

The role of the Community Health Worker in a Māori person's health journey

T. Forrest, P Neuwelt, R Gotty, S Crengle

Health Care Aotearoa and the University of Auckland

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About Health Care Aotearoa and the Research Team

This project was undertaken in collaboration by staff members of Health Care Aotearoa (HCA) and the University of Auckland, with HCA the lead organisation. It is part of the ‘indigenous node’ of the global research initiative entitled ‘Revitalizing Health For All’. In keeping with the global project, the four members of the team carried the roles of researcher, a leader from the organisation that would sponsor and make use of the research, and academic mentors.

Health Care Aotearoa

Health Care Aotearoa (HCA) is a Treaty of Waitangi based national network of community-driven and governed primary health care services. Its mission statement is *Transforming social inequalities through community inspired health services*.

HCA promotes accessible primary health care for all people. It offers its members advocacy, education, management and peer support programmes. HCA’s commitment to achieving health for all in Aotearoa is shown in our Whakakotahi Declaration.

HCA members are committed to addressing inequalities in health status that exist within Aotearoa. They provide comprehensive quality primary health care and innovative programmes for vulnerable populations.

The membership of HCA is spread from Te Tai Tokerau (Northland) to Otago (Christchurch). Collectively, they provide quality primary health care services for over 170,000 people – most of whom are Maori and Pacific peoples, refugees and low-income families, many with high health needs.

HCA members see health in its broadest sense. This means taking a holistic approach to primary health care. We view housing, income and employment as integral parts of a person’s overall well-being.

HCA supports the Declaration of Alma Ata in its call for ‘Health for all’ and the World Health Organisation Commission’s report on the social determinants of health, Closing the Gap in a Generation.

Tania Forrest is Ngati Whakaue of Te Arawa. She works as a research analyst for Health Care Aotearoa, and was the *early career researcher* on this project.

Pat Neuwelt (Dr.) is a non-Māori public health physician and senior lecturer at the School of Population Health, Faculty of Medical and Health Sciences, The University of Auckland. Her research is in the areas of comprehensive primary health care and health equity, and she was the lead *academic mentor* for this project.

Rowena Gotty is of Tuwharetoa, Te Whanau-a-Apanui, Ngati Toa, Ngati Raukawa and Te Atiawa descent. She was the Te Kaihautu (Co-National Coordinator) of Health Care Aotearoa (HCA) during the period of this project, although she is no longer employed by HCA, and she was the *researcher user* involved in this project.

Sue Crengle (Dr.) is from the Kai Tahu, Kati Mamoe, Waitaha tribes in Aotearoa/New Zealand. She is currently a Senior Lecturer in Te Kupenga Hauora Maori, and Co-Director of Tomaiora Maori Health Research Centre, Faculty of Medical and Health Sciences, The University of Auckland. Her current research interests include health services research, quality of care, and child and youth health, and she was the *indigenous academic mentor* for this project.

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SUMMARY

INTRODUCTION

In Aotearoa New Zealand, Māori health service providers play crucial roles in delivering primary health services that work for Māori, the indigenous peoples of Aotearoa New Zealand. They offer culturally distinctive care and provide a range of comprehensive primary health care programmes and services. Community health workers (CHWs) have emerged as primary health care team members, in Māori health service provision. This study explored the role of CHWs in the health journey of Māori, by undertaking a case study of a Māori health service provider in the Hutt Valley in the Wellington region. The research question was generated in response to a consultative discussion with a group of primary health care providers who are members of Health Care Aotearoa (HCA) a national network of comprehensive primary health care providers known to improve access to populations with high health needs. HCA members voiced the need for research to highlight the role of CHWs and their contributions to improving Māori health equity in order for the organisation to be in a stronger position to advocate for the role as a critical human resource strategy in the advancement of Māori health. A focus on whanau, the health service users, was promoted by HCA to ensure that data collected were not simply reflecting provider induced demand for greater resourcing of CHWs, and to ensure a strong kaupapa Māori research emphasis.

This research was undertaken by staff members of Health Care Aotearoa, although it was supported by two public health academic research mentors (one Māori) at the University of Auckland's School of Population Health. The principal researcher, TF, led the project for Health Care Aotearoa. HCA is an organisation member of the People's Health Movement in New Zealand (PHM-NZ). A research 'triad' concept was trialed as part of the international project approach to the theme 'Revitalising Health For All.' The aim of the triad model was to encourage greater participatory mechanisms, allowing research to be carried out by those in close proximity to the development and conceptualisation of the investigation (*beginning researcher*), supported by an experienced researcher with a view to wider publication potential (*research mentor*) and commitment from an identified stakeholder likely to benefit from the research outcomes (*research user*). (Our narrative reflection of the triad model is outlined in part 4 of this report.)

The research aim was to examine the role of the community health worker in a Māori person's health journey. The project was undertaken as a pilot study, and employed a case study investigation in which the 'case' was a Māori health service organisation providing comprehensive primary health care in an urban setting. A qualitative methodology, using a kaupapa Māori research approach, was adopted.

POSITIONING THE RESEARCH AS INDIGENOUS

Our 'Māori' focus for this research stems from the knowledge that 'indigeneity' is a key health determinant, characterised ultimately by shorter lives than non-indigenous peoples, even in industrialised nations (Gracey & King, 2009; King et al., 2009) and in New Zealand, even when controlled for other determinants such as income (Spurle, Pearce & Davis, 2002).

For the purpose of the study, we refer to the term 'indigenous' as a means to highlight the unique socio-political dimensions of being 'Māori' not just notions of culture and ethnicity. Parker & Kaufman (2009, p.1) refer to the work of Martinez Cobo (1987) for a definition: "Indigenous refers to communities, peoples and nations having a historical continuity with pre-

invasion and pre-colonial societies that developed on their territories, consider themselves distinct from other sectors of the societies now prevailing on those territories, or parts of them. They form at present non-dominant sectors of society and are determined to preserve, develop and transmit to future generations their ancestral territories, and their ethnic identity, as the basis of their continued existence as peoples, in accordance with their own cultural patterns, social institutions and legal system.”

Māori, the *tangata whenua* (people of the land) of Aotearoa New Zealand, make up approximately 15% of the New Zealand population, comprising some 624,000 (at census 2006) people. There are further expatriate Māori in Australia (estimated 150,000) and Britain (estimated 15,000). Māori are essentially a tribal society constructed from small family based units (whanau) organised into sub-tribes (hapu) which contribute to larger tribal entities (Jansen & Jansen, 2011).

As Māori within New Zealand, we have our own distinctive rights which flow from aboriginal title as evidenced by the 1835 Declaration of Independence and the 1840 Treaty of Waitangi (Durie, 1994). We have our own colonisation history (Robson & Reid, 2001) and persistent experiences of poverty and poorer life expectancy than non Māori (MOH 2004,) and our own timeline of socio-political activism in the pursuit of *tino rangatiratanga* self determination; *oritetanga*: equity and *kawanatanga*: self governance (Durie, 2003; Durie, 2005; Walker, Durie, Cooper, Snively et al, 2010) in our relationship with the Crown.

Within this indigenous context, this study recognises that whenever the health of Māori lags behind that of other New Zealanders (Whitehead, 1992), including their underutilisation of health services relative to need, it is a breach of the Treaty of Waitangi and of indigenous rights. Despite the recent gains in closing the gap between Māori and non-Māori, there is concern that these achievements will be lost if the lessons from comprehensive primary health care achievements are not sustained (Health Care Aotearoa, 2010). Māori continue to suffer the worst health outcomes in New Zealand, which are largely preventable (Tobias & Yeh, 2009). This study is based on an acknowledgement of the importance of ‘By Māori For Māori’ participation in health service provision through Māori health service providers (MOH 2002a), Māori health workforce development (MOH, 2006), and the recent introduction of the Māori-led Whānau Ora policy aimed to facilitate health and social sectors and their stakeholders to operate more whānau-centric systems of care (Durie, Cooper, Snively et al 2010). Consistent with this indigenous context, this research employed kaupapa Māori research principles, as discussed under ‘Methods’.

Furthermore, the authors recognise that the role community health workers play in achieving health gains for Māori whānau is largely silent, and support the identified need (see Boulton, Gifford, Potaka-Osbourne, 2009) for further recognition of their unique role within Māori comprehensive primary health care settings.

(NOTE: a glossary of Māori words is located in the appendices.)

LITERATURE REVIEW

This section of the report focuses on the background literature review, which further sets the scene for the research. It begins with a discussion about Māori health statistics and access to health care, then discusses Māori health service provision in Aotearoa New Zealand, and then discusses literature on the role of community health workers in New Zealand and elsewhere.

The literature search included both academic and gray literature from New Zealand and international sources. Particular efforts were made to retrieve New Zealand research and evaluations; however, such literature was rare. Where it was available, it has been given prominence in this report. The information about CHWs in New Zealand was retrieved primarily from gray literature, and only one piece of research was found that focused on the role of Māori community health workers.

Māori Health Statistics and Access to Health Care

Māori have the poorest health status of any ethnic group in New Zealand (see Table 1). While there remain further inequities within the non-Māori population, particularly for Pacific and new migrant populations, Table 1 does not disaggregate the data to highlight these groups.

Table 1: Life table for the Māori and non-Māori population, by gender, 2000-2002 (Robson & Harris, 2007).

Age	Expected years of life remaining (years)		Expected years of life remaining (years)	
	Māori female	Non-Māori female	Māori male	Non-Māori male
0 years	73.2	81.9	69.0	77.2
25 years	49.3	57.7	45.6	53.3
45years	30.4	38.3	27.3	34.4
65years	15.1	20.2	12.7	16.9
85years	5.2	6.5	5.2	5.2

There is inequity in access to care and outcomes at all levels of the New Zealand health system from community and screening services, through primary care and injury treatment services, to secondary and tertiary services and back to post-hospital in-home services (Barwick 2000; Arroll et al 2002; Ajwani et al 2003; ACC 2004; Crengle, Yay-lee & Pearson, 2005). Disparities are seen even where services are free at the point of care (MOH, 2008b) and after taking account of the differing age structures and socio-economic status of populations.

