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Health literacy in action: Kaupapa Māori evaluation of a cardiovascular disease medications health literacy intervention

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Abstract

The healthcare system is complex and challenging to virtually everyone but more so to those who are marginalised, impoverished, and isolated—all factors that exacerbate health literacy barriers. This article reports on an analysis of qualitative data collected for a kaupapa Māori evaluation of a *Cardiovascular Disease Medications Health Literacy Intervention*. The evaluation study involved a kaupapa Māori evaluation of the effectiveness of the intervention and the discussion of wider learnings in relation to health literacy interventions with Māori and other Indigenous communities. Findings are grouped into three key themes: Whakaaro, tūrangatira, and whanaungatanga. Whakaaro—fluidity of understanding—refers to the importance of maintaining patient medication knowledge and nurturing relationships between patients and health professionals. Tūrangatira—presence—refers to changes in participation practices between patients and health professionals, as well as the limitations and outcomes of the intervention approach. Whanaungatanga—building relationships—covers the intervention structure and design and the role of the research nurse. This study highlighted that the responsibility for improving health literacy lies with everybody in making substantial systemic change. In this intervention, the focus of responsibility for building health literacy skills in patients and whānau *(family)* sat with front-line health professionals.

Keywords

cardiovascular disease, evaluation practices, health literacy, Indigenous, kaupapa Māori evaluation, medications

Introduction

Persistent health inequities exist in New Zealand (Aotearoa), including significantly higher rates of "all-cause mortality" and shorter life expectancy for Māori compared with Tauiwi or non-Māori (Ministry of Health, 2015b, 2017). Cardiovascular disease (CVD) is the leading cause of morbidity and mortality and a key factor in disparities between Māori and Tauiwi, after adjusting for socio-economic status and timing of diagnosis (Bramley, Hebert, Jackson, & Chassin, 2004; Curtis, Harwood, & Riddell, 2007; Ministry of Health, 2011; Robson & Harris, 2007). Reducing Māori CVD rates and inequities between Māori and non-Māori are urgent health priorities (Robson & Harris, 2007). An added layer of inequity also exists in remote and rural areas, which often have a higher proportion of Maori.

Health literacy

Health literacy has been widely and variously defined, for example, a systematic review found over 17 explicit definitions and 12 conceptual frameworks (Sørensen et al., 2012). In Aotearoa, health literacy has been defined as "the capacity to obtain, process and understand basic health information and services in order to make informed and appropriate decisions" (Ministry of Health, 2010, p. 1). While this definition focuses on individual capacity and skill, there has been a shift towards social and/or systemic factors that shape skills and ability (Pleasant et al., 2016). Engaging with health literacy may entail a focus on individual functionality, the testing of professional skills, and systemic demands and complexities (Pleasant et al., 2016). Social and cultural considerations, particularly those relating to indigeneity, are rarely discussed in the literature (Carlson, Moewaka Barnes, Reid, & McCreanor, 2016).

The *Cardiovascular Disease Medications Health Literacy Intervention* research project (Crengle et al., 2014) aimed to strengthen patient health literacy knowledge, skills, and practices among Indigenous peoples in Aotearoa, Australia, and Canada. A published article from

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the first phase of the research project (Lambert et al., 2014) argued that many health professionals had a narrow patient-focused understanding of health literacy and limited understanding of the barriers that Indigenous patients face within healthcare environments. Crengle (2016) reported that customised sessions and associated resources about CVD medications, delivered by Indigenous health professionals trained in health literacy practices, resulted in significant improvements in participants' knowledge of their medications.

Health literacy is embedded in social and cultural practices that are context-bound, rather than skills held by individuals (Carlson et al., 2016). Rudd, McCray, and Nutbeam (2012) acknowledged the importance of context in health literacy and called for consideration of patient agency and participation. Papen (2009) stressed critical analysis of information, social determinants of health, and engagement in collective action. Ross, Culbert, Gasper, and Kimmey (2009) suggested that strategies to improve health literacy must include multi-level approaches that practice collaborative, communitarian partnerships among people. However, these studies, while valuably contextualising key concepts, are mostly drawn from northern hemisphere contexts without consideration of the challenges presented by tensions between Indigenous and settler peoples.

