



# Whanaungatanga: A space to be ourselves

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## Abstract

Clinical engagement is often removed from everyday social processes familiar to Māori (indigenous people of Aotearoa [New Zealand]), as it can focus on health consumerism rather than communication and connection. The health encounter is not a routine social engagement, patients often feel unwell and experience a range of emotions; feeling unsure, vulnerable, nervous and out of their comfort zone. Patients are faced with health literacy (HL) demands, such as new information, words and concepts and may be faced with making quick decisions. Feeling guided, supported and safe are important factors in interactions with health professionals. Drawing on a literature review and some of the findings from a Kaupapa Māori Evaluation which analysed some participants' perspectives of the effectiveness and impact of a

cardiovascular disease (CVD) medicines health literacy intervention trial, this paper provides a distal understanding of interpersonal dynamics of HL that is vital to understanding how it might be more useful in the context of Māori communities. The paper highlights a shared health system experience expressed by CVD patients as their yearning for *whanaungatanga* (relationship, kinship, connection) and reciprocal and responsive relationships; a space to be ourselves, to be Māori.

**Keywords:** Kaupapa Māori evaluation, evaluation, cardiovascular disease, health literacy, medications.

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## Introduction

Having the ability to make informed and appropriate health decisions is an important part of managing the ever-changing and increasingly complex health situation of individuals and is fundamental to health literacy (HL) at personal and population levels (Berkman, Davis, & McCormack, 2010). HL is important to the clinical encounter, but such dynamics do not exist in a silo; systemic pressures are in play and assessing the communicative, resource and systemic demands on patients, also known as HL demands, is critical to successful outcomes between patients, health professionals and health care providers (McCreanor & Nairn, 2002a, 2002b; Ministry of Health, 2015; Winefield, 1992).

Patients do not come to the patient-health professional encounter as empty vessels passively awaiting the wisdom of the health professional (Blaxter, 1979). People's understandings of illness, disease and health are dynamic, contextual and emotionally fluid, navigating turbulence between personal experiences, beliefs and medical knowledge. Popay and Williams (1996) stated that lay people go through a "systematic process whereby experience is checked against life events, circumstances and history. They acquire an 'expert' body of knowledge, different from but equal to that of professionals in the public health field" (p. 760). Obtaining, processing, and understanding health information and services entail complex, varied, and often conflicted processes. HL recognises the communicative, resource, and systemic demands placed on patients (Institute of Medicine, 2004) and focusses not only on increasing patient knowledge around their healthcare but also on enabling patients to navigate and interact with the health system (Ministry of Health, 2015).

There is a variety of definitions of health literacy, which generally fall into two categories: health literacy as a set of individual capacities that allow a patient to successfully navigate a health care environment and; health literacy as an interaction between individual capacities of patients, *whānau* (family group, extended family) and health professionals and the health care environment in which they are operating

(Institute of Medicine, 2004; Kickbusch et al., 2005; Nutbeam, 2008; Pleasant et al., 2016; Rudd, Epstein Anderson, Oppenheimer, & Nath, 2007). Most research on health literacy has focussed on the first category. It is only in the last few years that research relating to the second category is starting to gather momentum. The practical application and assessment of health literacy requires a working definition incorporating settings, modalities and media facets along with unique relationship of HL to empowerment, health behaviours and practices (Pleasant et al., 2016).

In this paper we explore the dynamics and manifestations of HL in Aotearoa (New Zealand) with a particular emphasis on what it does and could mean for Māori with chronic conditions, particularly cardiovascular disease (CVD). As researchers working within a critical Māori public health paradigm, we present analyses of qualitative data that challenge some epistemological underpinnings of HL and question its potential, in its conventional forms, to help reduce health disparities in Aotearoa.

### Patient-Health Professional Relationship

The ultimate goal for health professionals in their relationship with patients is improving their healthcare and patient satisfaction, and this is especially important in the management of chronic conditions (Goold & Lipkin, 1999; Ha & Longnecker, 2010; Kaplan, Greenfield, & Ware, 1989). Communication is viewed as a central component in an effective patient-health professional relationship (Beck, Daughtridge, & Sloane, 2002; Ha & Longnecker, 2010). Effective communication involves the health professional facilitating discussion, patient-centred questioning, exchanging information, attentive listening, reassurance, and empathy. Treatment options are then evaluated and tailored to the context of the patient's circumstances and needs (Parker, Clayton, & Hancock, 2007). Patients are involved in the decision-making process through consideration and exploration of their "expectations, outcome preferences, level of risk acceptance and any associated cost" (Ha & Longnecker, 2010, pp. 40–41).

