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Identifying eHealth Opportunities to Support Medication Adherence – Findings of a Focus Group Study

Yulong GU^{a, b, 1}, John KENNELY^b, Jim WARREN^b, Amelia Been AHN^b, Matire HARWOOD^b, Pat NEUWELT^b

^a*Stockton University, Galloway, New Jersey, United States of America*

^b*University of Auckland, Auckland, New Zealand*

Abstract. Background: The burden of cardiovascular disease (CVD) among New Zealand (NZ) indigenous people (Māori) is well recognized. A major challenge to CVD risk management is to improve adherence to long-term medications. Objectives: To elicit patients' and providers' perspectives on how to support Māori with high CVD risk and low medication adherence to achieve better adherence. Methods: Analysis of electronic health records (EHR) of four NZ general practices identified medication adherence status of Māori patients with high CVD risk ($\geq 15\%$, 5-year). A random sample of these patients participated in focus group discussions on barriers to long-term medication adherence. Their primary care providers also participated in separate focus groups on the same topic. Results: A range of factors are identified influencing adherence behaviour, including patient's medication knowledge, patient-doctor communication effectiveness and cost. Conclusion: Analysis of barriers to medication adherence in primary care suggests opportunities for health information technology to improve adherence, including patient education, decision support, clinician training and self-service facilities.

Keywords. Medication adherence, cardiovascular diseases, electronic health records, health information technology.

1. Introduction

New Zealand (NZ) indigenous people (Māori) are at high risk for cardiovascular disease (CVD), with 31.9 CVD hospitalizations per 1000 Māori (35+ years) and 2.9% dying from CVD annually [1]. NZ Māori suffer higher mortality and morbidity rates from CVD, with the mortality from coronary heart disease among Māori three to four times higher than in the general population [2, 3]. The NZ health system has a commendable focus on screening people for CVD risk, with guidelines recommending risk assessment for Māori, Pacific and Indo-Asian people 10 years earlier than other low-risk population groups (e.g., 35+ for Māori men and 45+ for Māori women) [4]. The challenge remains to improve the management of people with elevated risk, including populations at highest risk such as Māori. One key barrier is long-term adherence to evidence-based medication, as adherence to CVD medications is approaching only 50% among lower socio-economic groups [5]. Along with other risk factors, low medication adherence is likely to have contributed to the high CVD rates in Māori and Pacific people in NZ [6]. Among high-risk patients, those who adhered to medications had lower blood pressure, total-to-

¹ Corresponding Author: Yulong Gu, School of Health Sciences, Stockton University, 101 Vera King Farris Drive, Galloway, NJ 08205, USA. E-Mail: yulong.gu@stockton.edu.

HDL cholesterol ratio and HbA1c than non-adherers [7]. A 2013 systematic review highlighted association between adherence and improved outcomes as well as reduced costs [8]. Poor adherence has been recognized as a critical issue for public health in terms of both quality of life and health economics [9]. A 2011 estimate of the economic impact of medication non-adherence in the United States (US) accounted for \$290 billion per year in avoidable medical spending or 13% of total health care expenditures [10].

In previous studies, we developed and tested a structured primary care model to improve CVD medication adherence, predominantly in NZ Pacific populations [11-13]. Our experience suggested that patient counselling and education delivered in a general practice nurse led model can improve CVD medication adherence and physiological measures in high-needs population such as Pacific peoples [11, 12]. Health services must reconfigure themselves in order to support an active, voluntary and collaborative establishment of treatment goals between patients and providers. The findings demonstrated effectiveness, but improvement in adherence rates was only achieved with substantial additional nursing time and cost [11]. Building on this experience, we conducted a qualitative study with focus group interviews to understand the perspectives of Māori patients and their primary care providers regarding what is (not) working and what might work in primary care to achieve better adherence to CVD medication among Māori. We aimed to inform the development of appropriate, effective and sustainable interventions to improve CVD risk management among Māori.