In Aotearoa, it is understood that the environment of healthcare organisations can affect the ability of patients to navigate, understand, and act on information within services (Ministry of Health, 2015a). The value organisations place on health literacy plays an important role in the quality of care experienced by patients. Health literacy practices include actively reducing health literacy barriers for patients, providing culturally safe environments, and focusing on quality health professional–patient engagement (Koh et al., 2012; Koh, Brach, Harris, & Parchman, 2013; Walsh, Shuker, & Merry, 2015).

Causes of inequity

Health inequities are systematic differences that have been analysed and evaluated as unjust and unfair (Pacquiao & Douglas, 2019). Many possible explanations of inequities in health outcomes are proposed in the literature (Axelsson, Kukutai, & Kippen, 2016). Māori are over-represented in mortality and morbidity statistics, but explanations as to why are limited, and research specifically focusing on CVD is rare.

The social conditions within which people are born, grow up, work, and die play an important role in the health status and outcomes of individuals and groups (Marmot & Wilkinson, 2006). The World Health Organization (WHO) Commission on Social Determinants of Health (2008) provided a conceptual framework depicting the situational and relational impacts of social determinants on the well-being of individuals, communities, and populations. Moewaka Barnes et al. (2013) extended this framing to include an analysis of the effects of colonisation and racism on health outcomes.

Māori CVD outcomes can be broadly located within four domains: macro—governance, colonisation, cultural and societal norms, and policy; mezzo—community, place, and whānau *(family)*; micro—material, psychosocial, behavioural, and biological; and systemic (exo)—health services located within life-course and intergenerational conditions (Moewaka Barnes et al., 2013). Inequities are exacerbated by the lack of control Māori have in shaping their futures, and the "mal-distribution of health-promoting and sustaining social commodities" (Brown et al., 2010, p. 265) crucial for the development and delivery of health systems and services. Although Māori are frequently identified as having the highest risk for and prevalence of CVD, few studies or interventions have involved Māori solutions, community engagement, and action.

This article focuses on intervention within the exo domain of health systems and services. Substantial research-based evidence supports the argument that, in order to improve Māori health status and outcomes, health systems and services need to be based on Māori social structures, delivery systems, health contexts, and personnel (Cram, 2007; Masters-Awatere, 2015; Matheson et al., 2018; Moewaka Barnes, 2012; Penney, Moewaka Barnes, & McCreanor, 2011).

Role of health services

Health systems, which include policies, resources, and services, play an important role in determining differential outcomes of illness (Solar & Irwin, 2007). Within this system, service features that mitigate health inequities include preferential health benefits for socially marginalised groups, inter-sectoral action across providers, need-based resourcing distribution, culturally responsive healthcare, and health equity policies (Benzeval, Judge, & Whitehead, 1995; Gilson, Doherty, Loewenson, & Francis, 2007).

Culture plays a vital role in the quality of care, and health services have a responsibility to provide appropriate care (Reid & Robson, 2007). In Aotearoa, the social and cultural acceptability of health services are strongly recognised as key factors in accessibility of services, reflecting government obligations under Te Tiriti o Waitangi (Came, 2012). The social and cultural acceptability factors are written into the New Zealand Public Health and Disability Act 2000, creating a greater emphasis on primary healthcare (Sheridan et al., 2011) and providing mechanisms to enable Māori decision-making on, and participation in, the delivery of services. Factors related to patient and service interactions that contribute to poorer health outcomes for Māori CVD include inadequate prescribing of effective therapies (Riddell, Jackson, Wells, Broad, & Bannink, 2007; Riddell et al., 2008), inadequate follow-up of individuals at risk (Riddell et al., 2007), and poor communication by healthcare professionals (Jansen, Bacal, & Buetow, 2011; McCreanor and Nairn, 2002a, 2002b).