Good communication has the potential to help stabilise patients' emotions, facilitate comprehension of medical information, allow for identification of patient needs and address both patient and health professionals' perceptions and expectations (Ong, de Haes, Hoos, & Lammes, 1995; Stewart et al., 1999; Stewart, 1995). When effective communication happens patients are more likely to share personal and important information for an accurate diagnosis, feel satisfied with the relationship, follow advice and adhere to prescribed medications (DiMatteo, 1997; Little et al., 2001; Mazur & Hickam, 1997; Stewart, 1995).

When it comes to the perception of effective communication, there is a clear discrepancy in the experiences of patients and health professionals. Patients have consistently reported misperception, lack of connection, poor communication and social conformity pressures with their health professionals (Duffy, Gordon, Whelan, Cole-Kelly, & Frankel, 2004; Fischer & Ereaut, 2012; Frosch, May, Rendle, Tietbohl, & Elwyn, 2012). Doctors however, report that they effectively communicate with patients and remain satisfied with their abilities (Bensing & Dronkers, 1992; Cooper et al., 2003; Fischer & Ereaut, 2012; Ha & Longnecker, 2010; Marvel, Epstein, Flowers, & Beckman, 1999).

International literature indicates the culture of healthcare practice, or at least the perception of it on the part of the patients, is an important factor in the interaction process between patients and health professionals (Makoul & Curry, 2007; Mauksch, Dugdale, Dodson, & Epstein, 2008; Prideaux & Edmondson, 2001; Stewart, 1995). Lyons and Chamberlain (2006) highlight that ethnic minorities living in a Western-dominated society often have different information requirements and prefer to communicate differently from those of the dominant culture; unrecognised, this can lead to problematic and dissatisfying interactions with health professionals. Lyons and Chamberlain (2006) state it is vital for health professionals to have a sense of cultural awareness and consideration and respect for the cultural context, communicate with and advise people for whom they are providing care. The social

and cultural context of patients should be central to any medical decisions made by health professionals including treatment options and medications (Makoul & Curry, 2007; Mauksch et al., 2008; Penney, Moewaka Barnes, & McCreanor, 2011; Prideaux & Edmondson, 2001; Stewart, 1995). These competencies then become important factors to consider when building health literacy through better individual interactions and a systems perspective.

Illness-focussed systems tend to view individuals as *cases* and undervalue the sociocultural and humanistic aspects of patient care (Green, Carrillo, & Betancourt, 2002). Particularly in the currently widespread neoliberal political climate, the patient's role has become that of a consumer/client and the health professional has become more of a social health coordinator. This change has meant that HL has developed to recognise issues of equity, equality and power when using the health system (de Leeuw, 2012). Traditional notions of HL suggest skills required to navigate the system are associated with patient advocacy and empowerment but, more recently, the evolving HL literature (Nutbeam, 2008) identified that health system literacy "is something that should not, or possibly least, be attributed to or owned (in a real or rhetorical sense) by patients" (de Leeuw, 2012, p. 2).

One of the critical growth points for HL, identified by Chinn (2011), involves shifting the focus from an analysis of literacy as a set of skills and practices to the examination of literacy as "a set of practices embedded in broader social goals and cultural imperatives" (p. 61). HL needs to be understood as situated social practices that are the sum of many everyday lived realities and decisions that occur outside the consultation room, where it becomes a shared resource frequently achieved collectively by people, whānau and communities (Papen, 2009; Peerson & Saunders, 2009). In practice HL, whatever the hegemonic commitments, is best realised when the expectations, preferences and skills of patients and whānau who are seeking health information and services, align with the expectations, preferences and skills of those providing the information and services (Institute of Medicine, 2004).

## Healthcare Relations in Aotearoa

Research has consistently highlighted that some doctors treat Māori patients differently than non-Māori and research comparing Māori and non-Māori experiences of general practice services has consistently found Māori demonstrate differential usage of primary healthcare. Māori present with higher health needs than non-Māori, present for treatment late, have shorter consultation times, lower referral rates and are less likely to be offered choices at their general practice, to be seen in time or to be seen within their preferred timeframe (Crengle, Lay-Yee, Davis, & Pearson, 2005; Jansen, Bacal, & Buetow, 2011; McAvoy, Davis, Raymont, & Gribben, 1994). These studies indicate that Māori do not receive the same standard of care relative to that of *tauiwi* (non-Māori). Additionally, the *New Zealand Health Survey* (Gerritsen, Stefanogiannis, & Galloway, 2008), found that 4.5 percent of Māori surveyed reported unfair treatment, compared to 1.5 percent of non-Māori, Māori were almost 10 times more likely to experience multiple types of discrimination compared to non-Māori (Harris et al., 2006).