Even when income is accounted for, wealthier Māori still have worse outcomes than wealthier non-Māori (Sporle, Pearce & Davis, 2002). Just under 11% of Māori are unemployed as opposed to 5% of the general population (Statistics NZ, 2009). In terms of health statistics, Māori infants die more frequently from SIDS and have lower birth weight than non-Māori children (MOH, 1999). In 2007 UNICEF reported New Zealand had the worst child and youth statistics for injury and accidents in the developed world, most whom are Māori. While reductions in smoking have been dramatic in New Zealand with only 22% of the population who still smoke, smoking rates

among Māori are still almost double at around 44% (Ministry of Social Development, 2008). New Zealand has a higher rate of death from cancer than Australia with Māori accounting for two thirds of the excess male cancer deaths and one quarter of the excess female cancer deaths (Skegg, McCredie, 2002). Māori women have rates of breast, cervical, and lung cancer that are several times those of non-Māori women (MOH, 1999). There is higher incidence of obesity in the Māori community (27 percent versus 16 percent) which contributes to higher incidence of diabetes (8 percent versus 3 percent) and the younger age at diagnosis (43 years versus 55 years). The lower rates of diagnosis and lesser access to effective treatment (Crengle, Lay-ye, Davis, Pearson, 2005) also contribute to the avoidable death rates which are almost double for Māori than for other New Zealanders (Ring & Brown, 2003). New Zealand Ministry of Health data show that initial access into the health system is an issue for Māori. Māori experience double the rates of unmet GP need – times when they needed to see a GP but were unable to (MOH, 2008a) and this is partly likely to be due to GPs locating in areas where there is less deprivation. Despite the recent efforts in primary care made by reducing costs to primary care, emergency admission rates for Māori remain flat. Some nine percent of admissions to emergency departments around the country are for ailments that could have been treated by a GP (Crengle, et al 2005) and 9% of patients don't turn up for their specialist appointments.

Researchers have shown that cardiac care required relative to need for Māori is lower (Westbrook, Baxter, Hogan, 2001), and 30-40% fewer national screening rates for breast and cervical cancer for Māori women despite their much higher incidence rates. Some surveys of opinion showed Māori have a higher reported incidence of racism within the system as one explanation for why disparities in access occur (Harris, 2006; Crengle et al 2005). A National Medical Care Survey was a study of data collected in 2001 and 2002 from 199 private general practices, 24 physicians in community governed practices and 21 doctors who worked with Māori providers (Crengle et al, 2005). Results demonstrated Māori are seen at a disproportionately low rate compared to the general population, doctors reported lower levels of rapport and spent less time on average with their Māori patients. They also ordered fewer tests and investigations for their Māori patients and blood lipid and glucose tests were ordered at lower rates despite the higher diabetes incidence. Referrals and follow-up visits within three months were also at lower rates for Māori.

Jansen and Smith (2006) compared access disparities with areas of relatively equal access between Māori and non-Māori. Access to emergency transport and specialist accident related treatment once a referral had been made was almost equal between Māori and non-Māori. These scenarios were reported to be types of care dictated by protocol; that is, what must be done rather than what might be done with no regard to other factors such as provider preference, ability to pay, or to provider/patient relationships. However, the authors reported once the emergency situation passed, utilisation of services by Māori appears to revert to that seen outside the emergency situation. Barriers for Māori are reinstated and less than optimal care is provided. No single reason why Māori patients receive less care than non-Māori in a primary care setting exists. However looking to the health care functions of the health system, Jansen & Smith (2006) highlight that patients require knowledge of how the system is organised, who the key players are and the relationships between different parts of the health care system in order to receive the best standard of care. Furthermore they emphasize the health system reflects values associated with individualism and self-advocacy and therefore provides care in a manner which advantages certain groups including higher socio-economic groups; non-Māori, non-Pacific groups; and those without disabilities. Patients at greatest disadvantage in health terms were reported to be

those with the least influence on the health care system and therefore require greater support from health care providers in order to access needed care. Solutions promoted in the study to reduce access and treatment disparities for Māori patients begins with an understanding and understandable health care provider, and the appropriate management of barriers including cost, communication skills and attitudes of health care providers, health service funding and policy settings (Jansen & Smith, 2006).

Māori Providers

As described previously, Māori do not get comparable outputs from the New Zealand health system, relative to non-Māori (Barwick 2000; Arroll et al 2002; Ajwani et al 2003; ACC 2004; Crengle et al 2005). Māori health outcomes suffer, as a result. Indigenous peoples in many countries have secured more control over community based health services, in the hope of improving access and responsiveness (United Nations, 2002) with claims that indigenous self-government is fundamentally linked to improved community well-being (Lavoie, Forget, Prakash et al, 2010; Durie, 1998, 2001). Given it can be very difficult to evaluate the effectiveness of preventative or public health interventions, it has also been a research challenge to link indigenous self-determination and health outcomes in both OECD and low-and-middle-income countries (Liu, Hotchkiss, & Bose, 2008). Ultimately this evidence gap continues to make it politically easy to overlook the important contributions that Māori providers make towards improving the health of the populations they serve, and undermines their untapped potential for further development.

Only recently, in a Canadian study by Lavoie et al, (2010), have direct correlations between indigenous self-determination and health outcomes been demonstrated. This quantitative study sought to document the relationship between local access to primary care, measures of community control, and the rates of hospitalisations for First Nations on-reserve populations in Canada. While the authors identified limitations in terms of the study design transferability, the findings showed that in indigenous communities where local access to GPs was constrained, indigenous-controlled multidisciplinary primary health care solutions led to better primary care access and reduced avoidable hospitalisations.

By 2009, there were 264 recorded Māori health service providers (Māori providers) in New Zealand (MOH, 2009). Māori providers offer comprehensive primary health care, which usually includes medical care. While the majority of the Māori population access mainstream primary care services, surveys indicate that Māori are more likely to use a Māori provider if the option is available (MOH, 2008). Pilot studies have shown that Māori respond well to services that use Māori outreach workers (Ellison-Loschmann & Pearce, 2006). Crengle (2000) identified that Māori providers use Māori models of health and promote positive Māori development as the key philosophies underpinning Māori health services. Māori cultural processes are used as a basis for developing and delivering contemporary health services that support self-sufficiency and Māori control. These factors are identified as crucial to the success of these provider organisations (Crengle, 2000). In addition, a range of strategies to address access include extensive mobile services and outreach clinics alongside a health centre service base, free or low cost care, employment of primarily Māori (who are more likely to have access to Māori consumers in their communities), and active inclusion of Māori communities in the planning and delivery of services.

Māori providers continue to face a number of difficulties which limit their potential. A lack of good primary health data such as ethnicity data was reported to have limited the potential of many Māori health providers (Ellison-Loschmann, 2006). Another challenge is the small size of the professional Māori health workforce, which is 3.2% yet Māori comprise 15% of the total New Zealand population (Medical Council NZ, 2009).. In addition, there are persistent challenges for Māori providers to attract Māori health workers, due to disparities in pay that exists between other health sector workers and those who work for Māori providers. This has made it increasingly difficult to attract and retain staff, with reports that many Māori provider workers were being poached by mainstream health providers taking their skills, qualifications and experience with them (Nagel, 2005). According to Te Whiringa Trust, a national Māori Community Health Worker network, Māori CHWs make up at least half of the total Māori health workforce (Te Whiringa Trust, 2010). If CHW numbers were to be included in statistics for Māori health workforce then this would increase the Māori health workforce to approximately 6.4% representing the total number of Māori working in health.

Māori providers also sustain the burden of multiple contracts with short timeframes which require extensive renegotiations each year (Durie et al, 2010; Ellison & Loschmann, 2006) and onerous audit requirements (Te Wana, 2008). While health policy initiatives to improve indigenous health have been adopted in Canada and Australia, there is early evidence that the contractual environments in these countries, which lean toward single multiyear funding contracts for CPHC, and are more efficient for indigenous health providers and promote better health outcomes (Lavoie, 2003). Finally, because Māori providers work primarily with families with high levels of health need, increased costs of service provision are inevitable if health gains are to be achieved, and funders must take this situation into account (Durie et al, 2010, Ellison-Loschmann, 2006).

Community Health Workers

There is no accepted universal definition for the term ‘community health worker’ or CHW (Berman et al., 1987; Gibling, 1989; Witner et al., 1995; Love et al., 1997). We searched for a New Zealand interpretation. CHWs are voluntary or salaried health workers who, alongside their communities work to translate western medical ideas of health promotion and education into activities and tasks relevant to Māori community health and well-being (Laing, 1988). Haretuku defines CHWs as community advocates, bridging the health sector and Māori communities (Haretuku, 2000).

A selection of databases were searched (CiNAHL, Medline, EBSCO, PubMed) using the term *Community Health Worker*, *Indigenous Community Health Worker* and *Lay Health Worker* from the 1980s onward. In total 14 studies were used out of 213 retrieved. The search involved a three pronged focus. From references generated, particular efforts were made to retrieve systematic reviews, with a more refined search focused on indigenous CHWs. New Zealand literature was rare, however where it is available it has been given prominence in the report. A selection of grey material from a Māori Community Health Worker website was accessed for further background on CHWs in New Zealand. Only one New Zealand article was retrieved which focused solely on the role of Māori community health workers.

CHWs share an internationally recognised history of innovation and commitment to working with underserved populations (Sanders & Lehmann, 2007; Nemeck & Sabatier, 2003; Witner

Seifer & Finocchio, 1995) who are marginalised by unequal access to health resources and subject to health systems which undermine their universal right to access appropriate health care (Baum, 2007; Labonte, Sanders, Baum, 2008). The conception and practice of CHWs varied enormously across countries in the literature, conditioned by their aspirations and economic capacity (Prasad, Muraleedharan, 2007). The differing health systems and population health challenges across countries also highlights the range of contexts in which CHWs are being utilized. A number of studies report a lack of understanding of the CHW concept and a dearth of evaluation literature on CHWs are two important factors contributing to CHW underutilization (Boulton, Gifford, Poutaka-Osbourne, 2009; Lehmann & Sanders, 2007; Prasad & Muraleedharan, 2007; Nemcek & Sabatier, 2003) All 14 studies explored conclude that CHWs are located in communities where there is underutilization of health services in both rural and urban settings in high, middle and low income countries. Moreover CHWs are recruited from the communities they serve and they play a key role in improving access to health services for marginalized populations. CHW opportunities for occupational recognition and protection is a challenge across all countries.

A number of systematic evaluations and reviews about CHWs suggest there is wide global interest in the effectiveness of CHW programmes and initiatives against specific interventions such as targeted health programmes and the researchers drew heavily on these reviews to gain an overall perspective on thematic issues. In particular we focused on studies which documented what made CHW initiatives successful or unsuccessful.

Prasad & Muraleedharan (2007) reviewed a total of 110 studies among both developed and developing countries to draw insights into effective CHW initiatives. Findings demonstrated the critical factors which influence the overall performance of CHWs includes the nature of employment, career prospects and incentives and training. In New Zealand the appropriateness and availability of training which reflects changing health needs, agreed best practice and equal access to training opportunities for CHWs are key. The review concludes that population coverage and the range of services offered at the community levels are vital in the design of effective CHW schemes. The smaller the population coverage, the more integrated and intensive the service offered by the CHW.

Lehmann & Sanders (2007) conducted an extensive review with at least eight systematic reviews and 250 publications. They found robust evidence that CHWs can undertake actions that lead to improved health outcomes, especially but not exclusively in the field of child health. They found the most successful CHW initiatives were large in scale, where community participation and CHW programmes were instituted and integrated throughout the health services and systems, not as an alternative but as an integrative part of the health system. In contrast CHW programme failure was linked to unrealistic expectations, poor planning and an underestimation of the effort and input required to make them work. The authors also highlight that CHWs are not a cheap option for providing care where there are health workforce shortages.

