



**New perspectives on
heart disease management
in Te Tai Tokerau: Māori
and Health Practitioners Talk**

Final Report

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Introduction

In October 2003 researchers¹ from Te Rōpu Whariki, with support from Professor Sally Casswell from the Centre for Social and Health Outcomes Research and Evaluation (SHORE), Massey University, were awarded a project grant (03/298) by the Health Research Council of New Zealand to undertake a project based in Te Tai Tokerau/Northland exploring the experience of healthcare for Māori with ischaemic heart disease (IHD) from the perspective of Māori patients, whānau, and healthcare practitioners including General Practitioners, Practice Nurses, Community Health Nurses, Community Health Workers, Medical and Nursing Specialists.

This is the second and final report of the project. The first report provided preliminary findings following phase one of the project and invited feedback from the research participants and wider stakeholders. Feedback has been included in the writing of this report. This second and final report provides a brief background to the research project, outlines the research methods and discusses the findings of all three phases of the project.

¹ Liane Penney, Helen Moewaka-Barnes, Dr Tim McCreanor.

Background

Cardiovascular disease mortality

Cardiovascular disease is the leading cause of death in Aotearoa/New Zealand, accounting for 40% of all deaths annually, followed by cancer deaths and deaths from chronic obstructive pulmonary disease (Hay, 2004).

Cardiovascular diseases are diseases affecting the heart and circulatory system. Of the cardiovascular diseases, coronary heart disease (CHD), also known as ischaemic heart disease (IHD), is the major cause of cardiovascular deaths, followed by stroke, which is the greatest cause of disability in older people. IHD is the narrowing or blocking of the coronary arteries that supply blood and oxygen to the heart. IHD can cause angina and heart attack and lead to heart failure.

Ischaemic heart disease mortality in the Māori population

The burden of cardiovascular disease and IHD falls disproportionately on Māori, with Māori death and disease rates from cardiovascular diseases being significantly higher than non-Māori; IHD is the leading single cause of death for Māori (Riddell and North, 2003). The earlier onset of disease among Māori is also significant, with IHD representing the leading cause of death for Māori from age 25 years onwards, compared with non-Māori from age 65 years onwards (Hay 1999). In 2003, the Māori male IHD mortality rate was 120% higher than the rate for the non-Māori male population and the rate for Māori females was 84% higher than the non-Māori female rate (MOH, 2006).

Change in cardiovascular disease mortality over time

Mortality or death rates for cardiovascular disease generally, and IHD specifically, in Aotearoa/New Zealand have been declining, however the decline in Māori cardiovascular mortality has occurred more slowly than that of other groups leading to an increase in disparities. By 1996–1999 the Māori male cardiovascular mortality was 3.0 times higher than that for non-Māori, non-Pacific males and the Māori female mortality rate was 4.2 times higher than that for non-Māori, non-Pacific females (Ajwani et al, 2003).

The relative inequalities between ethnic groups at the end of the 1990s were larger for IHD than for cardiovascular disease as a whole (Ajwani et al, 2003).

- The 1996-1999 Māori male IHD mortality rate in the 35-64 year age group was 3.4 times that of the non-Māori, non-Pacific male rate.
- For 65-74 year old Māori males the rate was just over twice that of non-Māori, non-Pacific males.
- For female Māori in the 35-64 year age group the mortality rate from IHD was 5.6 times that of non- Māori, non-Pacific females.
- For 65-74 year old Māori females the rate was 3.3 times the non- Māori, non-Pacific females.

Source: Ajwani et al, 2003

Ischaemic heart disease mortality in Te Tai Tokerau/Northland

Of the four Northern region District Health Boards² (DHBs), Northland has the highest IHD mortality rate, and the rate is higher (by almost 10%) than the total Aotearoa/New Zealand IHD mortality rate (see table 1 and figure 2.)

Table 1: Northern region DHBs IHD mortality compared with Aotearoa/New Zealand 1997-99

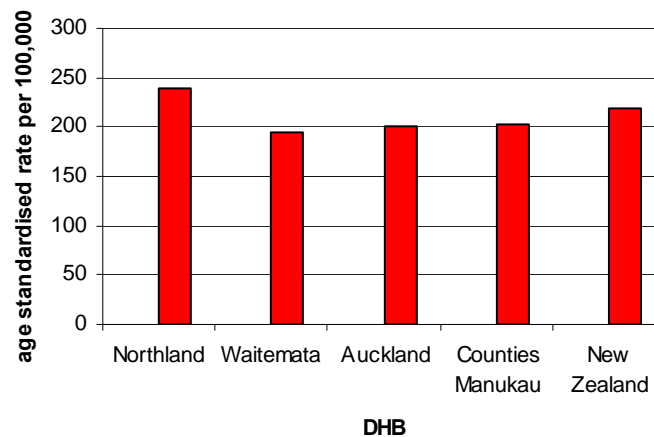
DHB	Rate 1997-1999
Northland	239.9
Waitemata	195.4
Auckland	201.3
Counties Manukau	202
New Zealand	218.9

Note: age-standardised rates per 100,000

Source: (Counties Manukau District Health Board 2003)

² The four Northern region DHBs are Northland, Waitemata, Auckland, and Counties Manukau District Health Boards

Figure 2: Northern region DHBs IHD mortality compared with Aotearoa/New Zealand 1997-99



Source: (Counties Manukau District Health Board 2003)

For the 1996-98 period, the Northland Māori rate of IHD mortality was 78% higher than the total Northland rate, and compared with all Aotearoa/New Zealand Māori, the Northland Māori IHD mortality rate was 22% higher (table 2 and figure 3).

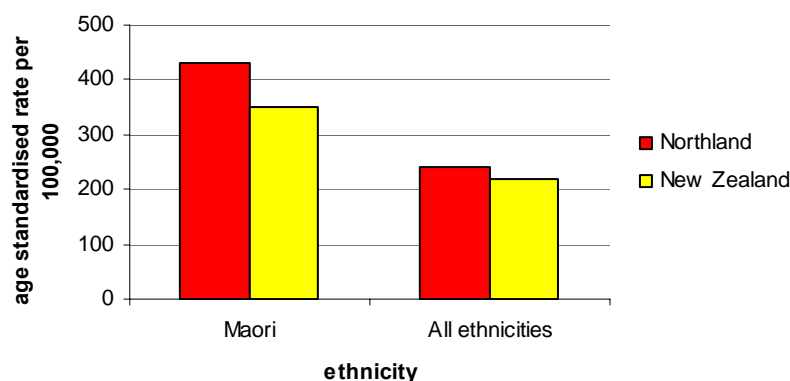
Table 2: Te Tai Tokerau/Northland IHD mortality - Māori and all ethnicities compared with Aotearoa/New Zealand 1996-98

Northland DHB		New Zealand	
Māori	Total	Māori	Total
429.1	240.3	350.8	219.2

Note: age-standardised rates per 100,000

Source: (Counties Manukau Māori Population Health Indicators 2002)

Figure 3: Te Tai Tokerau/Northland IHD mortality - Māori and all ethnicities compared with Aotearoa/New Zealand 1996-98



Source: (Counties Manukau Māori Population Health Indicators 2002)

Ischaemic heart disease, socio-economic status and the life-course

IHD mortality increases with increasing socio-economic deprivation for both males and females.

