011).

Aotearoa = (location) used as the Māori name for New Zealand.

Hauora = (noun) health, vigour.

Kaupapa Māori (KM) = a philosophical doctrine, incorporating the knowledge, skills, attitudes and values of Māori society.

- Koha = (noun) gift, present, offering, donation that maintains social relationships and has connotations of reciprocity.
- Māori = (noun) Indigenous person of Aotearoa New Zealand.
- Tamaiti = (noun) child, boy - used only in the singular.
- Tamariki = (noun) children - normally used only in the plural.
- Tamariki Māori* = children of Māori heritage.
- Tamariki Ora* = ("Well Child") is a free service that is offered to all New Zealand children from birth to five years.
- Te Ao Māori* = the Māori world.
- Te reo Māori* = language of the Māori (indigenous) people.
- Waikato = (personal noun) collective name of the tribes living in the Waikato Basin. Also the name of the river from which they take their name.
- Whānau = (noun) extended family, family group, a familiar term of address to a number of people. Sometimes used to include friends who may not have any kinship ties to other members.
- Whānau Ora* = ("family health") is a major contemporary indigenous health initiative in New Zealand driven by Māori cultural values.
- Whanaungatanga = (noun) relationship, kinship, sense of family connection - a relationship through shared experiences and working together which provides people with a sense of belonging.
- Whare Ora* = is an initiative that supports whānau to create healthier homes that are warmer, drier, and safe.
- Whakawhanaungatanga = (verb) process of establishing connection. Extends to others to whom one develops a close familial, friendship or reciprocal relationship.

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