Qualitative research projects on Māori patients' health interactions with non-Māori general practice services and health organisations, found that primary healthcare services and Māori users of those primary health services reported strong opposing accounts of their interactions with each other (McCreanor & Nairn, 2002a, 2002b). Māori patients described the need for holistic, culturally appropriate, collaborative styles of consultation, and recounted the effort required and the barriers faced by Māori to obtain quality primary healthcare (Cram, Smith, & Johnstone, 1998, 2003; Durie, 1994a). Data from general practitioners (GP) conveyed the perception that Māori patients had poor quality health behaviours and choices, and Māori patients' behaviours were to blame for poor compliance levels (McCreanor & Nairn, 2002a, 2002b; Penney et al., 2011).

These stereotypes have the potential to influence health professional attitudes, interactions and treatment. Cram et al. (1998) report interaction difficulties that occur between Māori patients and non-Māori GPs are based on the differing health ideology perspectives

around accessing health information and care. While GPs consider themselves at the centre of the patient's primary healthcare, Māori consider them to be merely one source of information and treatment. "Within a Māori health ideology GPs are seen as just another service provider and Māori patients use multiple forms of resistance in their refusal to buy into the GP power base – a power base that is established within the context of being, or seeing oneself, as the health professional" (Cram et al., 1998, p. 6).

An action-orientated research project that examined Māori pathways and barriers to care for patients with ischemic heart disease, in which patients were empowered to narrate their experiences, generated research-based solutions that highlighted the power and control related barriers to effective healthcare (Kerr, Penney, Moewaka Barnes, & McCreanor, 2010). The study found major barriers to equitable provision of care could be traced to the ideologically-driven (and ethnically biased) attitudes and behaviours of health professionals. The action approach allowed systemic changes to be made within the service, highlighting the need to improve cultural competency among health professionals. A significant outcome from the study was that, by sharing the patients' experiences of the service, the system was modified, primarily by health professionals who held the most prominent position to "initiate effective systematic change, allowing Māori patients to work for change without having to take all the responsibility for creating it" (p. 27). This emphasises the power health professionals have to initiate immediate change in their interactions with patients; an example of health system HL. It is important that services and health professionals are challenged by alternative discourses and offered ways of building more equitable relationships with patients, which in turn are likely to contribute to more equitable access and outcomes for Māori (Penney et al., 2011). As with other parts of the health system, such changes could incorporate HL practices to make immediate and effective improvements to patient knowledge and understanding about their health.

## Health Literacy in Aotearoa

The HL field offers solutions to challenges that reduce the effectiveness of patient-health

professional encounters that can be identified at systemic, organisational and health professional levels; however consideration of cultural barriers that patients face within the HL field are rarely discussed in the literature.

The *Kōrero Mārama: Health Literacy and Māori* report survey (Ministry of Health, 2010) focused on prose and document literacy, numeracy and problem solving, which is largely consistent with Nutbeam's (2008) definition of basic-functional and communicative-interactive health literacy (Moewaka Barnes et al., 2013). Generally New Zealanders were reported to have poor literacy skills with Māori on average scoring below the minimum needed to counteract health literacy barriers faced in everyday life. Māori have much lower HL skill levels than non-Māori, regardless of age, gender, education, work status, household income and location. The survey highlights the failure of connection, knowledge exchange and skilled facilitation between Māori and health professionals.

An international Indigenous health literacy research project (Crengle et al., 2014) of which my study was an evaluation component, aimed to strengthen health literacy among Indigenous people who were using CVD medicines in Aotearoa, Australia and Canada. A paper from the first phase of the research project (Lambert et al., 2014) argued that many health professionals have limited knowledge of health literacy and, in particular, of the barriers that Indigenous patients face within healthcare environments. They concluded that health professionals' "lack of understanding, combined with the perceived barriers to improving health literacy, limit health professionals' ability to improve their Indigenous health literacy skills and may limit patients' capacity to improve understanding of their illness and instructions to manage their health condition/s" (Lambert et al., 2014, p. 1). Further findings from the research project (Crengle, 2016) provide insights into experiences of Māori using medications to control CVD, reporting that customised sessions about CVD medications, delivered by Indigenous health professionals trained in HL practices, resulted in significant improvements in participants' knowledge of their medications.