In keeping with the indigenous focus for this study (indigenous health users, indigenous health provider and mainly indigenous CHWs) the researchers examined the literature available about indigenous CHWs and in particular those CHWs working within indigenous primary health care providers. A growing belief in indigenous communities worldwide is that historical trauma, a condition that has its roots in the processes of colonisation and that continues to be reinforced through socioeconomic disadvantage and racism and discrimination, is a barrier to the

achievement of healthy indigenous communities. Therefore the inclusion of indigenous primary care providers and CHWs in healthcare settings can provide a vital and trusted cultural connection (Parker & Kaufman, 2009). Gibling (1989) described indigeness as being of the same community and subculture, assumed to represent a sharing of attitudes, values and behaviours between the provider and the client. Training of indigenous CHWs is less about the acquiring of specific program skills and more the effort to preserve the indigenous essence of the person.

Indigenous CHWs are a fundamental structure within indigenous health providers and in Canada they comprise greater than 40% of the First Nation health provider workforce (Parker & Kaufman, 2009). In New Zealand, Te Whiringa Trust, a national Māori CHW advocacy network claim Māori CHWs make up nearly half of the total Māori workforce. Boulton, Gifford, Potaka-Osborne (2009) acknowledge that Māori providers rely heavily on CHWs to implement their contracts. Therefore without them the indigenous health care system would collapse. Minore, Jacklin, Boone & Cromaty (2009) suggest that a majority of professionals who work in indigenous communities tend to be non-indigenous and are in many cases reluctant to commit to work for a significant period of time in places where there are high health needs, and often where the working conditions are difficult. Paraprofessional roles such as the CHW however tend to stay, providing a measure of stability and continuity. Again CHW issues identified are about the need for further clarity of the role by developing national practice standards and core competencies that result in targeted training, education and career laddering. Likewise there is evidence that these possibilities have been examined amongst New Zealand CHWs (Te Whiringa Trust, 2010) highlighting a need for greater recognition which includes fair remuneration, decreased strain and burnout from mounting and unfocused demands and enhanced interactions with health professionals.

Literature about Māori CHW contributions in primary care settings in New Zealand is limited, and health user perspectives supporting the identification of the CHW role is even fewer both locally and abroad. Boulton, Gifford, Potaka-Osborne (2009) examine the Māori CHW role highlighting cultural distinctions and the importance of CHW community connections with family whānau through ancestry or tribal affiliations (whakapapa) cultural knowledge and whānaungatanga (shared family and tribal activities). Tensions faced by CHWs and their managers in the study support earlier studies by (Laing 1988; Penny, 1996; Crengle, 1997; Gifford, 1999; Haretuku, 2000) demonstrating that the breadth and diversity of the role, alongside managing community expectation within 'governance by contract' work environments is a key challenge. Therefore the Māori CHW role is not without its challenges. Ultimately the future potential of Māori CHWs rests on cautionary progression toward ongoing CHW role development. Gibling (1989); Parker & Kaufman (2009) Minore et al (2009) warn of some of the potential pitfalls of establishing national standards. For example education and training opportunities if they were to become standardised may move CHWs out of their current position into a semi professional health occupation in response to national workforce needs. Qualities of deep community-rootedness and extensive family ties could hinder some CHWs contemplation of further study. Other issues such as childcare, work release time and anticipated concerns such as not being able to manage the academic requirements may actually take away what makes CHWs effective in the first place.

Most of the studies reviewed aligned to CHW feasibility and effectiveness against specific interventions such as targeted health programs (Lehman & Sanders, 2007) and while useful, they

highlight the need for a greater focus on the contexts in which CHWs are operating so transferrable gains can be shared. This study fills an important research gap whereby the CHW role is examined from the service user perspective to learn more about the role of the CHW in people's health journeys. The focus on CHW effectiveness is located around the service user in the context of an indigenous Māori health provider, so success and challenges of the CHW role can be better understood. In terms of overall CHW effectiveness we have aligned our focus using a case study approach of the selected Māori provider rich in policy and regional health data to highlight systemic health service utilization rates by Māori and health challenges. By doing so we aim to highlight the need for better Maori access to services in the Hutt Valley region, and the gains people have experienced from their contact with a CHW.

RESEARCH AIM

This study aimed to explore role of community health workers (CHWs) in the health journey of Māori.

The research question was generated in response to a consultative discussion with a group of primary health care providers who are members of Health Care Aotearoa (HCA), a national network of comprehensive primary health care providers known to improve access to populations with high health needs.

METHODS

This pilot project was undertaken using case study and qualitative methods, underpinned by a 'kaupapa Māori' research approach. This section begins by describing Kaupapa Māori research, and then outlines the methods used for sampling to find both the case study and participants, to collect data from individual participants, and to analyse those data.

Crengle (2009) describes the principles of kaupapa Māori research (KMR) as:

- Location of the research project within the wider context of tino rangatiratanga (self-determination). In the context of research this principle encompasses control of research and research processes, participation in all levels of research, and the delivery of information that will contribute to Māori development and autonomy (International Research Institute for Māori and Indigenous Education (IRI) & Te Rōpū Rangahau A Eru Pōmare, 2000; Smith, 1997; Smith, 1999).
- Connection with Māori philosophy and values and the incorporation of Māori attitudes, language, and ways of living in the world (Smith, 1999).
- Awareness and critique of the dominant accepted norms, assumptions, and power relationships and how these serve to maintain the 'status quo' that privileges the dominant (non-Māori) community and maintains disparities between Māori and non-Māori (Smith, 1999).
- The legitimacy and validity of Māori world views are taken for granted and seen as the norm, and KMR seeks to understand Māori knowledge and experience on its own terms (International Research Institute for Māori and Indigenous Education (IRI) & Te Rōpū Rangahau A Eru Pōmare, 2000; Smith, 1997; Smith, 1999).

- Moves Māori from the margin to the centre, allowing Māori concerns to be addressed, and provides information that addresses our self-identified priorities (Smith, 1999).
- The methods (practical techniques for gathering information in research projects) used to collect information are not prescribed and the method(s) most suitable for the task are employed.

In relation to this project, it focused on an issue of central concern to the Māori health sector and used methods that were culturally appropriate. The project was located within Māori health service providers, involved a Māori researcher, and will provide information that will be useful in supporting and developing the role of Māori community health workers in Māori health providers and communities.

SAMPLING

The study involved two processes of selection, both of which were purposive (Patton, 2002). The first was to identify an appropriate Māori health service provider (Māori provider) of comprehensive primary health care within HCA. This Māori provider would provide the setting for a case study of the role of Māori community health workers. A second selection process was used to recruit willing study participants from within that service provider. The purpose of selecting a Māori provider for the case study was to highlight the environmental and policy context of the CHW role within a kaupapa Māori primary health care organisation.

Sampling Process 1: Case Study

The researcher and research user set key criteria for selecting eligible Māori service providers for the case study. First, the Strategic Reference Group, a subgroup of the governing body of HCA, decided that the case site for this study would need to be local to the HCA national office, in order to minimise the cost of site visits by the researcher. Thus, it was agreed that the Māori service provider (Māori provider) for the case study would be located in the greater Wellington region. Further, the Māori provider would need to offer comprehensive primary health care (CPHC). The key selection criteria included the following:

- Must be a member organisation of HCA;
- Must be Māori owned and governed, and recorded as a Māori Provider within the Ministry of Health;
- Must be either an iwi-based provider, owned and governed by tangata whenua (tribal people of the land) or a pan tribal provider (service is led by Māori of other iwi but who are mandated by tangata whenua through agreed processes such as governance representation);
- Must be not-for-profit;
- Must have demonstrated commitment to improving health equity of Māori;
- Must offer a range of preventative, diagnostic, health promoting, curative and rehabilitative services, and population health programmes;

- Must have community health workers (CHWs) as part of their workforce;
- Must provide a General Practice service;
- Must be committed to community buy in and involvement in the design, development and implementation of their services (Te Toi Hauora-Nui, 2009)
- Must be located in the Wellington region.

Prior to excluding providers from outside the Wellington region, there were twelve eligible organisations; however, within Wellington there were only two providers that met the criteria. The two eligible organisations were Te Runanga o Toa Rangatira and Kokiri Marae. As Te Runanga o Toa Rangatira operates GP practices in all three sites of operation, the researcher and research user approached them first, with a letter of invitation outlining the aims of the research. They declined to participate.

Subsequently, the researcher and researcher user approached Kokiri Marae Health and Social Services (Kokiri), and requested a hui (meeting) to discuss the research objectives. A copy of the research proposal was sent to Kokiri ahead of the hui, and at the hui the organisation accepted the invitation to participate in the research. A memorandum of understanding was drawn up between HCA and Kokiri Marae identifying the roles of responsibilities of each party. This sampling process led to the identification of Kokiri Marae Health and Social Services (Kokiri) of the Hutt Valley area as the ‘case organisation’ for this study.

Sampling Process 2: Study Participants

Part two of the selection process involved purposive sampling techniques to gain the interest and consent of participants involved in Kokiri. As the research focus was the role of the CHW in a persons health journey through a Māori CPHC service, it was necessary to examine the views of Health service users as well as CHWs themselves, and their colleagues, in order to gain a broad understanding of the role from different perspectives. The key stakeholder groups, from which participants were drawn, included service managers, receptionists, nurses, and patients / service users, as well as community health workers themselves.

The researcher met with the Kokiri manager, and presented the information sheet and consent form. All CPHC team members were then briefed on the research project at a staff meeting, and they were invited to take part in focus group discussions or individual interviews. Kokiri was responsible for setting the venue date and time for the staff focus group. Unfortunately a GP was unavailable at the GP clinic site as they had just left the service. See Table 2 for details of final Kokiri staff participants. Two managers, two receptionists, two nurses and four CHWs (one from the GP clinic, Whaioranga) were recruited to the study. All ten staff members were women and all were Māori except for one CHW who was of Pacific ethnicity. The Māori CHWs engaged with Māori patients and communities, whereas the role of the Pacific CHW was to work with Pacific patients and communities.

Health service consumers (‘users’) were recruited differently. The criteria for users’ eligibility to participate in the study were that they must have used both GP and CHW services provided by Kokiri, and must have been accessing those services for a period of at least 6 months. A weekday in late 2009 was chosen as the sampling date. The decision to sample from late 2009 was to ensure that users had been accessing Kokiri services for a reasonable length of time and so would have experience to draw on for the study. A Kokiri receptionist randomly chose an October date; however, she ensured that the final date chosen was one on which CHW services were operating. All services users on that day, who were recorded in the clinic’s diary of recorded visits, were to be recruited by telephone to participate in the study (n=15). However, using this technique was unsuccessful in achieving participant recruitment, due to challenges in tracking down users by telephone. Most were not readily contactable using the clinic’s contact details. As the users perspectives were deemed critical to the study, the Kokiri CHWs were asked to invite users to participate in the study. They used the same method, of selecting a date and contacting all service users on that date as recorded in the clinic’s diary. When they failed to achieve participants from one day, they moved onto the next clinic day, until they had achieved a few verbal consents. This method of recruitment was successful at engaging five participants who were Kokiri service users (see Table 2). The service users were between the ages of 21 and 80 years of age, all were women, and all were Māori.