Response to treatment

Research into medication use in Aotearoa revealed people have a range of understandings and practices with regard to treatments: limited knowledge of medication in treatment regimens, non-completion of treatments, stockpiling medication, or sharing medications with others (Carlson, 2010; Dowell, Snadden, & Williams, 2018; Hodgetts et al., 2011; New Zealand National Advisory Committee on Health and Disability, 2007). Adherence to prescribed medications is an ever-present and complex problem (Thornley et al., 2011). It is particularly prevalent for those with CVD, the management of which is often multi-faceted and requires high doses of multiple long-term treatments (H. S. Wilson, Hutchinson, & Holzemer, 2002).

Although Indigenous peoples are commonly described as “less compliant” than non-Indigenous (Crengle, 2009), the literature is sparse. A qualitative study examining healthcare journeys of Māori patients with ischemic heart disease found that, in contrast to Māori patients’ accounts of being willing, attentive, and proactive in relation to their healthcare, clinician explanations focused on “non-compliance”, which they blamed on financial constraints, self-destructiveness, and ignorance (Penney et al., 2011). Similarly, McCreanor and Nairn (2002b) identified Tauiwi clinician bias against Māori that influenced beliefs that “non-compliance” was related to Māori culture. These accounts have serious implications for Māori health outcomes because they place responsibility on individuals, allowing health professionals to abdicate responsibility for their practices (Kerr, Penney, Moewaka Barnes, & McCreanor, 2010; Penney et al., 2011).

This study evaluates the effectiveness of the *Cardiovascular Disease Medicines Health Literacy Intervention* for Māori who were involved and explores the contribution kaupapa Māori theorising may offer to the evaluation of health literacy activities. We report on analysis of qualitative data from a kaupapa Māori evaluation of a *Cardiovascular Disease Medicines Health Literacy Intervention*, focusing on the experiences of Māori patients and health professionals. The evaluation was a part of the first author’s (T.C.) doctoral evaluation of the effectiveness of the intervention and the implications for health literacy interventions with Māori communities.

Methods

The primary objective of the parent project was to develop and trial an intervention that focused on improving health literacy in Indigenous (in Aotearoa, Māori) patients and their whānau in relation to CVD medications (Lambert et al., 2014). Two Māori organisations were involved in Aotearoa—an urban provider, Te Hononga O Tāmaki Me Hoturoa (Te Hononga), and a rural provider, Ngāti Porou Hauora (NPH)—and the study was run by Māori health researchers and the providers (Carlson, Moewaka Barnes, & McCreanor, 2017).

The research was carried out between 2013 and 2015 and was cited in the Ngāti Porou rohe which Ngāti Porou Hauora serves. The area has the highest overall mortality rate in Aotearoa, 66% above the national rate. The Māori mortality rate is 12% above the national Māori rate. Moreover, 91% of Ngāti Porou rohe live in deprived areas compared to both the Tairāwhiti at 52% and 20% for all of Aotearoa (Tan, 2016).

Patients were eligible to participate in the intervention if they were Māori adults 20 years or older, enrolled with the providers, and had been diagnosed with angina pectoris, myocardial infarction, transient ischaemic attacks, or stroke. In addition, they had to be taking at least two of the following types of medicines: statins, aspirin, beta blockers, or ACE inhibitors (Crengle et al., 2014). Furthermore, patients had to be registered with a Ngāti Porou Hauora health centre in the northern part of the extensive rohe (Iwi area) that the organisation serves.

The intervention, the development of which was informed through focus groups with some of the participating organisations’ patients and health professionals, consisted of three educational sessions delivered by a Māori research nurse at a venue of the patient’s choice—in most cases, their home. The nurse had received training in health literacy and related adult education principles, including strategies to support knowledge acquisition and skills development based on adult education principles.