- The 20 percent of males and females living in the most deprived areas of Aotearoa/New Zealand had an IHD mortality rate 1.6 and 1.5 times that of those living in the least deprived quintile (deciles 1&2 of the NZDep 96³).

Although IHD is related to current disadvantage, it is a disease which is determined by disadvantage across the entire life course from conditions existing at the time of conception and during intrauterine development, through nutrition, growth, and health in childhood, to social conditions, occupation, diet, physical activity, and smoking throughout adult life (Davey Smith et al 2001).

The Māori population is disproportionately represented in the most deprived census areas of Aotearoa/New Zealand, indicating the relative social and economic disadvantage of Māori compared with the rest of the Aotearoa/New Zealand population (Crampton et al, 2000). The relative low socio-economic status of the Māori population is an important contributing factor in the higher rates of IHD and cardiovascular disease.

- Over half of all Northlanders (sixty percent) live in the four most deprived deciles of NZDep 96 compared with forty percent of New Zealanders as a whole (Northland DHB, 2001).
- The Northland deprivation profile is similar to South Auckland, though a greater proportion of South Auckland residents compared with Northland residents live in the three least deprived deciles (Counties Manukau DHB, 2003), thus Northland has a poorer profile than South Auckland.

Prevalence of heart disease among respondents to the New Zealand Health Survey

The recent 2002/03 New Zealand Health Survey which interviewed over 12,000 New Zealanders about their health, found one in 10 adults (10.4%) had been diagnosed with heart disease (ie, heart attack, angina, abnormal heart rhythm or heart failure). In both males and females the prevalence of heart disease was slightly higher in the Māori respondents (MOH, 2004). Northland respondents to the survey, both Māori and non-Māori, had a slightly higher prevalence of heart disease than Aotearoa/New Zealand respondents overall (MOH, 2004).

³ NZDep 96 constructed from 9 variables from the 1996 Census data, provides a deprivation score from 1 to 10 for small areas, where 1 represents the least deprived ten percent of areas and 10 represents the most deprived ten percent of areas. The index describes the deprivation experienced by groups of people living in a small area.

Hospitalisation for ischaemic heart disease in Te Tai Tokerau/Northland

To date there is little information available regarding treatment of IHD in the primary health care sector. However, as cardiovascular disease screening and the Careplus programme⁴ is being implemented in a number of General Practices and Māori Primary Care providers in Te Tai Tokerau/Northland, more information on the amount and type of care provided in the primary care sector for IHD, is likely to become available in the future. Currently hospitalisation information does provide part of the picture of medical treatment for IHD in Te Tai Tokerau/Northland.

- The Māori hospitalisation rate for all cardiovascular diseases in Te Tai Tokerau/Northland is higher than that for all Northlanders and nearly one-third higher than the Aotearoa/New Zealand Māori hospitalisation rate.
- The hospitalisation rate for Māori in Te Tai Tokerau/Northland for IHD, is almost twice the non-Māori/non-Pacific hospitalisation rate, and higher than the IHD hospitalisation rate for Māori across Aotearoa/New Zealand.

Source: Northland DHB, 2001

It is difficult to determine from this hospital discharge information whether the higher hospitalisation rates of Māori Northlanders for cardiovascular disease means there is more serious cardiovascular disease in the Māori population in Northland than elsewhere in Aotearoa/New Zealand or whether health professionals in Northland admit Māori patients to hospital more often than elsewhere. However, given the higher prevalence of heart disease and higher death rates from heart disease in Northland it is reasonable to assume the hospitalisation rates reflect the burden of disease rather than different healthcare practices.

Potentially avoidable disease

- It has been estimated that approximately 36% of IHD deaths amongst New Zealanders are potentially avoidable.
- The same estimates consider approximately 78% of IHD deaths in the Māori population are potentially avoidable.
- These differences reflect, for the most part, the younger age at which Māori acquire IHD.

Source: Waitemata DHB, 2003

⁴ CarePlus is a national primary health care initiative for the management of chronic disease. In Northland the CarePlus programme is supported by an electronic system which includes data capture and reporting providing new information on chronic care management in primary care.

It is thought that a significant reduction in avoidable mortality could be achieved through a combination of population level interventions, including those targeted to improving the social and economic position of the less well off in Aotearoa/New Zealand, individual behaviour change, early detection and treatment usually in the primary care setting, and improved access to best practice medical or surgical treatments (MOH, 1999).

Avoidable hospitalisations

Avoidable hospitalisations are those which could be avoided by either preventing the illness or accident that lead to the admission in the first place, such as the provision of health promotion or disease prevention (eg, by preventing lung cancer through smokefree activities), or by better healthcare for patients in the community. Three of the top ten causes for avoidable hospitalisation in Te Tai Tokerau/Northland are related to IHD, i.e. angina, congestive heart failure and IHD (Northland DHB, 2001). There is no expectation that avoidable hospitalisations could be totally prevented.

- There were 31 394 avoidable hospitalisations in Te Tai Tokerau/Northland in the four years between 1996 and 2000.
- Avoidable hospitalisations make up 31.9% of all hospitalisations (slightly higher than the Aotearoa/New Zealand figure of 30%).
- Te Tai Tokerau/Northland has a significantly higher annual age-standardised avoidable hospitalisation rate for its total population than Aotearoa/New Zealand as a whole (51 per 1000 compared to 42.5 per 1000).
- Avoidable hospitalisation rates for Māori are higher than non-Māori throughout Aotearoa/New Zealand, and in Te Tai Tokerau/Northland the disparity between the Māori rate for avoidable admissions (75 per 1000) and the non-Māori rate (42.2 per 1000) is even higher.

Source: Northland DHB, 2001

Ambulatory-sensitive hospitalisations are a category of avoidable hospitalisation, and are those that could have been prevented by good access to high quality primary care and outpatient specialist services. Quality in this sense means not only effectiveness, but also acceptability of services and the removal of barriers to access such as cost and cultural issues (Northland DHB, 2001). Ambulatory-sensitive hospitalisations make up around two-thirds of the total avoidable hospitalisations.

- Ambulatory-sensitive hospitalisation rates in Te Tai Tokerau/Northland are significantly higher than the Aotearoa/New Zealand average (36.2 compared to 29.8 per 1000).
- One factor relating to this may be the lower GP/population ratio in the region compared to Aotearoa/New Zealand overall.
- The Māori ambulatory-sensitive hospitalisation rate is 55.7 per 1000 while the non-Māori rate is 28.6 per 1000.
- This suggests that Māori in particular would benefit from improved access to appropriate primary care services.

Source: Northland DHB, 2001

Prevention and treatment of IHD

Addressing the historical, political, social, and economic structures and processes that underpin the over-representation of Māori in the most deprived deciles of the NZ Dep Index and the negative health and social wellbeing statistics of Aotearoa/New Zealand, including IHD, is critical. Without change at a societal and structural level, to address the social and economic stratification of Aotearoa/New Zealand society by ethnicity, any other strategies, such as those aimed at reducing risk factors or improving access to quality health services, will only partially address disparities between Māori and non-Māori. Upholding Māori rights based on the Treaty of Waitangi, eliminating social exclusion of Māori, addressing the failures of the education system to successfully provide for Māori students, generating sustainable rural jobs, increasing government family assistance, improving housing assistance programmes, are all examples of the sorts of changes that could realistically impact on a wide range of health and social indicators, including IHD disparities.