As argued in the literature considered above, when patients and health professionals meet the parties need to understand each other's ways of being, including assumptions, beliefs, attitudes and practices (Ramsden, 1994). There are deep influences inextricably linked to power, as Māori face cultural misunderstanding, unconscious bias and institutional marginalisation (Cram et al., 2003; Penney et al., 2010). Because the clinical and positional power lies with health professionals, it is important for them to take the lead in facilitating the relationship and providing a space for connection, reciprocity, value and practice that is shared, negotiated and respected. Health professionals have the ability and, in most instances, the will to be the change makers in our health system. Health professionals hold the power to diagnose, treat and prevent human illness, injury and other physical and mental conditions in accordance with the needs of the people they serve (Ramsden, 1994; Richardson & MacGibbon, 2010). Currently, Māori are not served well in the health system. Māori experience the health system differently to non-Māori and, if Māori are less familiar/knowledgeable at all stages of the health system, it is likely that patient and whānau outcomes will be worse.

A promising aspect of the health professional field is the acknowledgement of these issues and the development of guidelines for practitioner cultural competencies. Written by the Māori Ora Associates, the *Best health outcomes for Māori: Practice implications* provides a guide for doctors to work towards producing optimum outcomes for Māori patients. The booklet and its statement publication (Medical Council of New Zealand, 2006) provides practical approaches for non-Māori practitioners to improve care for Māori patients and whānau. Ten years after its publication however, health disparities persist (Minister of Science and Innovation and Minister of Health, 2016). The latest perioperative mortality report (Perioperative Mortality Review Committee, 2015) highlights the inequities and inequalities that exist with the delivery of healthcare to Māori with Māori experiencing higher rates of perioperative mortality than all other groups. Health inequalities have been exacerbated by an inequitable distribution of health resources,

which the Medical Council of New Zealand determines as unjust and unfair (Perioperative Mortality Review Committee, 2015).

This paper draws from the findings of a qualitative Kaupapa Māori Evaluation (KME) that explored the understandings of HL of six participating Māori patients and their attending whānau. Data were also gathered from three Māori health professionals about their experiences and perspectives of the effectiveness of the HL intervention around CVD and prescribed medicines in a Māori community. Thematic analyses present patterns in participants' narratives about their journeys through CVD and their yearning for *whanaungatanga* (relationship, kinship, connection), reciprocal and responsive relationships with their clinicians. The work sheds light on the interpersonal dynamics surrounding HL, its potential to become a space to be ourselves, to be Māori, and what is vital to understanding how HL might be more useful in the context of Māori communities.

## Methods

An international Indigenous research collaboration spanning Australia, Canada and Aotearoa, developed a research project entitled *Strengthening Health Literacy among Indigenous people living with cardiovascular disease, their families, and health care providers*. The Aotearoa research project known as the *CVD Medicines Health Literacy Intervention* was developed and implemented by a team of Māori health researchers and two Māori health providers. The objective was to test a customised, structured CVD medication programme delivered by health professionals that focused on the development of health literacy with Māori patients and their whānau. Secondary outcomes focused on examining changes in patient CVD medication knowledge and HL practices (Crengle et al., 2014).

Patients were eligible to participate in CVD Medicines Health Literacy Intervention if they were taking at least two CVD medications, which included a statin, aspirin, a beta blocker, or an ACE inhibitor (Crengle et al., 2014). All patients had been diagnosed with some combination of angina pectoris, myocardial

infarction, transient ischaemic attacks or stroke. All eligible patients were invited to participate in the intervention as well as the evaluation (Lambert et al., 2014). Our study sought to understand the effectiveness of the HL intervention within one Māori health provider location. Six of the 56 patients participating in the intervention at Ngāti Porou Hauora (NPH) were invited to participate in our KME project (Carlson, 2013). Those six evaluation patients were enrolled in one of the three small rural health centers participating in the wider research project from amongst NPH's six health centres.

Our KME approach focussed on aspirations of co-ownership, mutually beneficial outcomes and shared power, by prioritising the participants' voices to shape and develop the criteria to determine the effectiveness of the intervention. Invitations to participate were an important part of the collaborative process as NPH were involved in the methodological decisions, interpretation of data, analysis and concluding stages of the evaluation. Our research was approved by Massey University Ethics Committee (MUHECN 12/095) and the patient and health professional interview schedules were developed with feedback/approval from the NPH research co-ordinator and parent project team members.