The first and second sessions were one week apart, followed by a final session a month later. Each session ran for 30–75 min. Each patient was provided with a CVD information booklet, information about medication use in general, and the four types of CVD medication (statins, aspirin, beta blockers, and ACE inhibitors) in particular. The information given was tailored to the medications patients were taking. During the session, an interactive tablet application was used to ensure the nurse covered CVD medication information in a structured and consistent manner. A personalised pill card with images of the participant’s medications was also provided. The research nurse also conducted pre- and post-session data collection in relation to medication knowledge and health literacy practices as part of each of the three sessions described above.

Evaluation

Kaupapa Māori evaluations (KME) are collections of culturally embedded activities that endeavour to contribute towards Māori agendas (Masters-Awatere, 2015). These activities assess the quality and value of interventions, making judgements against clear aims, objectives, goals, and aspirations. The purpose of this study was to carry out a KME of the *Cardiovascular Disease Medications Health Literacy Intervention* outlined above with a few of the participants in the NPH site only. The evaluation aimed to benefit NPH and the community it served by exploring the effectiveness of the intervention (as defined by the NPH patient participants and selected health professionals working with the organisation). This involved semi-structured interviews with 6[1] of the 56 patients participating in the intervention plus three of the health professionals involved.

The KME included impact and outcome components to identify experienced strengths of the intervention and suggested improvements. The evaluation specifically aimed to identify patient and whānau (a) experiences of the intervention; (b) reports of changes in medication practices; (c) changes in understandings of CVD medications; (d) satisfaction with the intervention, including interactions with research nurse, use of CVD medication booklet, electronic tablet application, and pill card; and (e) suggestions for potential improvements.

The KME approach focused on aspirations of co-ownership, mutually beneficial outcomes, and shared power by prioritising the patients' voices to shape the evaluation criteria for defining the intervention as "effective". Invitations to participate were part of the collaborative process. NPH were involved in methodological decisions, interpretation of data, and the analysis and discussion stages of the evaluation. The research was approved by Massey University Ethics Committee (MUHECN 12/095), and patient and health professional interview schedules were developed with feedback and approval from the NPH research co-ordinator and other parent project team members.

Patients. Three 60 to 120 min semi-structured, face-to-face interviews were conducted with each of the six patients and their attending whānau, with whom the research nurse also had delivered the parent project intervention (Crengle, 2016). The three interviews were carried out after the six patients' first and third intervention sessions, and 6 to 7 months after the intervention; a total of 18 interviews.

Health professionals. Three NPH health professionals directly involved with the parent project intervention trial were interviewed: the research nurse, kaiāwhina (*community support worker*), and general practitioner-based at the NPH Matakaoa and Tikitiki Health Centres in those communities at the northern end of East Coast. These interviews were 60 min in duration, semi-structured, and face-to-face, and were carried out immediately after the completion of the intervention and then again 6 to 7 months later.

Analysis

Interviews were audio-recorded and transcribed verbatim. Thematic analysis (Braun & Clarke, 2006) was used to identify, explore, and describe patterns within the data. This method allowed the researcher to draw on content, rhetorical, discursive, and narrative analytic techniques as required (Yanchar, Gantt, & Clay, 2005).

Feedback was sought from NPH on the draft theme development and findings from analysis of the interviews. The NPH research advisory group included a pākeke (*Elder, providing cultural advice*) (Māori), a NPH board member (Māori), the NPH research coordinator and "local investigator" on the parent project team (Pākehā), a manager (Māori), a chronic care nurse (Māori), a general practitioner (Pākehā), and a kaiāwhina (Māori).

Health literacy in action

Analysis of the data identified five core themes. This article concentrates on three core themes with a particular focus on the six patients' experiences of the health literacy intervention in action, its effectiveness, and potential ways to improve and implement it as "service as usual". The three core themes of Whakaaro—fluidity of understanding, tūrangatira—presence, and whanaungatanga—building relationships were selected because of their interconnection with the relational prominence of health literacy in action. They focus on patient experience, understanding, belief, and practice in relation to the intervention.