Healthcare for IHD

The reality of the disparities requires a pragmatic approach to those already afflicted with IHD and one strategy is to seek improved quality of life in spite of the condition. To effectively advise and support patients and their whānau to prevent IHD or live 'well' with it, the health system needs to provide:

- effective health promotion (at a national, regional and local level)
- effective primary health care (general practice, Māori provider and other community health services)
- effective secondary and tertiary care (specialist services for treatment and rehabilitation in hospitals and communities)

Through an effective health care system these different levels of health service should provide:

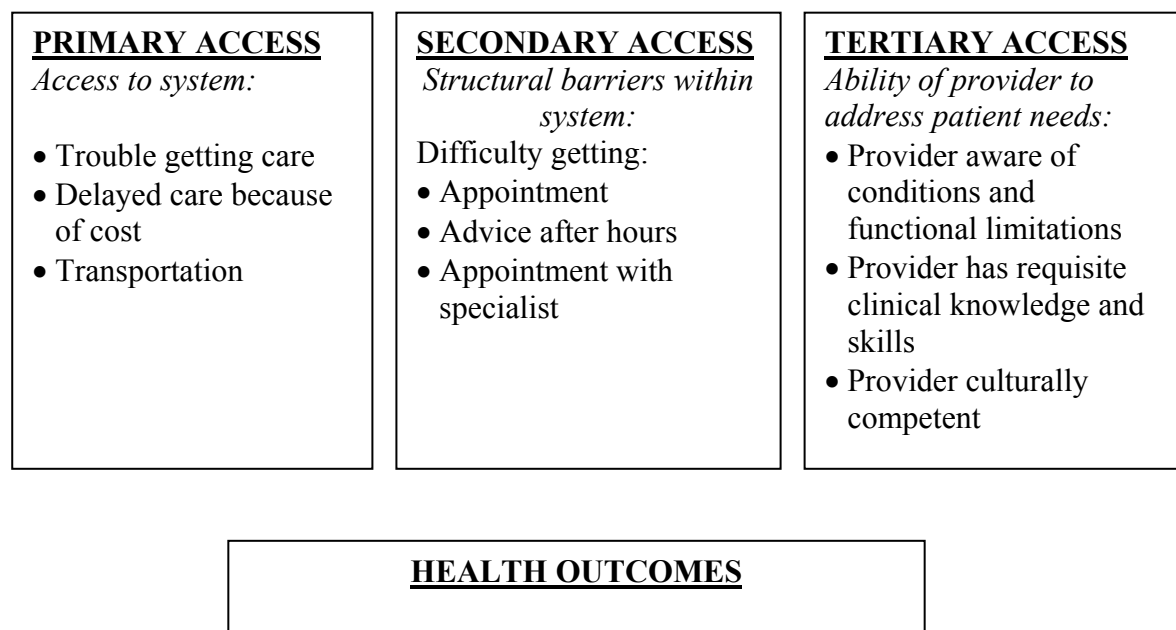
- supportive environments e.g. smoke free legislation, affordable access to better nutrition options, free access to public sporting facilities

- information and effective communication to support the development of knowledge and understanding of IHD, its prevention and management amongst patients and their families
- programmes to support individuals and families to make lifestyle changes such as smoking cessation programmes, nutrition and physical activity programmes
- the right medications at the right time, e.g. for lowering cholesterol, managing hypertension, managing angina and irregular heart rhythms
- the right specialist medical and surgical treatment at the right time

Access to health care

The provision of health services does not necessarily mean patients will be able to access them. There is evidence that people from lower socio-economic groups face a number of barriers to accessing health care (Malcolm, 1996; Gribben, 1999; Comari and DeBoer, 1995; Dovey et al, 1992; Gribben, 1993) and that access to a wide range of health care services across the continuum of care is poorer for Māori in Aotearoa/New Zealand than non-Māori after controlling for socio-economic status (Ellison-Loschmann, and Pearce 2006; Cormack et al, 2005; Schoen et al 2004; Baxter, 2002; Schoen et al 2002; Westbrooke et al 2001; Crengle, 2000). Barriers to accessing healthcare have conventionally been described in terms of availability of services, cost, transport and socio-organisational (in other words the way the services are organised and delivered e.g. not child friendly, not culturally comfortable). These descriptions of healthcare access issues often emphasised the factors associated with the patient that impacted on healthcare utilisation, rather than system factors. More recent analyses have described access to healthcare in terms of primary, secondary and tertiary access that consider the structural and system factors (secondary access) and the practitioner factors such as requisite clinical knowledge and ability to understand and meet the patient's needs, in other words the processes involved in providing services (tertiary access) that impact on pathways through healthcare, alongside the availability of services and factors associated with patients such as transport difficulties (primary access) (Bierman et al, 1998; Lurie, 2002; Cormack et al, 2005), see figure 4.

Figure 4: Dimensions of access



Source Bierman et al 1998

Unequal treatment

As we identify in the Bierman model, gaining access to the right health service does not necessarily guarantee access to the right treatment. Neither does it necessarily guarantee equivalent treatment. Ethnicity, gender and socio-economic position are frequently associated with differential treatment (Geiger 2003; Krieger 2003; Van Ryn 2003; Krieger and Sidney 1996). Evidence of unequal treatment of Māori compared with non-Māori in Aotearoa/New Zealand has been reported in asthma treatment (Pomare et al 1991; Mitchell 1991), diabetes care (Simmons 1998), treatment for depression (Arroll et al 2002), cancer treatment (Robson et al 2006; Cormack et al 2005), quality of hospital care measured by adverse events (Davis et al 2006) and intervention cardiology (Tukuitonga and Bindman 2002; Westbrooke et al 2001; Curtis 2002).

Racism in the delivery of healthcare and how it impacts on patient's access to and through services has been described in terms of institutional, personally mediated and internalised racism (Jones, 2000) and an emerging literature from the Aotearoa/New Zealand context (McCreanor and Nairn, 2002a; McCreanor and Nairn, 2002b; Cram et al, 2003; Harris et al, 2006; Johnstone and Read, 2000; Mcleod et al 2004) has explored the role of negative stereotyping of Māori in the unequal treatment and health outcomes of Māori. The most recent Aotearoa/New Zealand Health Survey 2002/2003 included questions on self reported experience of discrimination including in the health care setting. Māori were more likely to report experiences of self-reported racial discrimination in all instances assessed and were almost ten times more likely to experience discrimination in three or more settings than were Europeans (Harris et al 2006)

Clinical care pathways and Care Plus

Clinical care pathways or care plans are a tool that can be used by health professionals to improve the quality and equity of health care according to the best evidence. Clinical care pathways or care plans have been described by the Ministry of Health (2002d) as "evidence based, multidisciplinary plans of care. They may be for patients who have been diagnosed with a specific condition (diagnosis based), who are having a particular procedure (procedure based), or who are presenting with a particular symptom (symptom based)". Cook (2005) further describes clinical care pathways and care plans as, "time- and stage-oriented tools, used to synchronise the activities of health care teams to achieve predetermined patient outcomes and provide a continuum of care, the key features of these clinical pathways and care plans appear to be their purpose for multidisciplinary co-ordination."