Table 2: Study Participant Numbers, by Role and Ethnicity (NB: all were women)

ROLE	NUMBER of Participants	Ethnicity of Participants
Managers	2	Māori
Receptionists	2	Māori
Nurses	2	Māori
Community Health Workers	4	3 Māori, 1 Pacific CHW
Service Users (patients)	5	Māori

DATA COLLECTION

Data were gathered on both the case study site, and from individual participants. The case study data collection and findings are summarised in the next section. This section will describe methods used for data collection with individual participants from Kokiri. The study used qualitative methods based on kaupapa Māori research principles, as discussed previously. Semi-structured interviews and focus groups were carried out with 5 service users and ten Kokiri staff members. Data were collected from four CHWs, two nurses, two receptionists and two managers.

Participants were offered the choice of being interviewed individually or being part of a ‘role-specific’ focus group. The researcher conducted three individual semi-structured interviews with service users, one of which included two users, as was their choice. The staff members opted to participate in focus groups. Four CHWs participated in one focus group, and other members of the primary health care team (nurses, managers and receptionists) participated in a focus group together.

Interviews with service users were conducted by the researcher, at a time and place that suited the participants. They were all interviewed in their homes, except the joint interview, which took place at Kokiri’s GP clinic. Interviews were carried out as informal discussions in which the researcher prompted responses by asking key questions. Topics about which discussion was invited included the following (see Appendix for full interview schedule):

- What do you value most about CHWs
- What do CHWs do in their roles
- How Health service users came to be involved with their CHW
- How are CHWs involved in people's health journey
- Challenges and strengths about the role

Each interview lasted about 70 minutes.

Focus groups were carried out at Kokiri marae in their 'hui room'. A kaumatua (Māori elder) opened each of the two focus groups. His role was to bless the process, and to accompany the staff through the research process. Food was offered to participants at the end of each focus group, as a koha (gift), as is usual at hui. The HCA quality manager attended the focus groups, along with the researcher (TF). The researcher explained the research in detail and answered questions before each focus group began. She allowed participants the freedom to discuss her questions among themselves (see Appendix for interview schedule). She prompted, as needed, to ensure the relevant material had been discussed. Each focus group took about one hour and twenty minutes.

All interviews and focus groups were audiorecorded using a digital voice recorder, with full consent of participants, and transcribed in detail by a transcriber employed by HCA for the task.

DATA ANALYSIS

The data from interviews and focus groups were analysed by the researcher using an inductive 'constant comparative method' of analysis (Thomas 2006). This method involved the researcher reading and re-reading the transcripts of the interviews and focus groups, and checking the audio recordings when data were unclear.

No software was employed to assist with the analysis; rather, the researcher highlighted key findings thematically on the transcripts, then combined all important quotes thematically. During this transcript review process, key themes became evident to the researcher. These were documented as preliminary analysis and sent, along with transcripts, to the research mentors (PN and SC) and the service user (RG) for further analysis and thematic development of findings. The 'richest' interview data -- those interviews in which participants demonstrated the most valuable insights on the research topic -- came from the CHWs and the service users, and these data were given special emphasis. Three key themes emerged from the data, and these were confirmed with the research mentors before being written about in detail as key findings.

The Case Study: Kokiri Marae Health and Social Services

A mission of passion, dedication, vision and skills of service according to need, and to our clients dreams. Flexible, yet structured, challenging yet supportive, focused yet holistic so our people may come to reclaim and honour their past, prepare for the challenges and chances of the present and create a future that enhances the life of the nation and the tino rangatiratanga of the people (J.Ferris-Delemare, n.d.)



Introduction

As part of the research project, data were gathered on Kokiri Marae Health and Social Services (KMHSS) in order to gather a clear profile of the organisation as a Māori CPHC service provider. Documents and quality improvement review reports were reviewed by the researcher, and summarised under key headings as follows:

- General history and vision of the provider
- Primary care services provided
- Population served
- Contracts and funding
- Workforce
- Brief strategic policy overview of regional health sector
- Demographic profile
- Health Utilisation outcomes for 2009
- Health statistics
- Regional health targets

Kokiri Marae Health and Social Services (KMHSS) is a long established urban marae-based health provider with a strong reputation for effectively engaging with whānau. The organisation is located at a seaward industrial area in the Hutt Valley region of greater Wellington (capital city). The main site is a modern marae epitome, and resembles an activity centre for Māori community leadership, collective health and well-being programmes and services within a te ao Māori (Māori knowledge, resources and worldview) environment. The kaupapa or Māori ‘heart’ of the organisation is transmitted through its founding people and their descendents who continue to be involved in the governance and operation of the organisation, and wider whanau including the workforce and community. Currently KMHSS and its affiliate service provider Whaioranga o te Iwi serve a population of approximately 12000 within the Hutt Valley area, who experience high health and social needs.

History

The genesis of Kokiri services grew from an inspirational Māori woman who worked hard with local Māori and iwi, to gain greater control over the declining social issues amongst Māori in the community. Initially KMHSS set up in the 1960s to deal with unemployment and socially troubled Māori youth, and those seeking collective identity within local gangs. Today, in 2011

the expansive operation reflects a remarkable transformation from its early beginnings and now offers a range of social and health services targeted at Māori and other vulnerable groups. The organisational structure demonstrates a number of trusts and incorporated societies representing different health and social programmes however all are affiliated to KMHSS allowing each programme a degree of independent governance and strategic flexibility while remaining part of the marae-based collective in which cultural values are shared. KMHSS is a Māori health centre of excellence, a hub of community development, innovative care delivery for those who need care the most, where research and policy activities are developed through collaborative community action and training programmes are offered to other Māori providers.

Services provided

All services provided by KMHSS are free and provided in communities and homes. Whanau accessing Whaioranga o Te Iwi clinic pay low cost primary health fees to access a general medical practitioner (GP). Whaioranga is a separate entity, with its own governance body, that serves an enrolled population of six thousand. It is a general practice that was established by Kokiri to meet the needs of people in a relatively isolated suburb. The two organisations work in partnership, and share clients.

Kokiri Marae Health and Social Services	Whaioranga o te Iwi Services
Māori Asthma Support Diabetes Support Well Child / Tamariki Ora programme Outreach immunization Injury Prevention Family Well being Smoking Cessation Mens Health Elderly health Adolescent health Nutrition	Sexual health services Mobile nursing Primary mental health nursing Support to manage chronic conditions Counselling Midwifery Community Health Worker = 1.3 full time equivalent for population of 6000 patients

KMHSS contract features

KMHSS operate within a fragmented contractual environment. The service holds 13 different contracts with central government including the Ministry of Health, Ministry of Social Development and also their District Health Board via their member Primary Health Organisation.

KMHSS Funding

Additional funding is sought through contestable funding opportunities within the Māori Health Directorate within the Ministry of Health. These funding opportunities allow for innovations, quality improvement, workforce development, governance development and

The regional health system of KMHSS

The health sector environment of KMHSS presents a typical profile in terms of government purchasing of primary, secondary and public health services via 21 regionally defined District Health Boards (DHBs) across the country. A percentage of the DHB governance boards are community representatives elected by the community and the remaining percentage including the chairmanship is appointed by the Minister of Health.

DHBs are committed to a set of national targets and have the discretionary powers through their governance arrangements to decide how these national targets will be met. All DHBs are required to have a Māori health plan for their area and monitoring of DHB performance against national health targets are reported publicly via the Ministry of Health each quarterly.

Primary care funding is allocated to Primary Health Organisations who then fund their member health providers such as KMHSS to deliver primary care in communities. Funding formulae for primary care is complicated and evidence shows that services operating effective models of primary care which improve access for high need populations are disadvantaged by inequitable funding arrangements (HCA, 2010). Furthermore these inequities create difficult funding and contracting arrangements, impacting on providers ability to employ CHWs to provide effective access and coverage. These challenges are best reflected in the recent Annual Report of the Hutt Valley District Health Board. It is unfortunate that these data are not adequately quantified masking the measure of inequity in the identified areas apart from avoidable hospital admissions.

Māori access to care in the Hutt Valley DHB region (KMHSS population coverage area)

In order to draw some alignments about the state of Māori health and Māori access to primary and secondary care services in the Hutt Valley Area, and the role of Māori providers the researcher accessed the previous annual report (HVDHB, 2010) for the following information:

Population of Hutt Valley (DHB) area: 136,000 (Statistics NZ, 2006), Māori population 14.5% equal to the national percentage.

Primary and Community Service information

- Highest causes of hospitalisation: respiratory conditions, cellulitis, preventative injury
- Below number of GPs and Practice Nurses required to serve Hutt Valley population
- Ability of enrolled population to get timely access to care when they need it
- Sustainability of After Hours continues to be a challenge
- High rates of avoidable hospital admissions
- Inequalities in relation to avoidable hospital admission, annual checks and follow up management for people with diabetes
- Lower number of GP and Practice Nurse consultations for high needs populations
- Low number of dental enrolments for Māori and Pacific youth
- Higher than average expenditure on community pharmaceuticals for the Hutt Valley population

Māori access and utilisation data for the Hutt Valley

- Higher Māori use of Emergency services 14.5% of the population but 25% if Avoidable Hospital admissions.
- Māori experience higher rates of unmet GP
- High rates of chronic disease
- Higher rates of Lung disease
- Higher rates of risk taking behavior
- Lower use of elective services
- Consume less fresh fruit and vegetables

RESEARCH FINDINGS

This research focused on gaining insights about the role of the community health worker in a Māori person's health journey. Four key themes arose out of our analysis of the data from interviews and focus groups with service users, CHWs, and other staff members from Kokiri Marae Health and Social Services. The first key finding relates to Māori service users' experience of Māori CHWs as providing culturally distinctive care that is person and whanau-centre, rather than focusing on the health system. The second related finding is that CHWs play a vital role in improving people's access not only to health care but to social services in general. The third theme presented is that CHWs add significant value as team members of a Māori health service, improving both service delivery and links with other agencies. Finally, the challenges facing both CHWs and Kokiri, which employs them, is discussed. These four thematic findings will be presented, with quotes to illustrate each one. The second theme will be presented in a table, to clearly identify the ways in which CHWs reduce the barriers to accessing services identified by service users. Although derived from the experience of staff and health service users of Kokiri Marae Health and Social Services, these themes are likely to tell a more general story of the community health worker's role in a person's health journey within a Māori CPHC service provider.

Culturally Distinctive Care in a Therapeutic Relationship

All participants identified that CHWs who are Māori offer culturally distinctive care centred on the person and their whanau (extended family), rather than on needs of the health system. They emphasised the therapeutic features of the relationship CHWs share with service users in their health journey as the most valued part of the role. They highlighted cultural and community competencies and CHWs connection with the 'lived experience' making the CHW acceptable in high need communities and unlike any other relationship they experienced. Expressions of high satisfaction with the time CHWs were able to offer in their interactions with whanau, particularly in their own home settings, helped them build a relationship which felt more like an alliance rather than a traditional expert with a dependent client or whanau.