Whakaaro—fluidity of understanding

Patients spoke about building knowledge around their CVD medications during the intervention and gaining a sense of understanding of what their medications were for, including generic and brand names, categories and sub-categories, their look, how to administer them, and side effects:

> She [research nurse] more or less told us what they're really for. The Metoprolol slows your heart down and you're supposed to have it every 24 hours. I didn't know that. Like, I used to have it sometimes at lunch time. It makes your heart play up if you don't take them. And that one's for life, gonna have to keep taking that Metoprolol. I didn't know that. (Hemi; first interview)

This excerpt reflects other patients' accounts in which they spoke about gaining understanding from interactions with the research nurse and learning what their medications were "really for". It is clear that Hemi has learned about his medications when he articulates what his medications are for. Beyond this excerpt, Hemi indicated that what he was told about his medications before the intervention was not sufficient. There was inadequate information given at the time of prescription, despite the fact that some were life-long medications.

Patients spoke about becoming more aware of their medications' side effects and feeling a sense of relief at having their questions answered by the research nurse:

> . . . now that I'm doing this (laughs) [intervention] I want to learn more about myself. You know. I'm starting to ask questions yeah, before oh well I just accepted [the information] . . . now you ask for second opinions, not just take his [the GP's] word. (George; second interview)

For George, the health literacy sessions ignited curiosity to expand understanding—a shift from acceptance towards practices of reflection and asking questions. He suggests that participation in the intervention gave him confidence to ask for a second opinion.

Health professionals spoke about patients' knowledge increasing as they learnt their medication names and categories, making it easier to confirm what medications they were taking. The local General Practitioner (GP) gave his account:

> It made it a lot easier to figure out what they were taking. I think adherence is probably the biggest thing I struggle with: "What are you taking?" "Oh, I forget my pills," full stop. And then it became: "Oh what are you taking?". . . They have their charts out and "I'm taking these ones and these ones . . . and I remember what they are called." So that helped. (Matt; first interview)

Matt spoke about a shift in conversations with his patients, from silence (“full stop”) to patients utilising the intervention resources and communicating their understandings.

All patients spoke about changing their behaviour in relation to their medications. Patients started monitoring and recording health information and having conversations about their medications. All spoke of talking about their medications with whānau and whanaunga *(kin)*, where previously they had not. Conversations were not only occurring in the home but also in clinic waiting rooms and more public spaces like their local Marae:

> We just say “how’re things going? How’s the pills?”, then we say “don’t forget your pills”, whaikōreo (speeches) on the marae and say to the old people “don’t forget to take your pills” [laughing]. I make sure I tell everyone “don’t forget everyone, take your pills tonight”, throw it at each other, just joke about it. But we mean it seriously though aye. (Kiriama; first interview)

The actions of Kiriama, in sharing his advice in public settings, underscore the message of collective responsibility among those present to “take your pills tonight”; his actions embody urgency as well as manaaki *(support)* and aroha *(compassion)* for his peers, his people.

In the third round of interviews, patients widely acknowledged that the intervention was valuable, to be shared and available for all, including as a preventive measure for those that have not had “an event”—heart attack or stroke:

> I think it’s a good thing. I think it makes us more aware of how important it is for us to know what we’re swallowing these pills for . . . it made me realise how important it is to know. . . I think it’s a good thing, but they should look at not only us, but all our people, especially those in their fifties-up. (Kiriama; third interview)

Overall, patients spoke about the significance of the intervention for them in relation to how they gained an understanding of the importance of taking their medications. However, as with most forms of human understanding, the newly attained CVD medication knowledge wavered over time; it was experienced as a fluid rather than fixed or static state:

> **Kiriama:** We did understand what the medications are for, but now that I’ve got new ones.
>
> **Interviewer:** So are you uncertain about taking your medications now?
>
> **Kiriama:** Nah, yeah just back to swallowing them.
>
> **Interviewer:** What would support you in your understanding more?
>
> **Kiriama:** It’s hard we don’t have a doctor anymore. (Third interview)

Kiriama made it clear that he does not have the resource, knowledge, or skill to understand his new medications and has receded “back to swallowing them”.