Care Plus is a new service which has been introduced through PHOs since July 2004. It is aimed at people who need to visit their GP or nurse often because of significant chronic illnesses such as diabetes or heart disease, and have acute medical or mental health needs, or a terminal illness.

Care Plus aims to improved management of chronic conditions; reduced inequalities and improved teamwork within PHOs. Care Plus patients receive:

- low or reduced cost access to nurse and/or doctor expertise and time
- continuity of care that includes a Care Plan jointly developed with the patient and ongoing support through pre-planned regular reviews
- advice on improving health outcomes through better self management, with support to identify and meet realistic personal health goals
- lower cost services for high-need primary health users

Health promotion

Health promotion activity and programmes to create supportive environments for making lifestyle change relevant to heart disease are provided by organisations such as the National Heart Foundation and Te Hotu Manawa Māori nationally. Northland Health and the Northland Māori provider organisations provide local health promotion for example auahi kore/smokefree environments and aukati kai paipa/smoking cessation. These organisations also provide physical activity and nutrition promotion programmes. The Aukati Kai Paipa programme has shown positive quit rates for Māori women compared with other programmes nationally and internationally (MOH, 2003a).

Information and effective communication

General practitioners and nursing staff in primary health care – both mainstream and Māori providers, are the main providers of information to patients and whānau about heart disease, its prevention and treatment. Ensuring the right information is imparted in an effective way so that patients and whānau understand the issues around heart disease, requires contact with these services in the first instance, and then a good relationship with effective communication. It has been reported that communication between patients and health professionals significantly impacts on health, that it is not always positive or effective, and there may be particular difficulties in communication between tauwi health professionals and Māori patients (Cram et al, 2003; McCreanor

and Nairn, 2002a; McCreanor and Nairn, 2002b; Silverman, 1988; Simpson, 1991, Jansen, 2006). Communication between health professional and patient is increasingly regarded as central to the practice of primary healthcare, directly and indirectly determining the outcome and therefore the efficacy of such enterprise (McCreanor and Nairn 2002a).

Medication treatment

Among adult survey respondents diagnosed with heart disease, males (76.3%) were significantly more likely than females (61.7%) to receive medical treatment (aspirin, other medicines, tablets or pills, bypass surgery or angioplasty) (MOH, 2004).

In males, the proportion receiving medical treatment for heart disease was highest in the Asian ethnic group, followed by Pacific, European/Other and Māori ethnic groups, although these differences were not significant. European/Other, Māori and Pacific females were similarly likely to receive medical treatment for heart disease (MOH, 2004).

With respect to optimal medication in the treatment of IHD there is limited information on quality of prescribing or uptake of prescriptions. However, it is estimated that more than 100,000 people eligible for treatment (patients with or at high risk of coronary heart disease) with Statin medication for cholesterol lowering, are not receiving it. (Sharpe and Wilkins, 2004) In the year 2000, Northland rated 21st out of 21 DHBs (lowest) in its dispensing rates of statins (Metcalf and Moodie 2002). A recent national audit of hospital care for acute coronary syndrome also showed the use of discharge medications of proven benefit was generally low throughout Aotearoa/New Zealand (Ellis et al, 2004).

Surgical intervention

Surgical procedures for the treatment of IHD may involve angiography, angioplasty (also known as percutaneous coronary intervention - PCI, or percutaneous transluminal coronary angioplasty - PTCA) and coronary artery bypass grafts (CABG). Angioplasty, PCI, PTCA and CABG are also known as re-vascularisation procedures.

▪ Coronary angiography is an x-ray procedure to examine the arteries of the heart. The purpose of the test is to obtain vital information about the severity and position of any narrowing in the coronary arteries, to measure the blood pressure within the heart chambers, and to check the functioning of the heart valves.

▪ Coronary angioplasty, PCI or PTCA is the procedure used to widen the narrowing in a coronary artery using a special balloon and sometimes a stent.

▪ A coronary artery bypass graft (CABG) is an operation to bypass a narrowed or blocked segment of a coronary artery using a graft.

For people with severe angina and coronary artery disease, surgical interventions may be life saving and are important in improving the quality of life through relieving the pain and functional limitations.

Māori access to surgical interventions nationally

For almost two decades data has been published that illustrates Māori are under represented in surgical interventions for coronary heart disease, despite experiencing significantly higher IHD mortality rates than other New Zealanders (Pomare 1988, Pomare and de Boer 1988, Pomare et al 1995, Westbrook et al 2001, Tukuitonga and Bindman 2002).

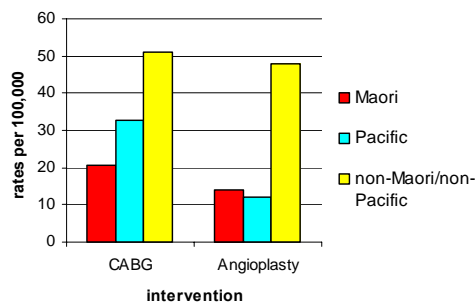
An analysis of the Aotearoa/New Zealand cardiac register in the 1980s found that Māori men were three and a half times less likely to receive publicly-funded coronary artery bypass graft surgery than non-Māori men, despite being one and a half times more likely to die of coronary heart disease at this time (Phillips 1991).

Tukuitonga and Bindman (2002) using information from the National Minimum Dataset and the Auckland Coronary Artery and Stroke (ARCOS) Study, examined ethnic and gender variations in the use of coronary artery revascularisation procedures in Aotearoa/New Zealand. They investigated CABG and PTCA rates for men and women aged 40 years and over in the years 1990-1999. They found during this time period, 10,413 CABG procedures were performed on men and 3,500 on women in Aotearoa/New Zealand. Of these, 321 were for Māori men and 166 for Māori women. During the same period 9,419 PTCA procedures were performed on men and 4,248 in women with 232 in Māori men and 120 in Māori women (Tukuitonga and Bindman 2002).

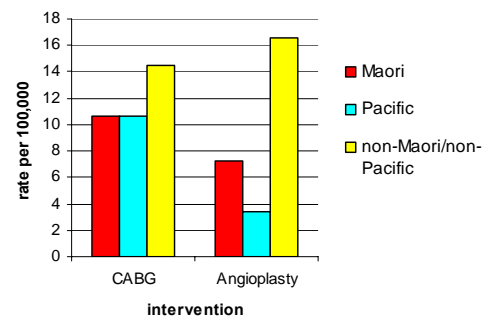
They report that compared to ‘other New Zealand men’ (i.e. Non-Māori, and Non-Pacific), Māori men had a mean age standardised CABG and PTCA intervention rate ratio of 0.40 and 0.29 respectively. For Māori women compared to ‘other New Zealand women’ (i.e. non-Māori, non-Pacific), for CABG and PTCA the rate ratios were 0.74 and 0.43 respectively (Tukuitonga and Bindman 2002). The authors conclude that despite Māori having higher rates of coronary artery disease morbidity and mortality, re-vascularisation rates were lower for Māori during this time period (see figures 5a & 5b) (Tukuitonga and Bindman 2002).