In the relationships between CHWs and whanau (family groups), shared culture was highlighted as the single most important aspect of the CHW role. In particular, Māori service users highlighted the value of their CHW 'being Māori', because whanau felt they could 'be themselves' with confidence that the CHW would understand their needs.

*It's good that our CHW is a Māori - they understand our feelings and how we need the help and services. **Health service user***

References to iwi (tribal) connection were viewed as important especially for kaumatua (elders) living away from their iwi of origin.

*It is great B [CHW] is from Ngati Porou [tribe], we know a lot of the same whanau. After that we were away and the relationship was paved. To me that is everything, I know they [CHWs] truly care... our own people. **Health service user***

*Iwi connections when living in areas we don't come from is very important....I know whanau who are from my iwi in this area and we can instantly connect around whakapapa [ancestry], so the doors are open and they can be themselves. **CHW***

CHWs identified cultural knowledge was effective in how they related with whanau because behaviours guided by tikanga (learned cultural protocols) created relationships which placed whanau and their goals at the centre.

*Our commitment to tikanga is what guides our relationship with whanau when we go into homes we know we are visitors. Whanau lead the relationship not us. We are there to assist them achieve their goals, offer support and help them on that journey. **CHW***

Whanau held perceptions that CHWs shared common life experiences, that were absent in relationships with other health professionals and staff, which helped them connect meaningfully with their CHW.

*Our relationship is not like an official sort of one, it's more like a friendship in some ways. C [CHW] understands - she's been there I can tell by the way she talks and the information she knows, ... that's what I value, other health people don't work like that. **Health service user***

Some CHWs identified 'lived experiences' helped connect them to their role as a CHW

*I love working with our people. I want to make a difference out there. Being a CHW it has helped me heal from things in my own life and give hope to others...that is what our people connect with....the lived experience. **CHW***

To other Kokiri staff members, CHWs were valued as much for their community networks as for their cultural knowledge. They were identified as role models in communities, who transmit cultural knowledge and values, and possess strong community links.

*The biggest thing I am looking for is actually nothing to do with any qualifications, I'm looking for their networks and linkages and how their linkages are in the Hutt Valley that's the biggest thing. Our services are designed for whanau who don't access the health system. These people don't behave like mainstream. Our CHWs have linkages into these communities through whakapapa [ancestry], whanaungatanga [kinship] and their lived experiences with these communities. **Manager***

In summary, CHWs were valued both by health service users and their Kokiri colleagues for their cultural knowledge and values, their lived experience, and their community networks. Both health service users and CHWs recognised that the relationships they built were unique, compared with the kinds of relationships health service users had with other members of the primary (or secondary) health care team. Relationships between users and CHWs were based on mutuality, both in terms of shared cultural values and shared life experiences. They were therapeutic relationships. Thus, for Māori service users, the indigeneity of their CHWs was pivotal.

Improved Access and Participation

While the directions and destinations of a person’s health journey differed amongst health service users, they shared similar perceptions that the CHW role supported them to address barriers they experienced which prevented them from accessing care, resources and the knowledge they needed to maintain or restore their health. Service user discussions demonstrated that cost was not the only factor which prevented them from accessing timely and appropriate primary care. They described a range of systemic issues which impacted on their ability to access services, and in turn influenced their own health seeking behaviours.

CHWs were described by participants as improving access and increasing whanau capacity to participate in the wider health system as well as in their own communities. These benefits were most clearly articulated by both health service users and CHWs. Health service users conceptualised the CHW role as diverse and responsive to their (users) self-identified needs. All participants, and in particular the service users, shared stories describing barriers to services and resources (both material and human) and the remedial role of the CHW in overcoming or addressing identified ‘gaps’ in their journeys.

‘They fill in all the gaps, you know that stop me from getting the help I need’

These identified gaps related to not only engaging with health services but also social services. Health service users described barriers to knowledge and resources impacted on their ability to act on advice or remedy situations they felt needed intervention. They reported that CHW advocacy and support when attending appointments increased their ability to understand clinical advice and information, and legitimated applications for income assistance, access to budgeting services and better housing conditions. The barriers to care were identified by both health service users and CPHC team members. Those barriers identified by participants are presented in a table format (see Figure 1) as experiences in a Māori person’s health journey. Alongside these findings are explanatory quotes highlighting each barrier, and examples of how CHWs address those barriers, either indirectly or through deliberate intervention.

Figure 1: The role of CHWs in helping Māori people overcome identified ‘gaps’ in their health journey

Health Journey ‘Gap’ / Barrier	Explanatory Quote	CHW Role
<p>Not knowing what services are available or what to expect from them.</p>	<p><i>Since I met D [CHW] it’s like all these other services came with her.</i> Health service user</p> <p><i>My dad has diabetes and lung problems. We didn’t know about all these other services until we got to see our CHW. She makes sure to phone the blood results, and that he keeps his appointments. Now he goes to the marae on Wednesday and that gets him out the house so it’s good. She works with all of us [whanau] and</i></p>	<p>CHWs provide links between services and people/communities. They come from the communities they serve and are known and trusted by them.</p> <p>Community connection/whanaungatanga <i>I was looking back thinking, when I was going to a mainstream GP service none of these services were in place. You had to find out for yourself what was out there. Now I’m dealing with these kind of patients and whanau that are not going out there to find out what is available to them. We fill that gap for them..so this is what’s</i></p>

	<p><i>meets all of us instead of just dad at the clinic. Now we know how to deal with his problems better and what not to do. Nobody was telling us what we should and shouldn't be doing with kai (food) and just stuff like that.</i></p> <p>Health service user</p> <p><i>My CHW helped me learn about the services out there that you can use. I reckon a lot of people who really need the services just don't know about them or they just don't know what to expect. Yea that's how I got to start seeing a counsellor from some problems I was having.</i></p> <p>Health service user</p>	<p><i>available, come lets go, I'll show you.</i></p> <p>CHW</p> <p>Sharing working knowledge of the health and social systems.</p> <p><i>A big part of our role is knowing the community, and also the health system, Work and Income, and housing systems and relaying that information to whanau.</i></p> <p>CHW</p>
<p>Health not viewed as a priority, due to other more pressing priorities.</p>	<p><i>At the end of the day health just isn't a priority for some whanau with high needs. They are busy trying to get food on the table and worrying about how far away payday is. They go see a doctor when they really need help, they aren't on that preventative path</i></p> <p>CHW</p> <p><i>I think health is something you only think about when you get sick.</i></p> <p>Health service user</p> <p><i>My mate told me about the CHW who did a promo at her work about getting our cervical done. She was awesome. She picked us up and came in with me to see the nurse. My mother had cancer, we talked about that too. I wouldn't have gone if it wasn't for the CHW and my mate. She has a big job out there. There should be more of them.</i></p> <p>Health service user</p>	<p>Provide outcome-focused support: appointment scheduling, transport, referral, accompaniment.</p> <p><i>We really promote some things to whanau like child vaccinations. We take those barriers away. If it's transport, we deal with it. If it's just not a priority, we explain why it's important and how to make it happen even if we have to arrange the time, then remind them, and support them to get it done. We fill in those gaps. That's our role.</i></p> <p>CHW</p> <p><i>Whanau often don't use the full range of primary care services, like our screening services or self management groups for chronic conditions, that sort of thing. So a lot of our work is about encouraging them by walking that journey with them, to make those changes and building their self management strengths together.</i></p> <p>CHW</p>
<p>Previous negative experiences with health and social services</p>	<p><i>I was having problems with my doctor. She wasn't listening to me. She was giving me prescriptions for 2 weeks at a time then I would have to go back and every time it would cost me a fee. My old doctor did monthly scripts and I told her this. We had this argument. In the end, B [CHW] came with me</i></p>	<p>CHWs assist whānau to realise the best results possible when they interact with health stakeholders.</p> <p><i>Some of our whanau are really whakama [shy / ashamed] when it comes to appointments. They will nod their heads and pretend they understand everything being said to them.</i></p>

	<p>into my appointment and got it all sorted. They are life savers, CHWs. There should be more of them.</p> <p>Health service user</p> <p><i>I think the way they [CHW] advocate for you is a really important thing they do.</i></p> <p><i>I have fronted up at WINZ in the past trying to get an emergency grant so I wouldn't get the electricity cut off. But they can sit there and talk you out of anything and you walk away with nothing. C came to my last appointment and it worked out well so yea they do a good job. Health service user</i></p>	<p>CHW</p> <p><i>People with high needs don't work like mainstream. A lot of the time they get moved on. There's a disconnect there and issues don't get addressed. We do a lot of advocacy and support so these issues get sorted and whanau get their needs met appropriately.</i></p> <p>CHW</p> <p><i>I think there is a lot of policy mention about access but when it comes down to it funders don't really commit to this.</i></p> <p>CHWs</p>
<p>Lack of confidence that modifiable causes of ill health can be addressed</p>	<p><i>I was chasing the medication path with the asthma, but I knew it was mainly the problems with the damp and coldness of the house. X [CHW] helped us get into another place and helped with the housing people and all that. Health service user</i></p> <p><i>They are awesome down at Kokiri and you don't have to go to a whole lot of places. They come to you or you can go to the marae and they do education sessions about real things in your life. We had budgeting advice, how to seek legal advice, knowing your rights when in WINZ and stuff like that. Or they get the nurses to come and talk about something important. Yeah, the CHWs aren't just focused on all the health stuff. They know what we go through and how they can help us. Health service user</i></p>	<p>CHWs are a dedicated workforce to address wider determinants of health</p> <p><i>All our CHWs are trained in budgeting. They work collaboratively with the agencies who provide the training and the CHWs are then able to support whanau. This cuts down on the amount of services whanau need to access. We may hold a group education session.</i></p> <p>Manager</p> <p>Outreach</p> <p><i>Home visits allow us to see the realities of people's lives. Whanau are often just chasing a cycle of problems and get shunted from here to there but really it's about housing, income, stress and all that. We focus on that, social stuff.</i></p> <p>CHW</p> <p><i>Doctors can't fix social problems and that's what needs to be fixed first. If you miss the social stuff with whanau the medical stuff often won't get a look in.</i></p> <p>CHW</p>
<p>Services are far away and not accessible</p>	<p><i>I don't drive over the hill, and my son works during the day so he can't take me. The CHW is great. She takes me when I need to see my specialist and she comes to the appointment and that's mighty because she makes sure I understand what is going on. I</i></p>	<p>Support referral uptake</p> <p><i>A huge part of the role is transport mainly to important specialist appointments and if we didn't provide it they simply wouldn't go. I don't think there are any contracts which fund appropriately for this, so these costs fall on us the provider. CHWs do a lot of work outside their role and that happens</i></p>