2. Methods

Participants were recruited into either patient or provider focus groups. Potential patient participants were identified by analysis of the electronic health records (EHR) data of four NZ general practices (two in a metropolitan region and two in rural regions). Extraction and analysis methods of EHR data (including demographics, CVD risk screening results, and CVD medication prescription records) were based on previous studies [6]. Analysis of the EHR data extracted in 2014 for this study identified medication adherence status of all adult Māori patients (20+ years) with high CVD event risk ($\geq 15\%$, 5-year risk) who were enrolled and funded at the participating practices. Using EHR prescription records on three classes of CVD medication (antihypertensive, cholesterol and oral diabetic medication), we calculated medication possession ratio and defined adherence as 1) having at least 80% of days in last fifteen months covered by the prescribed CVD medication(s), and 2) having at least one prescription written in the past six months for the classes of drugs the patient was on. A random sample of patients with high CVD risk who had self-identified as Māori was drawn and invited to participate in a focus group session, including those with high CVD medication adherence status and those with low adherence (e.g. four adherers and four non-adherers per practice). The patients' families ('whānau') were encouraged to participate, as recommended in best practice guidelines for undertaking research and developing medicine interventions with Māori [14]. Four patient focus groups (one per practice) were led by the research team. Patient-perceived barriers to adherence were discussed in depth and suggestions on how to support patients were sought from the patients and families. The researcher introduced some potential intervention options (based on the literature and previous research by the authors) in each new session as topic prompts, to test face-value and acceptance. These included process improvement, additional protocols (e.g. our experience of nursing support [12, 13]) and technology options such as automatically-generated text message

reminders, and smart bottle / dispensing (including blister pack). The goal of discussion was to explore combination and tailoring of options most acceptable to patients.

In the provider focus groups (one per practice) a summary of EHR analysis findings was reported by a researcher, including aggregated adherence levels in the practice and CVD risk assessment status. This analysis was discussed to identify opportunities for clinical care quality improvement in the practice, particularly addressing adherence. Provider feedback was gathered on enablers, challenges, and suggestions on how to improve adherence among their Māori patients. Patient and provider group findings up to that point, including suggested protocols, interventions and technologies were discussed in each new provider group to assess the perceived feasibility of implementing such interventions. Constant comparison and triangulation of literature, patient perspectives, and provider perceptions across different practices were undertaken to identify interventions that might be acceptable to a wide group of Māori patients and general practice staff, and might be achievable within current health workforce constraints; i.e. promoting a transformation of ‘usual care’ that can be delivered by the same people using no more than the same amount of time as current practice.

We adopted an iterative participatory action research approach to bring together action and reflection, theory and practice, in the pursuit of practical solutions to issues of concern to individual persons and their communities [15]. The goal was to identify key components of feasible interventions for medication adherence promotion among Māori. Each practice served as an iteration. Data collected from their participants were compared by JK and YG with that collected from other practices and with literature. Then findings were synthesized and topics brought into the next practice’s discussions. General inductive analysis, constant comparison and data triangulation were used throughout data analysis to identify key themes of the discussions.

3. Results and Discussion

3.1. Medication adherence gaps among high-risk Māori

The analysis included 3,414 Māori adults, with 16% (N=549) having ≥15% CVD risk. Among the high-risk Māori, only 59% had ≥80% CVD medication adherence (Table 1). Adherence related issues were discussed with practice staff in provider focus groups. A random sample of high-CVD-risk Māori were invited to participate in patient focus groups and an average of six patient/family participants attended each group.