Figures 5a & 5b: CABG and PTCA intervention rates (1990-1999) per 100,000 population by ethnic group

A) NZ Males



B) NZ Females



Source: Tukuitonga and Bindman 2002

A Health Funding Authority analysis calculated an expected number of CABGs for Māori during a one-year period from July 1998 to July 1999 (HFA 2000). Expected numbers of CABGs were based on the proportion of Māori aged over 40 years in the population and the ratio of mortality between Māori and non-Māori. The study found a national deficit of 174 Māori CABGs during this period. In other words, 174 Māori men and women who were ‘expected’ to have received a CABG during this time period did not receive one (HFA 2000).

Westbrooke et al. (2001) found differences between Māori and non-Māori rates of cardiac interventions and demonstrated that the lower Māori rates remained within the NZ Dep 96 deprivation deciles. Non-Māori rates of CABG and PTCA were significantly higher than Māori within each deprivation decile highlighting that the rate difference is related to ethnicity separate and in addition to that associated with deprivation (Westbrooke et al, 2001).

- There has been an increase in standardised discharge rates for most cardiac procedures in public hospitals over the five years to June 2002.
- Although the rates of angioplasty have increased for all ethnicities, the disparities between groups have not improved.
- The gap between ethnicities has narrowed for coronary artery bypass grafts in the public hospital sector.
- Overall, rates of cardiac procedures (also including pacemaker and valvular procedures) are improving for Māori and Pacific peoples but, because those ethnic groups have much higher rates of incidence and mortality from cardiovascular diseases, there are likely to be many people in these groups who do not receive the appropriate treatments.

(Ministry of Health, 2003).

Regarding the intervention rates above, it should be noted that because these rates of intervention only describe the picture in public hospitals they do not show the total rates of surgical intervention for IHD. Because less Māori have private health insurance, if surgical interventions in private hospitals were included in the analysis, the gap between Māori and non-Māori access to CABGs and PTCA would likely be larger.

Access to surgical interventions for Northlanders and Māori in Te Tai Tokerau/Northland

Available information on Northlanders' access to angiography, angioplasty and CABGs, is for public hospital interventions only, therefore the rates for procedures described below do not include procedures carried out in private hospitals. Māori are less likely to have private health insurance than non-Māori. Therefore there are likely to be more Non-Māori residents from Northland accessing cardiac surgery privately than Māori. Consequently the gap between Māori and non-Māori Northland residents' rates of cardiac intervention is likely to be wider than shown below. Furthermore the smaller numbers of Māori mean rates should be read with caution with wider confidence intervals around the Māori rates than the non-Māori rates.

- For angiography, Northlanders have lower access than any other Northern region DHB residents and lower than New Zealanders in total, however there was a steady increase in access over the time period 2001 – 2003 (Counties Manukau DHB 2003).
- For PCI, PTCA or angioplasty in public hospitals the data shows Northlanders had lower access than any other Northern region DHB residents and lower than New Zealanders in total, however as with angiography, there was a steady increase in access over the period 2001 – 2003 (Counties Manukau DHB 2003).
- Northlanders had similar access to that of residents from the Auckland and Counties Manukau region in 2001 for CABGs. In 2002 there was a drop in the rate of CABGs for Northland residents to lowest in the region and then in 2003 Northlanders received a higher rate of public hospital CABGs than residents of the Waitemata region. In all three of these years the data shows Northlanders had a greater access to CABGs than New Zealanders overall (Counties Manukau DHB 2003).

This data, derived from Counties Manukau DHB analysis does however contradict data from the New Zealand Health Information Service that annually produces standardised discharge ratios for a number of surgical procedures including CABG. The ratio takes into account the particular sex, age, ethnicity and social deprivation mix of each DHB's population.

- For the 2002/03 year, the Northland DHB standardised discharge ratio for CABG was 0.90, and for 2003/04 the ratio was 0.93, that is, less than the average rate of CABGs in Aotearoa/New Zealand for both years.

Source: New Zealand Health Information Service
<http://www.nzhis.govt.nz/stats/surgical/index>

Calculations of Northland residents' public hospital cardiac intervention rates by ethnicity for 2001, 2002 and 2003 below are for Māori compared with non-Māori / non-Pacific peoples. Data for Pacific peoples have not been included because the numbers are very small (mostly 1 or 2 interventions per year) and therefore rates are particularly prone to error. The caveats regarding the exclusion of private hospital procedures and small numbers of Māori apply particularly to this information therefore the data should be read with caution.

- For all three procedures in 2001, Māori received considerably lower rates of intervention. Māori had a significantly lower rate of angioplasty than non-Māori / non-Pacific.
- There was an increase in Northland Māori residents' rates for angiography and angioplasty in 2002, and a smaller increase in CABGs. For all three procedures the public hospital rates for Māori appear higher than non-Māori/non-Pacific residents of Northland DHB area but this is not statistically significant.
- In 2003, the angiography rate for Northland Māori residents was similar, though slightly higher than the 2002 rate and higher than the non-Māori/non-Pacific rate, the angioplasty rate for Māori dropped in 2003 to lower than the non-Māori/non-Pacific rate and the CABG rate increased further and was higher than the non-Māori/non-Pacific resident rate but not statistically significant.

Source: Counties Manukau DHB, 2003

The research

Aims and Objectives

This project arose out of a commitment to the improvement of Māori health in Te Tai Tokerau/Northland and was conceptualised and planned in collaboration with the Māori primary health care providers of Te Tai Tokerau – Whakawhiti Ora Pai, Te Hauora o Te Hiku o Te Ika, Hauora Whanui, and Ki a Ora Ngati Wai and First Health, who at the time, were the management representative organisation of the General Practitioners of the Mid and Far North areas. Since the planning of this project these organisations and Te Runanga o Te Rarawa have joined up to become Te Tai Tokerau Primary Health Care Organisation (PHO). The research was approved by the Northern Regional Health and Disability Ethics Committee in October 2003.

The research aimed to improve healthcare practice and Māori access to and experience of health care by:

- developing an understanding of Māori pathways to and through healthcare for management of IHD
- identifying barriers and enablers to utilising services for IHD management as perceived by Māori and health care providers
- examining Māori and practitioners' perceptions of the issues that impact on Māori experience of IHD and associated healthcare
- exploring the appropriateness and acceptability of Clinical Care Pathways and the Careplus programme for Māori
- examining what impacts the formation of PHOs is having on Māori and providers

The research used qualitative methods within a kaupapa Māori action research approach (Moewaka Barnes, 2000; Smith, 1999).

There were three phases to the project: phase one in-depth interviews; phase two change facilitation; and phase three in-depth interviews.

Given the kaupapa Māori, action research approach to this project, working in collaboration with key stakeholders was critical. To this end in early 2004, prior to beginning phase one interviews, we held a series of planning meetings with the management and leadership of mainstream and Māori health organisations in Te Tai Tokerau to introduce the project and seek advice and input.