A series of three semi-structured qualitative interviews were conducted with each patient to gain an understanding of their CVD experience including medication use, understandings of health situation, relationships with health professionals and to discuss expectations, and perceptions of the impact and effectiveness of the intervention. These evaluation interviews lasted between 60-120mins and took place in the patients' homes with varying attendance by whānau. Patients were re-interviewed within two weeks then again at six to seven months totalling 18 interviews overall. Weekly telephone calls were also conducted with the participants ranging from 10-30 mins for the first month. At the time of the interviews, the patients accessed the services of their health centre's rostered clinical staff. The multiple interviews were an effective method allowing the creation of follow-up questions, expanding understandings, enabling contradictions to be explored and key themes to be reiterated. Multiple interview

processes separated by short intervals is suggested in chronic illness research as it provides particularly rich data sets (Mishler, 1999).

Three health professionals that were directly involved with the intervention, including the research nurse, *kaiāwhina* (support staff) and GP, were interviewed twice each in 60-minute semi-structured, face-to-face sessions. The first was carried out immediately after the intervention was completed to gain an understanding of perceived outcomes, impacts and effectiveness of the intervention while the second was conducted six to seven months later to probe medium-term outcomes.

A total of 24 interviews were audio-recorded and transcribed verbatim. A thematic analysis was completed to identify, analyse and highlight patterns within the data (Boyatzis, 1998; Braun & Clarke, 2006). Here we report on five key themes, drawing in participant data and presenting analyses of these to show how themes articulate with each other and account for the understandings of the HL intervention.

## Findings

### Shared Health System Experience

Understandings, traditions and principles can significantly impact not only on perceptions of health and illness but also on expectations, perceptions, and choices of our medical journey. The six patients interviewed for the evaluation had a long history in the health system. They had all experienced a cardiac event and were taking some form of CVD medication. Five out of the six had been taking CVD medications for at least five years. Their ever-changing health situations ranged from ailments, short and long term conditions, disabilities, surgeries and post-care experiences.

During the evaluation interviews with the patients, the most constant and vital theme in their accounts of their experiences were people; whānau, support people and health professionals. Whānau is the fundamental unit of Māori society (Durie, 1994b) and understanding whānau is key to understanding patients' interpretations, expectations,

responsibilities, and practices of health and their wellbeing.

Participants' relationships with others, from short encounters with health professionals to long-standing relationships with their GPs, were the most important part of patients' health system experiences. Successful and productive relationships were described as having a foundation of whanaungatanga, reciprocity and mutual respect.

Whanaungatanga embraces *whakapapa* (genealogy), and focuses on connection, understanding and relationships (Mead, 2003). Individuals expect support from their whānau, close or distant and whānau expect individuals to support the collective need. Whanaungatanga also encompasses non-kin relationships that have become like kin through shared experience, friendship, *aroha* (love) and aspirations (Durie, 1994b, 2004; Mead, 2003). For patients, whanaungatanga played an important role in the interactions with health professionals and was the distinction between a negative or positive experience. Whanaungatanga, in the form of whānau, whakapapa, *manaaki* (support), reciprocity, friendship and quality time was developed through shared interests and through consistency of care; that is, building a relationship by seeing the same health professional.

### Appreciating Whānau

All the patients spoke about their responsibilities to their whānau and how their health and wellbeing was interwoven into the collective health of whānau.

**Interviewer:** What is important to you when it comes to your health?

**Joan:** I have trust in the doc or the nurse that they are educated enough to know . . . When they talk to me about things and I get angry then I won't do whatever it is and that's it. I got better things to think about like more important things like my whānau, their wellbeing, so what does that say about my health? It's not that [it's] not important, but they drive me to be well for them, so as long as I feel good, I don't got to worry about things. So when I don't feel good, well, that's when I come to the doctors. (First Interview).

For Joan, whānau wellbeing is important, it is a priority for her. This highlights the imperative to consider the role of whānau in order to understand perceptions of individual and collectivist health responsibilities about prevention methods, treatment and care (LaVeist & Nuru-Jeter, 2002).

During the interviews patients spoke about their relationship with the research nurse. They described her as *relatable* and embodying *manaakitanga* (hospitality, kindness, generosity). Most importantly the patients spoke about how they felt about the nurse; they said she cared, described her approach and demeanor positively and felt it was a reciprocal relationship. Moreover, the nurse took time to learn about their whānau, who was who and what role they played in their lives.

**Interviewer:** How did you find the sessions with [the research nurse]?

**Nellie:** Really good, she's been really good, she's got a good ahua, she's nice person, you can relate with her, she's got a nice ahua . . . she's good at her job, she's a good girl.

**Interviewer:** What makes her good at her job?

**Nellie:** She listens; she's interested in our whānau, what's going on. . . She asks about my moko, she knows her pāpā. (First interview).