Table 1. CVD medication adherence status of funded adult Māori patients with identified high CVD risk

| Adherence status | N | % |
|---|------------|-------------|
| ≥80% adherence to all CVD medications prescribed | 322 | 59% |
| <80% adherence to ≥1 CVD medication prescribed | 127 | 23% |
| No antihypertensive, cholesterol or oral diabetic medication prescribed in last two years | 100 | 18% |
| Total: | 549 | 100% |

3.2. Key factors influencing long-term medication adherence

A range of factors were reported by participating patients and family as influencing their long-term medication adherence behaviour, including patients’ knowledge about medication, side effects, doctor-patient communication effectiveness, costs and value of medication and of clinic visits, and forgetfulness. These factors were repeatedly

mentioned across practices as having either positive or negative impact on adherence-related beliefs and behaviors. These factors appear interrelated and were also identified by participating practice staff. For instance, the level of patients' knowledge about their medication(s), including understanding of effects and potential side effects, is associated with how effective doctor-patient communications are perceived to be by both sides.

Doctor-patient communication requires doctors' ability to convey information and knowledge, as well as their active listening skills. Finding an effective and convenient medication for an individual often takes more than one appointment. It is a continuous and productive interaction process between provider and patient. This interaction depends on patients being informed and activated, and staff being prepared and proactive [16]. The process involves patient education and a 'trial' with the drug class, dosage, effects, to determine whether it disrupts the patient's work / life, and how it fits into her/his daily schedule. As related by a patient, "these pills that make you smell when you pass water. It's caused by these pills, and they [doctors] know it. And I said I found out what's causing that stink, it's these pills of yours. So when I've taken it I go, chuck those out and take the pink ones for the blood thinners. And the other ones, out it goes. ... Because we keep each other informed they [doctors] are going to change those pills."

The medication trial process can inform clinicians and remind them to involve the patient in shared decision-making and to take patient's circumstances into consideration when choosing or changing medications. For instance, with patients who work night shifts, adherence is difficult and shared decision-making with providers to create suitable solutions is desired, "like a tailor made system for a person that works different hours," as suggested by one patient. Without close monitoring and open communication in the trial process, patient safety may be at risk and those patients who experience side effects or inconvenience may not take the medication as prescribed, if at all. As suggested by a patient, "I really believe that when they change, putting you on blockers to lower your blood pressure or anything like that, I believe that it should be monitored for at least a week, or maybe 2 weeks. ... Because it's so easy and it happens a lot, and the next minute you're wondering why you get all light headed when you stand up, and your bloody blood pressure's too low." Another patient mentioned, "I have high blood pressure as well, and that one [diuretic] that makes you wee, oh I don't want that then. Because when you're working you don't want to be running to the loo all the time. Anyway, I stopped that." Interestingly, the patient went on describing the following experience, "I checked my blood pressure too with the little cuff and it went up to 166 [mmHg] over 90 [mmHg] I think. So I took that little pill for 2 or 3 days, came back, checked it again, 130 [mmHg]."

Participants, both patients and providers, agreed that effective communication between doctors and patients plays a crucial role in promoting adherence and delivering high quality care. A patient related, "it's having the ability to talk to the health professionals on a one on one and face to face [base], and voice your concerns. Working with them I think has been a big step forward." A challenge for patients is to keep up their understanding when a medication is changed. Confusion of a drug's generic name versus brand name also requires provider attention. One approach to improve communication may be to involve family, as mentioned by a patient, "Well there's whānau, my mother-in-law, [wife's name] talks for her. She [mother-in-law] wants to sit there and talk for herself, but [wife's name] has to talk for her because she's not telling the doctor the truth. You know, she's always hiding things." In addition to effective communication, the relationship is also influenced by factors such as trust, respect, manner, culture, and language barriers. As mentioned by several patients, "if you're not treated right they're not going to come back." "I think it starts with those reception girls.

They have to be welcoming. The last thing you want is to walk through that door and see a grumpy face.” “They actually need training in people skills and cultural awareness.”