Medication knowledge is complex, and the skills involved in applying that knowledge adds additional barriers. Patients and whānau are being asked to remember the information, understand it, apply it, and analyse and evaluate what is happening (side effects) in order to identify its importance and then, if necessary, to have a conversation with a health professional (Adams, 2015). In this intervention, knowledge was attained and expressed for moments in time, but had to be nurtured to be maintained in relation to changing and evolving health circumstances. This underlines the importance of the relational nature of the intervention, specifically the relationship building with the research nurse. In turn, this needed to be understood and sustained by health services; ideally, all health professionals would be trained and supported to use HL approaches and services.

Tūrangatira—presence

Tūrangatira is about participation practices between patients and health professionals which was an important focus of the intervention. Patients were encouraged to become more assertive and ask questions during their engagement with health professionals. Through the intervention, patients began to enquire about their medication side effects in consultations with the GP. The kaiāwhina shared her experience:

> **Interviewer:** Any feedback? Are they still on their medications? Still going okay?
>
> **Mereana:** Yes. I went to visit one of them and they said that the doctor changed their medications . . . they realised they could come back to the doctor and say that they were unhappy with it, and they did . . . one of them had like a cough, and he didn’t know it was related to the pill, the medication he was taking. Then he changed it and the cough went away. (Second interview)

In Mereana’s experience, patients learnt through participation in the intervention that they were entitled to ask questions and revisit medication scripts with their GPs. After many years of taking long-term medications, this was a powerful revelation for all patients, but depended on the knowledge bearers to pass on the information. A shared realisation that responsibility for health literacy lies with everybody is required to make substantial systemic change.

During the intervention, patients learned more about their medications and became familiar with their prescribed regime. In one instance, this led to discovery of a prescription mistake which she subsequently corrected, as described to the research nurse:

> I went and grabbed my [CVD medication booklet] and thought right I’m going to suss it out and see which one I have to take and when, I turned them over, it actually got breakfast wrong . . . I checked them and in the book it says that some have to be taken at night and not in the morning. (Joan; second interview)

The information that the patients attained in the sessions with the research nurse, coupled with the medications booklet, supported patients to exercise their health literacy skills to review and improve medication use. Patients made positive steps towards self-care in monitoring and reviewing medications.

Another aspect of knowledge acquisition was patients' lack of medication knowledge in relation to engagement practices with their GP. The research nurse reflected on her experience:

> I don't think that's necessarily the people not knowing about their meds, I think that's because they found that the doctors have been unapproachable, or they felt that they've taken up their time and they just felt that they've been a burden . . . I think patients have to be a bit more assertive, to come forward, talk about your pills, anything that you're unsure of, you have a voice and you have a right to speak. (Jen; first interview)

The nurse implies that the solution lies with the patient. However, engagement in the consultation room is about more than two individuals talking, where the doctor has power and the patient has power; it was about power acknowledgement and shift. The voice of the patient may not be about patients' right to speak and tone, content, and context. Rather, it may be about who is willing to listen with compassion and contextual and cultural understanding. The intervention may have provided patients with a platform of baseline knowledge about their medications and enabled them to execute their understandings in a way that was visible to health professionals. This approach, however, may have limited patients' whanaungatanga *(relationship, kinship, connection)* experience in health encounters, as they carried the weight of changing engagement practices:

Interviewer: Since the intervention, do you feel more confident about asking questions?

Hemi: I've always asked questions. So that hasn't changed much. It is hard though when all the doctors keep changing, you have to start fresh each time and it's just a matter of getting the basics done never mind "how are you?" (Third interview)

All patients made it clear that they did not have an issue with asking questions, and it was about whether the health professionals would engage with patients' rights and abilities to bring their own knowledge, skills, and power to the health encounter.