Nellie expresses her position as a *pakeke* (elder) by referring to the nurse as a girl – “she's a good girl”. This was said from the position of a pakeke to a younger *whanaunga* (kin). It reflects the social status relationship they built and their kinship connection. In terms of health literacy practices the nurse *listens for understanding*; she does this by taking an interest in her whānau, acknowledging the social connections and the importance of this in Nellie's health journey. She asks how they are, remembers their names, their whakapapa connections and asks about her whānau wellbeing.

### **Ko Wai Ahau? Ko Wai Koe? Willingness to Connect**

During the evaluation interviews, patients talked about connection on any level (place, space, people, experience) between the patients and their health professionals was very important to them. Whanaungatanga was developed through

the existence of experiences outside of the consultation room, just as much as inside, such as whakapapa, manaaki, reciprocity, friendship and shared interests. Quality time spent with patients was an important factor in developing a connection and a positive relationship.

**Interviewer:** So in your third session today how was that for you? How did you find it?

**Joan:** Oh very good, very comfortable, very easy going. We spent more [time] talking about our mokos than anything else. I don't know. I know she [nurse] asked me a few questions about how things[were] going blah, blah, blah, have you been to the doctors but it was sort of like in conversation, so I didn't really notice it so I actually thought she done very well in this session and even the second session 'cause it was all part of a conversation and she'll just write down as we went along. . . she would tell me about what was going to happen next so it seemed all straight forward no surprises. (Second interview).

Joan spoke of her connection to the nurse through their shared sense of aroha for their *moko* (grandchild[ren]). Through a common connection and value they developed and navigated through topics of health, medications and wellbeing seamlessly. Joan highlighted that the nurse anticipated the next steps for her as they went through the session, which is an important HL practice and part of building patients' HL knowledge and skills to meet their needs (Health Quality & Safety Commission New Zealand, 2013).

Interwoven into the patient-nurse relationship was manaaki. As well as making home visits to the pakeke she would go above and beyond her role as a health professional by sharing and giving *kai* (food), this was seen as a clear expression of manaaki through actions of caring, protection and respect.

**Interviewer:** Would you like any changes made?

**Kiriama:** No she's [nurse] doing a good job, she's good at her job. She's awesome.

**Interviewer:** Great, what makes her good at her job or the good things she does?

**Kiriama:** She brought me crayfish when I wasn't at home, she's a good girl. (Second interview).

Connection is displayed through whakapapa, making references to connection through ancestry, linking each other to a wider context to place, *wharennui* (meeting house), *whenua* (land), *awa* (river) and *maunga* (mountain). When asking patients about their relationships with their health professionals they would often refer to their GP by their first name, initially talking about them by their whakapapa connections, then whānau, and then their professional relationship.

**Nellie:** Yeah you know [GP] he's a young fulla, he's Tainui. (First interview).

**Kiriama:** My nurse she's going away, nice girl man, she is Apanui, she has a lovely partner and children. (Second interview).

**Hemi:** Yeah the GP I've been seeing him for a little while now, think he's from Waikato ways, think I know one of his whanaunga, good whānau, his wife likes the horse in Te Araroa, she goes riding with Rita-mae, Kelly and Tane. Think she really likes it. (Third interview).

When the patients spoke about the Māori GP or Māori nurses it was a common, normalised process to identify their iwi. Whakapapa was paramount to their connections, relationships, to know about their whānau, what they were interested in, to know them as a person, and to share.

Having trust in health professionals was a prominent theme. Patients regularly spoke of experiences where they would seek out trusted whānau or health professionals and take their advice over other health professionals.

**Joan:** When I was having the worst symptoms, my husband rang Doctor P, he's a close relation to my husband at Gisborne at the time and he said 'you better get her to the doctors and that'. I said to Doctor P 'we'll go see the local GP now [he] lives straight across the river.

**Interviewer:** Why did you choose to call Doctor P in the city not the local health service?

**Joan:** I trust him, plus we know we can call, it's not going to bother him, don't want to call 111 and then it's not even worth coming all the way up here. (First interview).

Trust with patients was built on relationships with a history of reliability, advocacy, reciprocity, compassion and continuity of care

(Arnold, Forrow, & Barker, 1995; Brody, 1992). Trust provides an opportunity for patients and providers to connect as people and provides a foundation for mutual decision making, thus allowing health professionals to become "better advocates for their patients and allows patients some power by virtue of the personal relationship" they have with the health professionals (Goold, 1996, p. 29).

### Striving Towards Wellbeing

During the interviews patients spoke of gaining a sense of wellbeing during the CVD medication health literacy intervention. They spoke about growing wellbeing, security, and peace of mind. In this excerpt Ma identifies the actions and practices that led to her wellbeing.