The cost and cost/value perception issue emerged as another key factor that affects patient behavior. Although the NZ government subsidizes long-term CVD medications, there is a dispensing fee (\$5NZ per prescribed medication) payable by patients at community pharmacies. Given the number of medications high-risk patients are taking to manage their CVD risk, often alongside medications for other comorbidities, several participants felt that their medications “cost too much.” Further barriers are the costs ($\geq \$15$ per visit) and time commitment (“an hour’s drive” to the practice in rural area, plus taking time off work / other life priorities) associated with travelling to see a doctor for repeat prescriptions. All the costs relevant to maintain a personal medication supply may hinder not only good medication adherence but also access to care in general.

A related issue raised by patients was the value of medication adherence, particularly in the absence of symptoms. Research has identified that patients are more likely to take medication when symptoms are present [17]. A participant related, “I take my pills when my body says it’s time to take pills now. As soon as I get the little boom, boom, boom in the back of the head, oh heck, my blood’s gone thick again, I’d better start taking them. ... over some years I’ve been taking my pills that way.” Patient-perceived value of medication appeared to be associated with their (dis)beliefs in the efficacy of modern medication. This issue was often discussed in contrast to ‘traditional’ therapies. A patient related, “like some of you I was brought up the same way, Māori medicine came first before anything else. And you know, they were freely available. You’ve got the cobwebs up the wall, and you peel a potato if you have earache ...” Another patient mentioned, “Because of that affordability they’d rather use the old method, the old ways, the bush, the sea, the ground, the land.” If patients didn’t see value in doctor-recommended medication, they were unlikely to adhere to it. From the provider perspective, adherence was of great concern, as one clinician related “I get the feeling that, well for a certain percentage of the patients, they see the doctor, you can hand them the medication; as soon as they walk out of the building, half of it would end up in the rubbish bin anyway.”

Patients also reported difficulty in remembering to take medication. “I definitely have problems remembering ... did I take it or didn’t I?” Another patient talked about a calendar system to keep track of medication “like a medication sheet.” Many believed that blister packs, which also mark the date and time, help manage medication by prompting to take the right medications at the right time. Remembering to pick up prescription from doctors and medications from pharmacists could be difficult with the fast pace of life as well. Providers mentioned some services available that assist patients in obtaining medications, such as postal delivery from pharmacy to patients at rural locations and, occasionally, mail order prescriptions without face-to-face consultation.

3.3. Potential technology opportunities to support medication adherence

Previous research has suggested that the more a patient knows about their long-term conditions and their medications, the better equipped they are in managing their health. This requires patient understanding of what a prescribed therapy (e.g., medication) is for and how it works. As suggested by a patient, “I think another thing that helps ... is if the doctors explain a little bit more what the pills do.” However, it is a challenging task to develop adequate health knowledge/literacy within limited doctor-patient interactions. One patient stated, “I don’t really listen when he [doctor] tells me what they [my medications] are for. And that’s half the trouble, if I don’t understand what I’m taking

and I don't know what they do, it's that mindset of oh it's okay, I can forget about taking it for today. And then I might miss a couple of days, and then I wonder why I get sick."

Targeting the information needs of patients is an opportunity for health information technologies (IT) development, e.g., to support clinicians in the patient education task, via a checklist to guide the conversation, and pointers to reliable sources of Internet information (e.g., sharing bookmarks to certified or accredited resources). They could also include decision support feature for patients and providers to use during and between appointments. A patient seeking medications information may ask their health providers, their personal contacts, or search on the Internet. The use of the Internet for patient health information has become regular, with the majority of US doctors reporting experience with a patient bringing Internet information to a visit [18]. As stated by one patient in this study, "Look it up, do a search on the Internet." However, the quality of Internet information remains of concern. To support both patients and providers, many governments have invested in providing quality Internet health information services, e.g., the NZ catalog on medicines and medical devices (<http://www.medsafe.govt.nz/>).