Phase one: in-depth interviews

Twenty five Māori with IHD were selected for interviews to explore their range of experiences in accessing and utilising healthcare for IHD, their knowledge and understanding of IHD and their responses to and perceptions of treatment/referral options offered. The participants were selected through Māori primary healthcare providers and general practice. A purposive sampling strategy was used to identify participants with differing experiences of IHD, treatment and outcomes, of different

age groups, gender, and from different localities within Te Tai Tokerau PHO provider areas.

Potential patient participants were first identified and approached by their primary health care provider and given written information about the research project. They were asked if they were willing to be contacted by the research team and if they agreed, the lead researcher called to discuss the project further and arrange a time to meet with the potential participant. At the first face to face meeting, further information was provided and written consent to participate was sought. Only two potential participants declined to be interviewed. Most interviews were carried out in the participant's own home and usually with whānau participating in the interview, which took between one and two hours. Phase one interviews were undertaken between February and July 2004. Table 3 below outlines the range of characteristics of the patient participants.

Table 3: Range of characteristics of patient participants

	40-49YRS	50-59YRS	60-69YRS	70YRS +
AGE	3	9	11	2
	MALE		FEMALE	
GENDER	14		11	
	YES		NO	
ANGIOGRAPHY	7		18	
	YES		NO	
REVASCLARISATION PROCEDURE	6		19	

Whānau were interviewed alongside Māori patients and in group interviews to provide a whānau perspective on the experience of Māori IHD and associated health service provision.

In addition, 19 in-depth interviews were carried out with healthcare professionals from a range of organisations including secondary care, mainstream general practice and Māori primary healthcare organisations. These participants were selected to capture a range of provider experiences in the provision of healthcare to Māori with IHD. They included GPs, Practice Nurses, Community Nurses, Medical Specialists, Nursing Specialists, and Community Health Workers. Both male and female health professionals were selected, with a range of length of service in Te Tai Tokerau/Northland. Practitioner interviews took between thirty minutes and one hour.

In total sixty five people were involved in in-depth interviews during 2004.

All interviews were carried out by Liane Penney – the primary researcher - and used an open ended but focussed approach, exploring the range of areas of interest as outlined in the objectives of the study.

Phase two: change facilitation

In accord with the principles of kaupapa Māori research (Moewaka Barnes, 2000; Smith, 1999) phase two of the project was designed to provide opportunities for a)

feedback between the researchers and the participants on the preliminary findings and b) the development of ideas or actions for change arising from phase one findings.

The process involved a series of hui and meetings during 2005; in the first instance, with the research participants, and then wider stakeholders including the collaborating organisations forming Te Tai Tokerau PHO; Te Tai Tokerau MaPO; the Northland DHB; the Ministry of Health and consumer groups.

Prior to meeting with the research participants, they were sent a draft report on phase one findings and, if they chose to, a full set of anonymous interview material.

Initially two hui were held in Kaitaia - one with patient and whānau participants and one with health practitioner participants - and two hui in Kawakawa - one with patient and whānau participants and one with health practitioner participants.

Other meetings to discuss the research findings and generate interest in change projects were held with the following organisations:

- The project advisory group
- Te Tai Tokerau PHO Board
- Te Tai Tokerau PHO management
- Te Tai Tokerau PHO health promotion steering committee
- Ngati Hine Health Trust
- Te Hauora o te Hiku o Te Ika
- Northland DHB Funding and Planning Team
- Northland DHB Kaunihera Council of Elders
- Northland DHB Health of Older Peoples Strategy Māori reference group
- Manaia PHO primary health care nurses, NDHB Medical Outreach team and Cardiac Rehabilitation team
- Te Tai Tokerau MaPO Trust, Manaia PHO and NDHB representatives
- Te Kete Hauora, Ministry of Health
- The Ministry of Health cross department Strategic Presentation

Rather than the researchers prescribing actions or change projects, the primary researcher presented the findings of the phase one interviews, ideas for possible areas of action and facilitated discussion. Development of ideas for change and the prioritising of possible actions emerged from the groups rather than the researchers. The researcher then provided ongoing input and support as requested by various stakeholders on actions they had prioritised.

During the change facilitation phase the Northland DHB invited the primary researcher to project manage the development of the Northland Cardiovascular Disease (CVD) Strategy. This presented an important opportunity to disseminate further the findings of phase one interviews and draw on this research to influence policy and practice that was relevant to effective, quality healthcare for Māori with IHD.

Phase three: in-depth interviews

All participants were invited to participate in a second interview after one year. The purpose of the phase three interviews was to examine what effects the collaborative processes arising out of the research might be having and the impacts of the PHO formation and Careplus implementation. Phase three interviews were also intended to provide further information, particularly in relation to Māori experiences of IHD over time.

Participants were advised from the beginning of the project that participation was voluntary and they could discontinue their involvement at any stage and that participation in the phase one interviews did not necessitate involvement in the subsequent phase two hui, and phase three interviews.

Of the patient and whānau participants five were lost to follow up. One patient had passed away, three patients were not contactable, and one patient declined a phase three interview.

Of the practitioner participants four were lost to follow up. Three practitioners were unable to be contacted because they had left the area or were on extended leave. One practitioner declined a phase three interview.

All phase three interviews were carried out by Liane Penney during 2005. The findings of the phase one interviews were discussed and further feedback sought. The change facilitation process and subsequent action was discussed. Participants were invited to discuss the impact of their involvement in the research project and any other issues of interest as outlined in the objectives of the study.

Transcription and analysis

All interviews were audio taped with the permission of the participants. The audiotapes were transcribed verbatim. Participants were given the option of receiving both transcripts and audio tapes.

Each transcript was checked by the interviewer against the audio tape for accuracy of transcription. The checking of each transcript also provided an important opportunity to hear the interview a second time thus enhancing the data analysis process. Transcripts were entered into QSR NVIVO a qualitative data analysis software package, to organise and code the data. A process of inductive thematic analysis was undertaken through multiple disciplined readings of each transcript.

Three main domains are described – understandings of IHD, pathways to healthcare, and pathways through healthcare. Within each domain a number of themes are reported and illustrated with quotes from the database. We present data from all sets of participants from both data gathering stages in the sections that follow.

Results: phase one and three interviews

Understandings of ischaemic heart disease

Māori patients and whānau were well informed on lifestyle impacts on CVD. They were aware of the associations of diet, physical activity and smoking to CVD and understood the need to manage obesity, hypertension, “high cholesterol” and type 2 diabetes. There was however limited knowledge and understanding amongst the patient and whānau participants of the lifecourse impact on CVD.

Māori patients and whānau also talked about family history, often in terms of genetic causation or heredity, as a key contributor to CVD in the Māori population. Commonly they described CVD as something that was “in my whakapapa”. Evident in the talk of Māori patients and whānau was a lack of clarity, perhaps not surprisingly, given confusion amongst health professionals, of the complex dynamics of family history involving genetic susceptibility, shared environment and common behaviours. The concern with perceptions of genetic causation, is the feeling of inevitability or lack of power to change the outcome, and there was some evidence of this in the discourses of Māori patients and whānau.