	<p>wouldn't have been able to go otherwise. Health service user</p> <p>A big barrier for whanau is that they don't know how the health system works. When they miss an important specialist appointment, for example, they may not be able to get another one for six months and their condition may become worse in the mean time. CHW</p>	<p>by the needs of whanau. Manager</p> <p>Transport Our role is to make sure that appointments are kept and they get the care they need. That may involve transport, coaching them about what is happening and why, and talking with other colleagues so you know you are giving accurate information. CHW</p>
The health system is 'time-centric'	<p>A pervasive lack of time in the health system was a recurrent theme in discussions. However, all participants identified that CHWs possess time flexibility in their roles. This flexibility enabled them to enhance care and improve other service efficiencies by sharing tasks with clinicians, who simply didn't have the time to do important coordinating activities.</p> <p>CHWs referred to time as a gap in service because people's issues didn't occur between 9 to 5 and felt after-hours support and care were needed.</p> <p>Another CHW voiced community expectations of the CHW went beyond their paid hours often demanding a degree of volunteerism, especially for CHWs in part-time positions.</p> <p><i>My CHW never comes for long but it is such a life saver. She pops in and she checks in with me making sure everything is going ok with the meds, or to see if I'm still doing my groups. It's great and I look forward to her coming. There's a lot of lonely kaumatua [male elders] out there. I often wished I was back ... where I come from, but my health wasn't good enough and I couldn't afford all the travel to see the doctor.</i> Health service user</p>	<p>CHW time schedules are centred around whanau needs</p> <p><i>I think it's just time itself, everyone is so busy, it kinda makes you feel like a nuisance. It's just the way it is, but the CHW often has the time, you know, to talk about stuff or take you to an appointment. You kinda forget what you want to say at time.</i> Health service user</p> <p><i>Doctors and nurses they all on time schedule these days, everything must fit around the system. I think CHWs are a bit more focused on what works for us so that is what we value.</i> Health service user</p> <p><i>CHWs are great for providing that extra support to clients. Even if our clinicians wanted to spend time with them discussing things in more depth, they can't, because there is a lot of demand out there and they have so many other patients to see.</i> Receptionist</p> <p><i>I hold CHWs in greater esteem than other health professionals. You know why, they negotiate with you better. They don't make everything centred around them and their service. Others will ring and say an appointment time has changed and they give you a new one. But the CHW, she will phone and ask to change an appointment. They respect you – you know, like your life is important too.</i> Health service user</p>
Difficulty understanding	<p><i>It's like their [doctor] language is</i></p>	<p>CHWs improve the health literacy</p>

<p>advice and information given</p>	<p><i>coded and I can't understand it.</i> Health service user</p> <p><i>They use plastic words those specialists. They don't mean much to me that's why C [CHW] comes with me, so I can understand what's happening.</i> Health service user</p>	<p>within communities</p> <p><i>A lot of whanau have trouble understanding clinicians and so a lot of our work is about putting information into simple language for them.</i> CHW</p> <p><i>I think CHWs are really creative about the way the translate information for our clients, especially when they do group education sessions...it's 'their baby' and we may come in as guest speakers.</i> Nurse</p>
<p>Experience of bigotry / racism</p>	<p><i>They treat you like you aren't going to pay and they ask why you haven't gone to your own doctor in front of everyone...they make you feel like you shouldn't be there. I think the CHW is more Māori friendly too so they know how to be with you</i> Health service user</p> <p><i>When you do things that are bad for you like smoking, you can feel like its your fault and you don't deserve the care when you need a doctor – like I get a bad cough at times and they always say – do you smoke? Just stuff like that....</i> Health service user</p> <p><i>I like the people at Kokiri and the CHWs because their staff are Māori and they understand you and they don't judge...</i> Health service user</p>	<p>CHWs have inherent knowledge of community, whanau and relationships</p> <p><i>I was thinking about the impacts the behaviour had on the client (as this was their self identified barrier). They just didn't believe they had a right based on how they were treated. I'm wondering if this treatment causes this lack of belief.</i> CHW</p>
<p>Unmet need for GP care</p>	<p><i>I had to wait a year before I could get into here. I had to go to the Hutt. Luckily I got referred to C [CHW]. She was great and I got involved with the Marae and started going to the kaumatua [elders] group there. They have speakers come and talk about making a will, budgeting, how to stay warm in the winter and staying connected in your community. They're mighty, the CHWs. There should be more of them.</i> Health service user</p>	<p><i>We link clients up with services in their community as well. Often they don't have any idea of services beyond medical, so our role is to get them involved with groups and agencies in their communities.</i> CHW</p> <p><i>Yes there are doctor shortages here. We have had a high turnover, particularly in the last year. Some of our work is about</i></p>

	<p>Some Health service users develop their own form of triage to deal with illness symptoms when they can't see their GP in the time they require.</p> <p><i>I know people who share their prescriptions so they don't have to go to a doctor, you always have to wait and so they try and manage without going the GP</i></p>	<p><i>informing whanau about how to deal with this and supporting them. CHW</i></p>
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The vulnerability of CPHC also led to increased health vulnerability of service users. For example the GP clinic at Whaioranga, part of Kokiri, frequently experienced a shortage of GPs. In turn, this shortage generated alternative health seeking behaviours such as increased use of emergency department services when service users could no longer cope without medical intervention. For some, this delay in presentation increased their health vulnerabilities with one service user in this study suggesting that people even share medications to avoid a GP visit when they couldn't get an appointment. Service users reported CHWs introduced them to other services in their community they were previously unaware of, and increased their ability to work the health system more effectively by providing transport or health information for example, so they could meet their health needs.

Some Health service users, simply didn't have the means to navigate the health system. Transport to specialist appointments and their ability to understand what was happening to them, were challenges the CHW helped them overcome. Service users reported better access to not only the quality of their GP consults, but a whole range of other services opened up in their community they would not have accessed without the CHW. Therefore the benefits of the CHW role reach wider parts of the community and health system such as a reduction in appointments not kept with in the hospital system, greater equity of access for Māori to services they require and increased community capacity to find solutions to health challenges.

Participants identified that health is not a priority for many whanau and their curative focus on health services meant they under-utilized other health promoting and preventative programmes available. Respondents were able to report on successes in whanau accessing a broader range of primary care programmes as result of CHW involvement.

Improved CPHC Services

The participants shared key strengths and challenges associated with the CHW role as part of the CPHC team. In particular, the staff participants highlighted in their focus groups that CHWs have played a crucial role in Kokiri CPHC service achieving effective population coverage, despite the fact that have they worked many more hours than they are employed for.

*The CHW role is critical not only in the implementation of our programmes but they also coordinate so many other process things involving our whanau from referrals, appointments, transport, or just supporting them in taking that first step to be involved with services to keep them well - we would be lost without them. **Manager***

*Our roles[clinicians & CHWs] complement each other. We work in tandem so it's timely and meets the needs of whānau, not us. **Nurse***

CHW involvement in a smooth and seamless transition throughout a person's health journey was highlighted as another key part of the role, which other professionals are unable to achieve, given the many potential gaps in that journey.

*CHWs are able to do tasks that we simply don't have the time or community knowledge to do. **Receptionist***

CHWs were described as an integral 'structure' within the CPHC team and overall Kokiri service. A nurse participant described well how the work of the CHWs fits into the service delivery at Kokiri.

*The CHW and I will contact every person on our books in an at-risk age range for certain screening services. It's the CHW who makes those links with whanau so we get them in the door. My role is to provide that clinical support. High needs whanau require a lot more relationship support. It's the journey of getting whanau to that stage of access that is the real challenge. What might take 10 – 15 minutes of clinical time for a lot of mainstream, will take triple that time for high needs whanau because of all the other stuff that must be dealt with and that is the challenge our CHWs can deal with – it's their specialty really – improving access for those who have the worst health. **Nurse***

A manager described CHWs as critical to ensuring better equity of access to services.

*At a population level our CHWs make sure we are getting to those whanau who aren't accessing services so we are making those differences to equity of access. **Manager***

There was little doubt expressed by other members of the CPHC team that CHWs contribute significantly to the value that Kokiri can offer to the communities and whanau served.

CHW Challenges

Despite the high value placed on the CHW role among Kokiri staff members and health service users, there were important challenges highlighted with regard to both employing and supporting CHWs. Both CHWs and their employers identified inadequate funding and inappropriate contracts to meet the demand for CHW services as serious issues.

*We manage the workload through a referral system, because our CHW is very busy. We just don't have enough of them and they are only funded part time yet the workload is triple the hours. **Manager***

*It is difficult also because our funding only allows us to employ CHWs part time and these people need full time work. **Manager***

*Contracts are difficult, like there is no room for the full coverage transport costs so we have to find this elsewhere in our service. **Manager***

Although they felt valued by their CPHC team colleagues, CHWs were very much aware of the issues raised by their employers. They described the tension between their employment contracts and the actual work they do.

*Our funding doesn't always allow us to work in a whānau centred way, it's about individual support and so when you are home visiting you may come across other whānau members who have needs. We can't ignore their concerns and so there is a tension. In our work you are often working with whānau not just the individual. **CHW***

Not only were funding and contractual limitations noted as challenges to employing CHWs but managers also highlighted the limited available training for CHWs in Aotearoa New Zealand as a problem faced by Kokiri.

*I think training is another area. We provide practical training support, which helps our CHWs be useful in their roles like, for example, they are all trained in budgeting advice. The programmes and funding don't cover the costs of ongoing professional development, supervision and issues like that. We absorb those costs ourselves. **Manager***

Overall, these findings suggest that CHWs at Kokiri provide an invaluable service to health service users and their families, and to other members of the CPHC team. Their cultural knowledge, life experience and community networks ensure that they are able to build strong relationships of trust with Māori, but also that they fill 'gaps' in knowledge and care not provided by others in the health care team. They contribute to improved health equity for Māori health service users, by supporting them in their engagement with health and other social services and by linking them to communities of support. The story of one health service user sums up well the contributions made by CHWs to the health and wellbeing of Māori in the Hutt Valley.

The story that follows, of one service user, aptly summarises the importance of the Kokiri CHWs to the welfare of Māori in their health journeys.

Before X became involved with her CHW, she lived an isolated life with little social contact, in a state house far too big for one person and expensive to heat in the winter time. X spent her days in her bedroom to keep warm as it was cheaper to heat one small room rather than a whole house. X described her depression as an enduring illness which gripped her life soon after her first child. Prior to X's involvement with the CHW, her health care was described as a frustrating experience that frequently led to her needs not being understood and heard appropriately.

X described her CHW as "a life-saver" and someone that that finally started to help her with the things that really mattered in her life. "when I first met B, I couldn't even walk to my letterbox... I suffered terribly from loneliness and depression. My search for 'ora' (well-being) has been enhanced by the CHW. I am no longer isolated and my relationship with my son has got so much better...B Has helped me through my loneliness. I get out there and have things to go to in the community now, like the Kaumatua (elders) groups at the marae. She helps me with my appointments too. I get my needs met better now and I am able to understand those health people.