**Interviewer:** Would you like to see any improvements or changes in terms of your sessions with the nurse?

**Ma:** No not over my head no. It's all good what you both are doing. I am settled, I'm happy. [Getting teary] Good for me and for my spirit and my mind, I'm not confused because she explains it to me in ways that I get it. It is true, I find myself more relaxed and comfortable with myself and with my meds and with my family. There's a lot of things that's come out of it actually with my spiritual feeling. Well for me I feel as someone cares about me to come and talk to me and tell me what I'm doing and what do I need, apart from the last four years no one's been to ask 'do you know what you're taking'. What you and [nurse] are doing [crying]. It's wonderful. . . I'm almost in tears but for me I'm all good about it and I'm sure there's a lot there who'd feel the same too. (Second interview).

Ma identified that wellbeing encompasses a spiritual feeling and includes experience, emotion and affect. Both the nurse and the lead author spent time with Ma in her home; we each visited on four separate occasions as we did with each patient. This led Ma to feel cared for, understood and connected. Ma was very emotional during this *kōrero* (discussion) and began to cry; her deep sense of appreciation and connection was palpable. Ma felt that the information she received from the nurse was relayed to her in a way that she understood and she was able to tell others much of the information she had learnt about her CVD medications. Ma said that she was asked *do you*

*know what you're taking?*, which is an important HL practice for health professionals as they are able to acknowledge, clarify incorrect knowledge and provide new information (Health Quality & Safety Commission New Zealand, 2013). Ma made it clear that gaining an understanding about her medications was not just about knowledge it was about awareness and consciousness, about how she feels.

Wellbeing was also expressed as therapy, creating a consciousness of connection of your *hinengaro* (mind) to your *tinana* (body).

**Interviewer:** What were the sessions like with the nurse?

**Nellie:** No it's good I enjoy having her come and talk to us because it's good therapy for me. I find it good therapy because she keeps me alert and aware of what's going on in my body. No it does, it makes me understand what's going on now in my body because I take time out, I think about what's going on in my body. (Second interview).

The nurse's visits created a time and space dedicated towards the patient's wellbeing, a time to reflect on their health, medications, personal understandings and management. The stimulus and reflections were seen as raising awareness in positive ways. George spoke about his state of wellbeing as feeling more relaxed and comfortable as the knowledge he gained gave him peace of mind.

**Interviewer:** . . . my role is to come to you and see if there's anything we can change

**George:** Oh I find it good, good . . . I found it's been really, really good and I'm more relaxed now than what I was before. [I] know what my meds are for as well, gives me great peace of mind for me. (Second interview).

Wellbeing was not fixed or defined. When it was discussed it was understood as a feeling, an emotion or an experience that was negotiated, moulded and fluid. It was a state of consciousness for the patient that was useful at these points along their health journey. The importance of wellbeing is the ability to continue and maintain such a state; this may be facilitated by positive relationships, willingness to connect and appreciating whānau through the

skilled facilitation and skilled knowledge sharing of the health professional.

### **Importance of Skilled Facilitation and Knowledge Sharing**

Skilled facilitation is an essential component of the interactions with patients and their whānau. Patients found that the research nurse and the Māori GP encompassed practices of facilitation as opposed to more traditional consultation approaches which they experienced at hospital based consultations and consultations in primary care. They provided a space for conversation to flow in contrast to their experience of being spoken at in a one-way direction where they would listen and nod. Knowledge was shared with them where they would build on their understandings rather than their previous experiences of being told what was wrong and what treatment was going to be offered.

**Joan:** . . . it wasn't until I was home, I was home for a few days anyway and said I to my husband 'oh I got to go see the doctor' cause I had these different specialists and I had bottles and bottles of pills and I went to see the doctor and I came down here and at the time it was Doctor G and I said to him 'I don't even know what happened' so he sort of explained what had happened.

**Interviewer:** So no-one explained to you at the hospital what happened to you? Did they use the word stroke?

**Joan:** No they never used that word they used other words that I didn't understand, so he sort of talked me through it and he said 'so what do you think?' and I said 'someone said infarction something like that' and he said 'that's a stroke'. I said to him 'oh so I had a stroke' and my husband is sitting there like this [shaking his head, with eyes wide open]. (First interview).

Relationships and experiences with health professionals were the most important part of the patient's health system experience. Patients spoke about both negative and positive experiences which were created on a foundation of whanaungatanga, connection and communication. Participants' negative experiences related to dialogue: the way things were said including tone, context and speed; the amount of information; being talked at; not being listened to; not being given the opportunity to ask questions and; receiving

conflicting information from health professionals. How the participants felt during the health literacy intervention conversations was an indication of how successful it was for them.