Wife: yeah he did smoke but as the specialist said it's an inheritance which is quite true

Patient: when we go back on my mum's side there's probably about 8 or 10 in our family that's died from heart attacks, but two brothers have had heart attacks and on my father's side there's one on my father's side that died of a heart attack so it's quite strong in our genes. PP14

Most commonly however the Māori patients and whānau viewed stress as the major contributor to Māori CVD. They talked about stress associated with loss and grief, unemployment and financial hardship.

Yes and it really came on bad at the time my dad had a heart attack and it actually brought mine on as well because it was only in a matter of a few hours when I was in hospital alongside him. Stress is one of the things that brings [chest pain] on but I don't stress anymore. PP8

Although Māori patients and whānau demonstrated a good knowledge of the known causal associations with CVD, when talking about their own health problems, they were less sure, in fact a number of the patients were quite unclear about how or why they had developed IHD. The Māori women patients were particularly unsure about how and why they had developed CVD. This phenomenon of understanding the causes of CVD but not necessarily understanding one's own personal trajectory, particularly for women, has been reported elsewhere. Other studies of other populations have also found that the most commonly held belief is that CVD, in particular, myocardial infarctions and strokes are caused by stress (Newman 2003; Meischke et al 2000; Mosca et al 2000; Gans et al 1999).

Although some health practitioners acknowledged the impact of social and economic factors on Māori health, they generally focussed their talk of the prevalence of CVD in the Māori community on lifestyle risk factors.

“You know, everyone smokes, well not everyone smokes, but huge, a very high percentage of people smoke. They drink a lot, take drugs, don’t exercise, and eat very high fat food. It’s just a huge amount of risk taking, you know, has a big input into how healthy they are.” Prov12

Pathways to healthcare

Māori patients and whānau described a wide range of pathways to care for IHD.

- presentation to GP for screening of cardiovascular disease risk factors, GP advice on lifestyle changes and treatment of risk factors
- presentation to GP with symptoms, GP management with medication
- presentation to GP with symptoms, referral for specialist assessment, medical management
- presentation to GP with symptoms, referral for specialist assessment, medical management and then some years later reassessment by specialist and surgical intervention
- presentation to GP for symptoms, referral for specialist assessment and immediate surgical intervention privately
- presentation to GP with symptoms, referral for specialist assessment at Greenlane Hospital (GLH), wait listed for surgical intervention
- presentation by ambulance to A&E, specialist assessment, medical management
- presentation by ambulance to A&E, specialist assessment, acute transfer to GLH for surgical intervention

Varied help seeking vs. late presentation

Participants sought healthcare and entered a pathway of care for IHD at a range of levels along the continuum; from the earliest stage of risk factor management, through to emergency admission for acute coronary syndrome having had no previous treatment for IHD or risk factors. Those who entered a pathway of care as a result of symptomatic illness described varying symptoms and health seeking responses. Some responded immediately to symptoms and others delayed seeking help.

For the patients and whānau who described delayed help seeking, they moved to action if symptoms didn’t abate or worsened. If symptoms did abate participants commonly described advising their GP of the symptoms the next time they visited. Some participants persisted in seeking help when they felt their problem had not been dealt with appropriately by the GP or hospital. Furthermore those who had suffered a serious cardiac event without previous symptoms or a diagnosis of IHD expressed concern that there were missed opportunities for assessment and diagnosis of IHD when visiting a GP for other health issues, prior to the acute cardiac event.

Expressed reasons for a delay included:

- confusion over their symptoms
- putting symptoms down to pre-existing conditions such as asthma, indigestion or general symptoms of ageing
- trying self management first to wait and see if the symptoms would abate
- believing they were too young to be suffering any serious problem

- fear of a serious problem
- not wanting to unnecessarily take up the time of health professionals
- waiting until the end of their work day
- waiting until normal surgery hours so as not to bother the GP out of hours

Whānau members and sometimes work colleagues were influential in coercing patients to seek help if they did delay.

With respect to delayed help seeking the participants descriptions of responses were consistent with the findings from other studies exploring patient variation in response to cardiac events (Ruston et al 1998; Ottesen et al 1996; Dracup et al 1997; Dracup et al 1995; Norris et al 1998). Factors determining immediate or delayed response previously reported are: whether or not there is recognition of symptoms as cardiac in origin; age and gender; whether or not the patient perceived themselves to be potentially at risk of heart disease; a previous cardiac event; trying self management first; and not wanting to disturb a doctor at night for what might be a trivial problem.

In contrast to Māori patients and whānau descriptions of pathways into healthcare, health practitioners talked about Māori patients as typically late presenters, often delaying seeking healthcare until very unwell. Typically, health practitioners drew on explanations of delayed presentation as related to Māori attitudes of inevitability of ill health, ambivalence towards health and healthcare, and fear of health services.

“If you’ve got bad access there comes a feeling like an inevitability, “of course everyone in my family dies of heart attacks, I’m going to die of heart attack”. So what’s the real worry about it, I’m just going to live the best I can, enjoy my life while I can. I’m going to die when my time comes.” Prov3

Health practitioners expressed difficulties assessing Māori patients at presentation, claiming Māori concealed symptoms and held back on providing information or asking questions, thus leading to a delay in diagnosis.

“They tend to conceal it too - the Māori tend to conceal that they’re getting a bit of chest pain whereas a European might be a little bit more concerned and get to the doctor immediately. The Māori patients are likely to think “oh well, it can’t be anything”, and probably a bit scared of actually what it might be so they don’t go they don’t want to find out. Oh [concealing symptoms] it’s almost devious sometimes. They’ll come in with a problem and that’s the very last thing to come up as they’re going out the door. They’ll come up with all these other problems that are just not really what they’re worried about, they might of wasted half an hour by the time, then you say “Ok then Bill, so you’ve covered pretty well everything?” – yeah, and as they’re going out the door “oh by the way I’ve had a bit of chest pain”. It’s very tempting if you’re a general practitioner you’ve already used up more than your time slot for that patient then you’ve got five patients in the waiting room, it’s very tempting to say “oh God, we’ll cover this another time”. I think that gets done a lot really... so I can think of several people that really should be investigated by now but they haven’t.” Prov2

As illustrated in the quote below, health practitioners commonly asserted the practice of Māori patients delaying seeking healthcare as a cultural trait.

“Well with putting bums on seats, getting them into the office is very difficult and then there's any Northland male, the fact that in the demographics that you know 60-70% of the Northland males in my practice are Māori doesn't make me treat anybody differently but it makes it very difficult to get people into the office for prevention. The Northland residents tend to stay at home and try and fix things until they're broken and that's just their culture and how you interrupt that cycle and suggest that people consider doctors and medical services from different views is very different... getting that group into the office is very difficult, that's the problem.” Prov9

Summary

In summary, Māori patient and whānau explanations of entering a pathway of care for IHD diverged significantly from health practitioners. Māori described:

- a wide range of health seeking behaviours from proactive wellness screening and treatment of risk factors for IHD, through to emergency admission for a cardiac event
- variable help seeking behaviour for symptoms both immediate and delayed
- delayed help seeking, related to confusion of symptoms, uncertainty of severity, fear of outcome, age related, and not wanting to unnecessarily bother a health service particularly out of hours
- persistence with help seeking if problems were not resolved
- missed opportunities at GP visits for earlier assessment and management of risk factors prior to a serious cardiac event.