X felt the CHW role was important because they were able to provide care that enhanced every other part of her health journey, and her cultural connections to her CHW made her feel that the CHW genuinely cared about her.

DISCUSSION

This study examined the role of the CHW in a Māori person's health journey through a case study of an indigenous comprehensive primary health care service provider within the Health Care Aotearoa national network. Kokiri Marae Health and Social Services in the Hutt Valley provided an ideal case study for this research, as it provided a rich setting, including a GP clinic, in which to explore the role of CHWs. The combined views of health service users, community health workers, receptionists, nurses and managers confirmed the value and breadth of the CHW role, embedded in cultural and community knowledge, and focused on addressing barriers to health care and social support for Māori. These findings are consistent with previous research that has highlighted the value and the complexity of the role of Māori CHWs. This research raises important questions about how CHWs could be better supported in their roles, both in policy and practice, as will be discussed below. This section will discuss barriers for Māori in their health journeys, the importance of 'therapeutic relationship' in addressing barriers, the undervaluing of CHWs, and the limitations of this study.

Barriers to care / barriers to people

The findings in this study confirm that the New Zealand health system demands high levels of self direction and knowledge to be able to access services. Māori in this study, as is likely the case for others who experience poverty and high health need, are unable to manoeuvre in the systems of care. The literature often discusses barriers to care (see, for example, Barnett & Coyle 1998, Lovell et al. 2007), but does not always elucidate what is needed to 'fill the gaps' in people's ability to manage health and social service systems. Further, the discourse in policy and in primary care practice places the responsibility on service users to access health care providers and social agencies. Yet, this research suggests that, for Māori, this discourse might well be turned on its head, with the responsibility resting on providers and agencies to 'access Māori'.

The stories of CHWs and their CPHC colleagues in this study demonstrate that some people are too busy surviving to worry about their health until they become sick. Further, the cost (in time, effort and finance) is too great for them to manage. Finally, and most distressingly, even when they do manage to 'access' care, that care is often inaccessible to them. Māori health service users described being treated in a judgmental manner by health professionals, being scorned by GPs for having unpaid primary care bills, and feeling too shy or ashamed to let on that they did not understand what they were being told by health professionals.

The gaps in the health journey identified in this study match regional District Health Board data on Māori access to health services in the Hutt Valley area relative to others with health needs, highlighting inequities for Māori in health status and access to both primary and secondary care health services (Robson & Harris, 2007). It is not only Māori who are vulnerable, however, it is Māori CPHC services.

Accessing people through 'therapeutic relationship'

The findings in this study suggest there is a high need for a therapeutic relationship between members of CPHC teams and individuals / whanau who have complex health and social needs. Therapeutic features included community linkages, cultural knowledge and familiarity with life circumstances. Indigeneity was seen as important, not simply cultural competence, as has been promoted widely in recent health policy (Medical Council of NZ, 2005). CHWs are in the

strongest position to hold that therapeutic relationship, if they are carefully chosen for the role.

The CHW role in many studies has been assessed for its strengths and challenges in achieving health gains for populations most at risk of service under-use and the difference CHWs have made to health outcomes.(NEEDS REF) This study confirms that measuring health outcomes is dependent on a multiplicity of factors, and circumstances. However study findings confirm that Māori who are at risk of under-use of comprehensive primary health care services, experience high levels of satisfaction and increased ability to access a broad range of primary health care services when they become involved with a CHW. Respondents oriented their discussion around the CHW role in addressing barriers to care and their ability to connect meaningfully with a health representative who appeared focused on their self identified needs which included broader issues associated with income, housing and for many a lack of knowledge and trust in health services beyond emergency care.

The Under-Valuing of Community Health Workers

Contrary to other research, (Boulton, Gifford et al 2009) CHWs interviewed in this study felt they were highly valued by their colleagues and community stakeholders. The CHWs emphasized the strong Māori values transmitted by the people of KMHS alongside the 'By Māori for Māori' approach provided a strong sense of team and community cohesion. CHWs were valued by their colleagues and seen as critical 'access enablers' with their own knowledge and skills which enhanced a person's health journey. Yet, CHWs continue to be undervalued in primary care and the wider health sector.

One of the key challenges associated with the CHW role is establishing it as a key role within CPHC services which are targeted at high need populations. Discussions among primary care teams and CHWs suggest that at present there is no optimum population coverage formula for CHWs and little consistency in how CHWs are funded. Most CHWs work far more hours than they are employed to work. CHW initiatives are not formally evaluated, and there is a lack of shared accountability between funders, policy makers and providers to undertake these important activities. These challenges faced by Kokiri in providing CHW services is likely to be experienced by other Māori health providers.

Māori CPHC service providers rely heavily on indigenous CHWs to successfully reach Māori who at risk of service under-use relative to their need (Boulton, Gifford & Potaka –Osborne, 2009; Te Whiringa Trust, 2010). Similarly, other non-profit community driven primary health services in New Zealand committed to reducing health inequities employ CHWs to ensure their services are accessible, appropriate and comprehensive for populations with the worst health outcomes and lowest rates of health service utilisation relative to their need (Crampton & Davis, 2004). However many initiatives to improve access to primary health care have not been formally evaluated in New Zealand. Without these evaluation activities, the effectiveness of CHWs and ongoing potential for role development remains unrecognised. The CHW role remains vulnerable to policy changes and funding cuts. There is a clear need to adequately resource CHWs in order to maximise their potential improve health equity for Māori through the delivery of comprehensive primary health care. It is a key Māori health workforce development issue, as well as an issue for the development of CHPC.

Study Limitations

Future studies of similar design should include all eligible HCA providers as this may generate greater commitment to the project rather than approaching an eligible provider and inviting them

to participate. While the object of minimizing costs should always be part of good project design the implications need to be assessed for risks and advantages. For example, had the provider selection process been more inclusive and participatory, the levels of required commitment and involvement in the study and its implementation may have achieved greater buy-in and enthusiasm for a two year project. An adaptation would be to invite expressions of interest from all eligible providers to be part of the study. This recommendation is also more suited to a 'research triad' approach. HCA in future designs similar to the pilot could play more of an administrative role rather than research user.

The initial method of recruiting participants to this study was ineffective. In reality, it appears that an in-person invitation delivered by someone with a pre-existing relationship (in this case, CHWs with the health service users) is the most effective means of engaging participation, particularly for vulnerable individuals and families.

The sample size in this study was small, yet rich data were collected. It is not possible to generalise the findings to all Māori CPHC providers or, even less, all indigenous CPHC providers who employ CHWs. Despite this reality, the trends found in this research are likely to be similar in comparable studies of other Māori CPHC providers and possibly other indigenous CPHC providers as well.

CONCLUSIONS: Recommendations for policy, practice and further research

This research explored the role of community health workers in the health journey of urban Maori, using a case study of an indigenous comprehensive primary health care service provider. The research question grew from the Health Care Aotearoa member services experience that CHWs are vital players in the achievement of comprehensive primary health care for Maori and other populations with high health need. The focus on the client journey provides clear evidence of the links between client involvement with a CHW and their self reported improved interactions with the health system, and their participation in a comprehensive range of preventative, rehabilitative and health promoting services with better connection to social agencies.

CHWs play a critical role in communities where there is under-use of primary care services relative to need, particularly for Māori. While common cultural heritage between the CHW and health service user was identified as a strong predictor of a therapeutic relationship, shared life experience was described as leading to strong alliances based on mutual understanding, rather than the expert / dependent dynamic so familiar in the doctor-patient relationship. Service users identified that CHWs offer care that other health professionals are unable to, address gaps in the health system for them, and support them to address their own self identified barriers to well being. Findings also demonstrate that CHWs are key players in ensuring whanau access to primary care throughout the life-span 'in sickness and in health', including health promotion, prevention and health planning inclusive of the community and family as key resources.

Despite the evidence for the important role played by CHWs in improving health equity for indigenous populations, CHWs remain 'minor players' in the primary care sector in Aotearoa New Zealand. They are an unregulated workforce, with limited evidence of their institution throughout primary health care systems and services. This study demonstrates that CHWs are a core structure within Maori providers, and are integral to a Maori persons health journey especially for those with high health and social needs. In this study Kokiri, a kaupapa Māori

service, lacked adequate funding to meet the demand for CHW services. Most Māori access primary care through mainstream services where there is more large scale underutilization of the CHW role, except for non-profit community governed services focused on high health need. CHWs are still not recognised as a critical part of CPHC within disadvantaged communities in New Zealand. In policy, the CHWs is a ‘nice to have role’ if the resources allow, rather than being a central role within primary health care teams, and a key bridge to communities.

CHWs are a valuable resource to whānau, communities and the wider health system, and enable multidisciplinary interventions to occur in a manner that is acceptable to whānau and integral to the implementation of ‘By Māori for Māori’ care delivery models. CHW programmes and initiatives are not inadequately resourced to be able to ensure health service utilisation relative to need. Greater attention to the value of CHWs, together with more appropriate funding and contracting for their roles, would go a long way to enhance the delivery of CPHC in Aotearoa New Zealand, particularly for the most vulnerable populations.

It is not only CHWs but also the CPHC model that is undervalued by the wider health sector. This raises questions of how well understood and instituted the concepts of CPHC are in New Zealand. The current policy climate in New Zealand encourages community governed not-for-profit CPHC health providers to align themselves with mainstream general practices, rather than with each other. As a result, the power of networks such as HCA, as advocates for CPHC, has been diminished.

Further research is required, including a wider evaluation of CHWs, to demonstrate their cost effectiveness within the health system and, even more importantly, the differences they make to whanau access to services. This research team hopes to engage in a larger project, evaluating the effectiveness of CHWs within the New Zealand health system.

IN SUMMARY

The role of the CHW within a multidisciplinary health team is analogous to a rugby team. The most important player is the one who passes the ball to his/her try-scoring teammate; however, the player who scores the try (goal) is the one who receives both team and public adoration for putting points on the scoreboard. In primary and secondary health care, the doctor almost always scores the try, and is recognised as the most valued player on the health care team. Yet, the player who got the ball (patient) to the try-scorer (doctor) is the most important player of all. CHWs are working behind the scenes to ensure that people engage with health and social services. Without their efforts, many people, and many Māori people, would never receive the services to which they are fully entitled.



REVIEW of the RESEARCH PROCESS

The TRIAD

Overall, we felt that the triad model was an interesting way of carrying out community-based research, like this project. The research user (RG) was very supportive of the research, for its potential use in advocating for better resourcing of CHWs in Health Care Aotearoa's CPHC services in New Zealand. The researcher (TF) was an employee of HCA who was interested in gaining research experience. At times, she floundered a bit with the research process, and struggled to carry on the research amidst her other work demands. She hesitated to seek support from the academic mentors, at times. For the mentors, it was difficult getting out of 'supervisor' mode to be simply a supportive advisor, called on as needed. In the end, this report was written by TF and PN, as it was too heavy a load for TF, who carries other responsibilities in her work.

The (Regional) Training

This team only participated in the first training, in Adelaide, as the second training workshop was not made available to us.