Another issue for patients was access—working to maintain relationships and rapport with their health professionals when they "keep changing". This made building health literacy practices a secondary focus. Health professionals stated that embedding the intervention in the community was invaluable:

> If we didn't have this intervention, I think it would have a significant impact on the patients and for those that are out there that missed out, that didn't have the opportunity, that's where I can make a difference to NPH, but who's going to make a difference to [our other centres], that's why it's highly imperative that the whole organisation does the health literacy. (Mereana; first interview)

Mereana is stressing the need to expand access to the intervention so that others on the East Coast may benefit. She highlights that the responsibility for building the health literacy skills of patients and whānau sits with clinical staff and, more broadly, NPH. A shift needs to occur not only in terms of access to the intervention, but also in providing health literacy training (a key component of this intervention) throughout the organisation and to implement the health literacy organisational review process.

Whanaungatanga—building relationships

In their accounts, the patients and health professionals stressed that the design of the intervention to support relationship building was its most effective feature. The intervention focused on valuing patients as autonomous beings holding their own importance and expert knowledge about their lives. The research nurse provided tūhononga *(connection)*, aroha *(compassion)*, manaaki *(support)*, and ahua *(energy)* within the intervention. From this foundation, relationships formed based on trust, reciprocity, and admiration.

> I will say one thing I have found by meeting with the nurse—I feel really safe . . . I feel safe because she supports us, we all benefit. So if anything comes out of this whole [intervention] is that I found [research nurse] is really good, . . . she's awesome . . . it was how she put it across and sometimes I felt "oh I'm so thick!" but she took her time. Sometimes she went longer, didn't push. (Joan; second interview)

For Joan, feeling safe was an important part of building a relationship with the research nurse, reinforcing practices of support and trust. Joan also spoke from a whānau and community perspective in acknowledging that the research nurse's presence in her home had positive effects for the community. The community is a small rural town where people live communally; therefore, the actions of one impacted on many: "We all benefit". The health professionals expressed a very similar view:

> The importance of relationships was one of the most important things in the intervention, especially with the [research nurse], they trusted her, she had been there for a long time, she was one of them, they could go to her if they had health issues, or even family issues, they could go to her. (Matt; first interview)

As a long-term member of the community who was passionately involved in community activities, the research nurse was trusted by her patients. She appreciated and connected with whānau, facilitated information-sharing, and effectively communicated knowledge:

> I think it's [intervention] made me a better person, better nurse, better person like I pride myself on communication, I think that without that you don't have much at all and our whole

> team is like that, but it's just doing this and doing the health literacy training . . . I think a big challenge was trying to get those patients that were just absolutely no, the ones that weren't taking their pills had to work a little bit harder but to see at the end of it . . . It's taught me patience, you can't just try and teach somebody in 10 minutes, if you're going to take on something like this then you have to give time, time is a huge factor. (Jen; second interview)

Jen's account sends a powerful message that she was not deterred by the challenge. She reflects that her role combined skills in patience, listening, and teaching, coupled with customised and structured resources and dedicated quality time.

An important finding was the importance of the research nurse's ability and time to develop strong positive relationships with patients. She made contact with patients in their own homes and to suit their time schedules; health care was not limited to the clinic environment and timeframes. The hard work and effort put into the intervention and gaining buy-in from the participants to complete the intervention was richly rewarded—56 patients completed the 3 educational sessions. The space and time allowed for building relationships between health professionals and patients was a very significant feature of the intervention. It may have not been as successful, had the research nurse not brought her already practised repertoire of engagement and connection. In turn, the intervention heightened her skill and took her health literacy practices to a new level of engagement and professionalism. Furthermore, the "extra time" built into the intervention being delivered in the context of timeframes factored into the research nurse contract was also a significant factor compared to timeframes available in clinical contracts.

Discussion

The effectiveness of the intervention approach for patients and health professionals, based on building patient knowledge of CVD medications, centred on four key factors: extended timeframes, being home- rather than clinic-based, tailored educational resources and materials for both staff and patients, and, most importantly, the connection and relationship with the research nurse who had been trained in health literacy skills.