It is also important to help patients understand the consequences of non-adherence. One patient said what many others expressed, "We need to take it and if we don't we'll get sick, so we take it." This demonstrated the process of associating perceived threat with the efficacy of recommended therapy to lower risks, as suggested in the health belief model. At one rural practice, staff described a successful education program (based on Lorig's model [19]) that they ran for CVD prevention using pictures, games, goal setting exercises, and outreach nurses conducting family group classes. A staff member related, "a lot of our Māori people up here are illiterate in some form as well, so to give them pamphlets just full of writing, or handouts full of writing ... They'll never read it and they can't read it, and they won't understand it." The key approach was "to try and explain the same thing using all different senses, then it gave everyone the opportunity, a chance to learn the same thing." IT may play a key role in sharing experience from successful programs such as this with wider practitioner community to encourage quicker program adoption and evaluation to build up evidence base.

Further, the technology environment of population groups with high health needs must be accounted for when designing patient-interacting systems. As put by one patient, "We live in the far north, we haven't got emails." As per a systematic review, although patient-oriented health IT can increase medication adherence, patient factors must be considered to ensure acceptance. Such factors include socio-demographic characteristics, health- and treatment-related variables, and prior experience or exposure to computer / health technology [20]. In this context, mobile phone text messaging may be a viable option to enhance patient-provider communication. Opportunity exists to develop features in the EHR to identify medication adherence gaps so as to support providers in patient management, and to trigger automatic text messages to patient as reminders for picking up prescriptions. Provider experience also suggested that reminder systems worked; for example, ringing up a patient about an overdue prescription. However, such actions take staff time and were considered unlikely to be sustainable within the current health system and workforce constraints, particularly with the shortage of Māori nursing and health workers. Automatic telephone services allowing patients to request repeat prescriptions were suggested by providers and patients, saving time when it is safe to do so. It was also suggested that kiosk technology, if installed in convenient locations and capable of data sharing, e.g., with PHRs, may assist self-monitoring, e.g., of biometrics such as blood pressure, and thus promote adherence to therapy. Information sharing of self-monitoring data with clinicians may also improve care quality and patient safety.

Blister packs were seen by participating patients as useful to manage complex medication regimen. Research trials on combination drug (polypill) also suggest advantage in promoting adherence [21]. Potentially, IT solutions such as smart bottle may serve the same purpose; and such technology may record better data on patient behavior to support further improvement. Table 2 summarizes the key aims of potential IT solutions to improve medication adherence by addressing key influencing factors.

Table 2. Potential health IT to address adherence factors

| Key target area for potential health IT | Adherence factors |
|---|---|
| To utilize quality Internet information services; to share education materials, experience, and information on consequences of non-adherence | Improving patient knowledge |
| To identify medication adherence gaps; to support patient self-monitoring; to deliver effective interventions to wider community; to facilitate provider training and knowledge sharing | Supporting patient-provider communication |
| To simplify prescription refill procedures; to support convenient data collection and sharing in patient monitoring | Reducing costs |
| To identify patient needs; to support data collection regarding patient behavior | Tackling forgetfulness |

3.4. Implications for eHealth practitioners

State-of-art health IT solutions, especially in knowledge management, clinical decision support, telehealth, patient health records (PHR), and mobile health, may help address adherence-related issues. The key challenges in this target area include:

- Provision of effective patient education on medication, including side-effects and impact of non-adherence. We call for developing locally-appropriate multimedia education materials, including materials to assist clinician-led education and consult (e.g., checklist-based) and self-help materials catering for patients with various levels of health literacy and deliverable via tablet computer (e.g., at clinics), kiosk (e.g., at community centers), and Internet.
- Decision support integrated with EHR to identify medication adherence gaps (e.g., based on our algorithm), and subsequently to prompt patients to act (e.g., via system-generated text messages) and providers to intervene (e.g., alerts).
- Clinician training with a focus on cultural sensitivity and competency. We recommend utilizing computer-based simulation technologies in this task.
- Patient support, in terms of self-monitoring, data management, and communication with providers. Kiosk, PHR (interoperable with EHR), and telehealth are promising technologies to reduce cost and empower patients.

In summary, there are opportunities for health IT to provide information and communication support to population groups with high health need, e.g., Māori in NZ.

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