**Interviewer:** How did you find the sessions with the [research] nurse?

**Kiriama:** Well the difference is when you go to the doctors he just tells you what each ones for, that's it and her [nurse]...

**Whānau member:** And we understand more now you see

**Whānau:** You know why you're taking it aye, gives you meaning behind it

**Kiriama:** You know she's doing a good thing

**Whānau member:** Whereas before you swallow them I don't know what they're for

**Kiriama:** Yeah, I just go to the doctor, get a pill and he'll say 'go home here take this' tell us why we taking it aye? What for and all that, yeah . . . now I know why I'm taking these pills. (Second interview).

Due to the nurse's ability to appreciate whānau, connect, facilitate, effectively communicate and build HL through knowledge and information sharing, patients spoke about gaining a better understanding around the CVD medications they were taking. For most patients they considered it was the first time they had been fully informed about their CVD medications; names, categories, purpose, how they worked and side effects. Patients spoke about gaining more meaning behind their medication use rather than just taking them as instructed.

Contextually patients' experiences with health professionals are enacted within the organisation and more broadly the health system. The Ngati Porou Hauora Strategic Plan 2010-2015 (Ngati Porou Hauora, 2014) included *improving health literacy* as one of their strategic aspirations. The established NPH service system allowed the research nurse to develop close connections with patients through whakapapa, whanaunga and long standing relationships. Nurses and kaiawhina engage in the community outside the clinic, visiting patients at home as required. In contrast GP positions are faced with a mix of fulltime and locum services, both of which turn

over more frequently, making it more difficult to maintain rapport (Brewin & Coggan, 2004).

## Conclusion

HL is the interface between knowledge and skills of individuals and the demands of health care environments (Institute of Medicine, 2004). The interface can be divided into two different perceptions; firstly, health literacy as a set of individual capacities that allow a patient to successfully navigate a health care environment; secondly, health literacy as an interaction between individual capacities of patients, whānau and health professionals and the health care environment in which they are operating.

Reducing HL demands for patients is an imperative part of increasing effective access to health information, care and services. The evaluation findings demonstrated whanaungatanga via reciprocal and responsive relationships and connections (particularly kin connections) underpins perceptions and acceptability of HL practices but is not exclusive to HL practices. As Moewaka Barnes (2006) has noted, knowledge from diverse cultural epistemologies is much more likely to be useful and productive when power relations between different systems are equitable. In this respect, the ever-increasing health literacy demands and along with the multiple barriers experienced by patients and their whānau in this study call for whanaunga practices of connection, continuity and collaboration to be implemented at a service level to guarantee the effective use of HL practices with Māori.

Low HL has been associated with a range of adverse health outcomes including lack of access to preventative services, poorer knowledge of illness, treatment and medicines, poorer management of chronic conditions, increased hospitalisations and high use of emergency services. The vital elements of appreciating whānau, a willingness to connect, striving towards wellbeing and the importance of skilled facilitation were the key findings representative of patients and their whānau experiences and perceptions. These findings highlight the lived expressions and realities of Māori who are trying to engage effectively with health professionals and other environments within the health

system. Without these fundamental components, HL practices cannot be supported and sustained in the clinical context; here the face to face home visit nature of the intervention was a highly appreciated factor as well as the extended contact time available to each patient. If we are interested in the concept of HL for Māori patients, it has, like other features of the Māori world, to be understood as relational, collective and centred in building the autonomy and self-determination of Māori communities.

This research explored the dynamics and manifestations of HL in Aotearoa with a particular emphasis on what it means for Māori with chronic conditions. However the identified social practices can have broader implications for public healthcare practice. It is important to situate HL as a multidimensional approach that incorporates fundamental Māori cultural engagements and processes of whanaungatanga. The presented findings are by no means an extensive exploration but it is a place where we can begin to explore the lived expressions of *Te Ao Māori*, our ways of being, in health engagements. This research offers a powerful message - to bring about change we need a deeper understanding of the nature of the relationship between clinicians and patients because they are at the heart of our health system.

This study supports and extends the conceptual development occurring in relation to the meaning and potentials of HL in such contexts (Ministry of Health, 2015). In short, HL needs to broaden its scope towards an examination of literacy as a set of practices embedded in broader social narratives and cultural agency that recognises issues of equity, equality and empowerment. HL needs to be understood and enacted as a situated social and cultural construction that is negotiated, fluid and shaped by people, whānau communities and the complex array of other stakeholders (Papen, 2009; Peerson & Saunders, 2009).

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