Patients viewed health literacy knowledge as dynamic—understood and practised for moments in time, but maintained and nurtured through health practitioner support. Health literacy practice was seen as more effective for patients if it was grounded in whanaungatanga—reciprocal, responsive relationships—that entailed active collaboration, shared power, partnership, and deliberative engagement. Whanaungatanga processes were nurtured by practices and systems that valued connection by linking patients and health practitioners through wider contexts of whenua, awa, maunga, and wharenui.

Health practitioner insights on effective health literacy practice centred around their responsibility for ensuring whānau understanding, taking ownership of their communication practices, and avoiding blaming patients for misunderstandings. The intervention delivered health literacy training to health professionals involved, incorporating the three-step model (Health Quality & Safety Commission New Zealand, 2013) into practice. The steps are to first ask in order to find out what the whānau know, then build on that knowledge, and finally check whether you have been clear and prompt to build any knowledge that the health professional was not clear about. These health literacy practices were vital to the effectiveness of the intervention sessions with patients. Health professionals made a conscious shift in their practice and took responsibility for not being clear if whānau did not understand, instead of focusing on patients as not understanding.

Whanaungatanga was also critically important to health practitioner roles in maintaining good health literacy practices and health literacy-promoting environments. Effective facilitation and knowledge sharing were seen as key skills needed by health practitioner to provide a safe space for conversations and to build patient and practitioner understandings.

Key informants felt that a values-based approach was needed to develop high-quality health literacy practices. Acknowledgement of cultural specificities and the context-dependent nature of health literacy practices and systems were a key part of this approach. They highlighted the systemic, institutional nature of problems with many current health literacy concepts and practices and advocated holistic approaches. Concerted efforts were seen as required at all levels of the health system to improve the effectiveness of health literacy practice.

The evaluation underlined that health literacy—obtaining, processing, and understanding health information and services—entails a complex, varied, fluid, and often conflicting state for patients. Patient accounts detailed that the knowledge and emerging understanding attained during the intervention was not enough to effect long-term sustainable change in relation to medication use and practice. However, when coupled with ongoing whanaungatanga *(relationship, kinship, connection)* practices, the intervention was far more powerful and influential (Carlson et al., 2016).

These major findings highlight the complexity and contextuality of health literacy and the challenges inherent in using this approach as a contribution to healthier lives for Ngāti Porou and other Indigenous people.

Conclusion

The healthcare system is complex and challenging to virtually everyone but more so to those who are marginalised, impoverished, and isolated; all factors which exacerbate health literacy barriers. The intervention highlighted that the responsibility for improving health literacy lies with everybody in making substantial systemic change. In this intervention, the focus of responsibility for building health literacy skills in patients and whānau sat with front-line health professionals, specifically some nurses and kaiāwhina.

The evaluation highlighted that basic functional literacy and numeracy skills and communicative-interactive (applying information to changing circumstance) skills related to medication use are some, but not the only, important components for improving health literacy with health professionals and Māori patients and their whānau. Much of the focus in health literacy research has been on analysing the associations between individual-level patient skill and various health outcomes.

In keeping with many interventions, this initiative was developed as part of a finite project. Given limited resourcing and multiple demands, many initiatives that show promise do not continue past their initial trail phase. Further support and resourcing is needed to promote and sustain the practices and resources developed and tested in the *CVD Medications Health Literacy Intervention*. Careful and considerate planning is needed to support the ongoing development of the intervention in order to embed and expand the promise of the initiative.

Here, we argue that health literacy approaches need to be implemented at a service level, where organisations are supported by the system to implement effective health literacy policies. The provision of health literacy training and systems design for health service policy and contract developers, governors, managers, and all front-line staff can in turn impact the type of service patients are receiving.

Compliance with ethical standards

Massey University Ethics Committee (MUHECN 12/095).

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Note

1. Constraint's entailed in the parent project meant availability of participants was restricted to the number of participants that were made available for the evaluation via the inclusion criteria of that study.

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