Comments about the training from the research user (RG who is no longer employed by HCA) are as follows:

- *Firstly this process enabled us as indigenous people to come together both mentors and community researchers.*
- *The sharing of knowledge and information I found hugely beneficial, just by being together and to discuss with the community researchers their findings, issues and experiences to date.*
- *Gave the opportunity to get a more in depth knowledge of how another culture operates in similar situations, there differences as well.*
- *That being indigenous there is always inequalities*
- *Training [in Adelaide] could have been better in terms of having more indigenous presenters but the content was good and did help with the research.*

The researcher had the following comment about the training:

- *Perhaps a greater training focus on analysis of the different forms of data collection could have been more helpful.*

The academic mentor (PN) made the following comments:

- *It was not entirely clear ahead of time whether I was a participant or an advisor in the training context.*
- *The Adelaide training failed to incorporate indigenous processes (for welcome, for meeting and greeting, for acknowledging ancestral ties, etc), including time for members of the group to get to know about each other's countries, regions and*

cultures. It was a big oversight, in my view, and created problems during the training workshop.

The Research Itself

An important comment that was offered by the research user (RG) is as follows:

- *The process in finding the participants for the research became an issue in terms of the selection of participants for the research, ie: community versus academic process*
- *Mentoring was good – better planning at HCA’s end would have helped but then this in itself is a reflection of capacity issues, common within NGO’s/community research*

The researcher (TF) raised the following recommendation with regard to evaluating the process of the global T-C project:

- *It would be helpful to gain more knowledge of how beginning researchers who work in part time roles for both their organisation and their research projects managed the shared accountabilities. This type of evaluation would provide important lessons for future triad experiences.*

The academic mentor (PN) had the following comment:

- *It was unrealistic, in my view, for beginning researchers to come up with a research question, design the study, carry it out, and write a comprehensive report. This turned into a miniature postgraduate-level dissertation, but with no educational qualification at the end of it, for the researcher!*
- *My involvement as an academic mentor ended up being largely on my own time, as this project was not recognised as part of my own research work, by my employer.*

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APPENDICES

GLOSSARY of TE REO (Māori) WORDS

Hapu: sub-tribe, group of whanau

Hui: a meeting or gathering of people

Iwi: indigenous tribe, tribal

Kaumatua: male elder(s)

Marae: meeting house, place of gathering for Maori whanau, hapu and iwi

Tikanga: learned cultural protocols

Whakapapa: ancestry

Whanau: family groups

Whanaungatanga: kinship



**INFORMATION SHEET
(Consumers and Health Workers)
Research Project
September 2009**

Title: Exploring the role of the community health worker in a person's health journey in a Maori comprehensive primary care service

Principle investigator: Tania Forrest

You are invited to take part in a research project about community health workers. This project aims to describe how community health workers contribute to a person's health journey. If you agree to take part in the study, you are free to withdraw at any time without having to give a reason.

About the study

Community health workers (CHWs) provide many health and social connection opportunities for people in their communities. By talking with community health workers, their clients and members of the health team we aim to describe the role of the community health worker and learn more about the work they do as part of a person's health journey. Access to care, the different types of CHW support offered and the life circumstances of the people CHWs serve will be some areas of focus.

Your involvement

The research would require an interview for about an hour at Kokiri Marae. Your views and comments about this topic will be asked through a set of questions.

There are no right or wrong answers, and you do not have to answer or comment on any issue you don't want to.

Our researchers will use tape recorded interviews with you, upon your consent. This ensures the researcher does not record what you say wrongly.

People who agree to participate do not need to know anything about the research topic before attending an interview.

You may choose to withdraw from the research project at any stage. Any information you provide prior to withdrawing from the project will be destroyed.

Respecting your right to privacy

What you tell us is strictly confidential. Your identity or name can never be identified.

Payment or recognition of your involvement

We will provide a koha or payment in kind for your time. This will be something like a grocery voucher. Your transport arrangements for attending interviews and snack/ drinks requirements will be provided by the research group.

Further information

If you have questions or would like to discuss the research more, you can contact the key investigator (Tania Forrest) OR a research advocate in details below.

The role of the advocate is to listen to any questions or concerns a person may have, and act on behalf of the person for a good outcome.

Research Advocate

To access a research advocate who acts on your behalf regarding any concerns or issues you have please contact

'Health and Disability Consumer Advocate'

Phone: 0800 555 050

Fax: 0800 2782 7678

advocacy@hdc.org.nz

Name: Tania Forrest

Position: Principle Investigator

Health Care Aotearoa

Phone: 04 472 1617

Fax: 04 472 1619

Mobile: 027 7394292

Email: taniaf@hca.org.nz

INFORMATION SHEET



(Focus Group) Research Project September 2009

Title: Exploring the role of the community health worker in a person's health journey in a Maori comprehensive primary care service

Principle investigator: Tania Forrest

You are invited to take part in a research project about community health workers.

This project aims to describe how community health workers contribute to a person's health journey.

If you agree to take part in the study, you are free to withdraw at any time without having to give a reason.

About the study

Community health workers (CHWs) provide many health and social connection opportunities for people in their communities. There is little formal information to support why CHWs are believed to be important members of primary health care services and care delivery teams. By talking with community health workers, their clients and members of the health team we aim to describe the role of the community health worker and learn more about the work they do as part of a person's health journey through and beyond the different types of health care and support.

Access to health care the different types of CHW support offered and the life circumstances of the people CHWs serve will be some areas of focus.

Your involvement

The research would require an interview for about an hour at Kokiri Marae. Your views and comments about this topic will be asked through a set of questions.

There are no right or wrong answers, and you do not have to answer or comment on any issue you don't want to.

Our researchers will use tape recorded interviews with you, upon your consent. This ensures the researcher does not record what you say wrongly.

People who agree to participate do not need to know anything about the research topic before attending an interview.

You may choose to withdraw from the research project at any stage. Any information you provide prior to withdrawing from the project will be destroyed.

Respecting your right to privacy

Group interviews (focus groups) require people to share information in front of others.

Group interviews can be a good way to stimulate thought and conversation amongst others.

You will be required to sign a confidentiality statement prior to the interview stating your commitment to others right privacy during the interview. People will be given the option to participate in individual interviews. Your identity or name can never be identified.

Payment or recognition of your involvement

We will provide a koha or payment in kind for your time. This will be something like a grocery voucher. Your transport arrangements for attending interviews and snack/ drinks requirements will be provided by the research group.

Further information

If you have questions or would like to discuss the research more, you can contact the key investigator (Tania Forrest) OR a research advocate (Rowena Gotty).

The role of the advocate is to listen to any questions or concerns a person may have, and act on behalf of the person for a good outcome.

Name: Rowena Gotty

Position: Research Advocate

Phone: 04 472 1617

Mobile: 027 205606

Email: rowenag@hca.org.nz

Name: Tania Forrest

Position: Principle Investigator

Health Care Aotearoa

Phone: 04 472 1617

Fax: 04 472 1619

Mobile: 027 7394292

Email: taniaf@hca.org.nz



**CONSENT FORM
Research Project**

**Exploring the role of the community health worker in a person's health journey
Maori comprehensive primary care service**

I **agree** to participate in the research project in which Kokiri Marae Health Services have agreed to support. I will take part in discussions through an interview process about "the role of the community health worker in a person's health journey.

I have read and I understand the information sheet dated September 2009 for volunteers taking part in the study. I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.

I have had the opportunity to use whanau support or a friend to help me ask questions and understand the study.

I understand that taking part in this study is voluntary (my choice), and that I may withdraw from the study at any time, and this will in no way affect my continuing health care or working relationship with Kokiri Marae Health Services.

I understand that my participation in this study is confidential and that no material that could identify me will be used in any reports on this study.

Y	N
---	---

I have had time to consider whether to take part in this study

Y	N
---	---

I know who to contact if I have any concerns about the study

Y	N
---	---

I know who to contact if I have any questions about the study

Y	N
---	---

I consent to my interview being audio taped

Y	N
---	---

I wish to receive a copy of the results of the interview and research study

Y	N
---	---

Request for interpreter

Māori	E hiahia ana ahau ki tetahi kaiwaka Māori/kaiwaka pakeha korero	Ae	Kao
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I(full name) hereby consent to take part in this study.

Date:

Signature:
Full names of researchers:

Contact phone number for researchers:

Project explained by:

Project role:

Signature:

Date:

HEALTH SERVICE USER INTERVIEW QUESTIONS

What is the role of the community health worker in a person's health journey?

1. Can you tell me how you came to be in contact with your community health worker (CHW)?
2. What type of service does your CHW provide? – When you see them what do they do? (Please take your time answering this question)
3. How is your CHW helpful or unhelpful?
4. CHWs should know their community. Do you agree? If so why?
5. People need to feel comfortable with their health professional – how well does your community health worker achieve this?
6. What do you value the most about your CHW?
7. Do you believe your CHW has assisted you to use other health and community services?
8. Does your CHW help you understand and manage your own health better?
9. In what settings do you see your CHW? eg: home, clinic
10. What, if any, difference has your CHW made to your life or general well being?

COMMUNITY HEALTH WORKER INTERVIEW QUESTIONS

What is the role of the community health worker in a person's health journey?

1. In your own words please describe your role as a CHW? Tell us what you do ?(Please take your time answering this question)
2. What do you think is most important about your role for the whanau that you visit?
3. What do you do that is different from other health professionals in your teams
4. What sort of relationship should CHWs have with the community.
5. Do you feel a connection with the people you work with? If so why?
6. What inspired you to become a CHW? How long have you been a CHW?
7. Do you receive ongoing training to broaden your knowledge in the field of work you do?
8. What if any are the challenges about being a community health worker?
9. What if any, qualifications do you need to be a CHW for this health provider?
10. How do you support people to live healthier lives when they are grappling with social and environmental conditions they live with?
11. Can you provide an example of how you have facilitated a person or whanau to be more self managing about their health?
12. CHWs are believed to improve the health and well being of people. Do you think that the work you do is accurately reflected in the data you input and the reports you write?
13. CHWs are their own identity – yet the role is hugely broad as well. What are some key aspects of your role that are in common with all CHWs.
14. Do you see yourself as an important part of the primary health care team?
15. Many community health workers have clients with high health and social needs. What inspires you to work with these people?

PRIMARY CARE TEAM INTERVIEW QUESTIONS
(receptionist, nurses, GP, social worker)

What is the role of the community health worker in a person's health journey?

1. Can you tell us how you are involved with the community health workers in your service.
2. Do you believe the role is an important part of the health team? If so can you tell us a bit about why you think this?
3. What do CHWs do as part of the primary care service?
4. What are the main health concerns in your area? What are the main health goals?
5. Do you think CHWs have a role in achieving the identified health goals?
6. Can you describe a situation that may assist us to understand how the CHW role enhances a person's health journey?
7. What do you value the most about the community health worker role?
8. Is there anything you find challenging about this role?
9. Is there anything you would like to add to this discussion? OR anything you think the researchers have not asked that is important about this topic?