Māori participants' reasons for delayed responses to symptomatic illness were highly consistent with those found in previous studies.

In contrast, health practitioners described:

- Māori as typically unlikely to present for screening and late presenting with IHD
- Māori avoidance of screening or late presentation was explained as attitudinal - ambivalence towards health and healthcare, an inevitability around illness, and a fear of health services, and these were considered cultural traits
- once Māori presented to health services, there may be missed opportunities for assessment and diagnosis of IHD because Māori conceal symptoms, and withhold information.

Pathways through healthcare

As presented and discussed above, Māori participants described a wide range of pathways *into* healthcare for IHD. Participants also described a wide range of treatment pathways *through* healthcare for IHD, from lifestyle advice through medical management and surgical intervention. Some participants held private health insurance policies but only one participant received a revascularisation procedure privately under his insurance cover. Other participants who were investigated with angiography and received PCI or CABG did so through the public health services. Patient participants used a range of services from community support agencies, Māori providers, general practice, and hospitals. The following discusses the key themes

arising from the discourses of Māori patients and whānau and health practitioners regarding treatment pathways.

Access

Access issues were a dominant theme in the interviews with Māori patients, whānau and health practitioners. Talking to their experiences of providing, receiving, or supporting a family member receiving healthcare for IHD, prompted reference to problems with getting the right care at the right time. Problems arose from the circumstances of patients, system factors – the way the health services are structured, and the way practitioners provide healthcare or process factors. We have organised the discussion of access issues below according to Bierman’s (1998) framework of primary, secondary and tertiary access.

Primary access – access to the system

With respect to getting to the services they were referred to, or encouraged to use, many participants talked about the long distances required to travel to centralised secondary services in Whangarei and tertiary services in Auckland. Long travel distances incurred considerable costs in terms of vehicle running expenses, time off work and child care. Although the cost burden didn’t deter Māori participants from attending what they perceived as essential specialist appointments, they were reluctant to travel long distances for appointments that they perceived were not adding enough value to their overall healthcare; for example travelling from the mid-North to Whangarei for Cardiac Rehabilitation services.

A number of Māori participants also referred to long distances to travel to community services for supporting lifestyle change; for example, travelling to weight watchers, which they found to be particularly effective, entailed long travelling distances for many rural residents. Some Māori participants also talked about limited options for support to increase their physical activity, specifically poor access to public swimming pools.

“There was a time in my life when I went to weight watchers and it worked...it worked for me because there was that constant support, and constant group getting together and it worked but the closest one that runs is a hundred kilometres a time and so you can't sort of think... oh well you know, that's a long way to go to get involved. I think some of the areas, I'm sure that I'm one of many who live in an isolated area who could do with that kind of support...” WH12

There was some concern that costs of travel in emergency situations were being unfairly shifted to them, when they were asked to drive to Whangarei or Auckland for urgent specialist cardiology services, rather than being taken by ambulance.

Primary care consultation costs were generally not considered to be a barrier to healthcare since fees had reduced with the introduction of PHOs. Patients noted GP consults were now significantly more affordable. There was talk however of high medication costs for a number of participants who were required to take drugs that were not fully subsidised.

Health practitioners acknowledged the considerable travel costs that many patients faced in Tai Tokerau/Northland to receive secondary or tertiary care. Many talked about the various travel assistance options they discussed with patients and some claimed travel shouldn't be a barrier given the free bus, WINZ and health subsidies for healthcare related travel.

Many practitioners also acknowledged costs of consultations and pharmaceuticals had, in the past and in some cases still do, created barriers to healthcare, although they referred to the introduction of PHOs significantly reducing primary healthcare costs. Others contested the notion that cost was a barrier to healthcare in Tai Tokerau/Northland and expressed their view that healthcare should be prioritised over other expenditure.

“I don't see that there should be any excuses from any population group in New Zealand that say that they can't afford to go to the doctors. Up here if people really put their minds to it and they put a little bit off effort into it they should have the means of getting to medical health in time, you know. I do not take this thing as you know, what will have to happen is it should be a management plan for how to work with the money. The money that they're going to spend seeing the doctor is a drop in the ocean compared to smoking, drinking, and doing all the other types of abuses that is prevalent up here.”
Prov19

Although two Māori patient participants referred to holding private health insurance policies only one patient accessed cardiology and surgical intervention through their policy. Other Māori participants did not raise the lack of private healthcare through health insurance as a perceived access barrier. However, many practitioners noted that few Māori patients held health insurance policies and contended that this significantly reduced their access to timely intervention cardiology compared with other population groups.

Secondary access – structural barriers within the system

Accessing a particular chosen GP was difficult for some Māori participants, particularly since the introduction of PHOs where use of Māori provider services precluded them accessing a GP outside of the Māori provider service.

“I had like two doctors up here that I really trusted. But now there is another doctor coming out...I had my diabetes readings with me, he never even looked at those, and I said to my husband, “you know, now I feel like no-one's looking after me”...so I've tried to transfer back, but you can't, all the doctors up here are full so you can't. It's taken like three years to get to this point and I sort of think I don't want to jeopardize it and I don't really like... I'm on so many pills I don't want anyone bar those two changing them. They used to work like hand in hand, like talk to each other and it's only since this other thing [the PHO] where you have to belong to one or the other”. PP7

Getting to see a chosen GP was also difficult for some Māori participants irrespective of whether or not they were using Māori provider services. They described this as due to heavy bookings as a result of a high patient to GP ratio and frequent use of locum GPs.

“Since I've had, you know since twenty years ago, I have really stuck to my doctors ... I shouldn't really say this, but they're always having locums come in and out...and I don't like that sort of thing, I'd rather just have my one doctor that I can just...because I go to the doctor every month, I'm a high user card, I go to my doctor every month even though it's just to have my blood pressure checked I go every month.” PP15

The provision of general practice services during business hours only was considered a barrier to accessing primary care by some Māori participants who found getting time off work difficult.

Long waiting lists were talked about by Māori participants as a barrier to timely assessment and treatment and the centralisation of some secondary services in Whangarei and tertiary services in Auckland created travel difficulties for Māori participants. They did generally overcome these, at a personal cost, not simply in terms of direct travel costs but also time off work and separation from whānau support. Māori participants did however make decisions not to use services that required long travel distances, if they deemed these services not to be adding value to their treatment and if they were not urged to by their GP.

Practitioners' talk of secondary access issues, or system factors that created barriers to accessing healthcare for Māori concurred with Māori participants in a number of ways. They too spoke of the centralisation of some specialist services to Whangarei and the limited availability of outreach specialist services at the small regional hospitals, in particular specialist assessment, exercise tolerance testing and cardiac rehabilitation. Waiting lists were also viewed as a significant system barrier to accessing timely specialist secondary and tertiary care for IHD. Some practitioners agreed that the hours of operation of primary health care services created access barriers for some people and talked about development of more occupation based primary health care, particularly for screening services, as a solution to this access problem.

Practitioners also referred to the shortage of medical staff, particularly GPs, although shortage of specialists and experienced nursing staff was also noted. However, rather than talking about this with respect to discontinuity of care, as patients had, they talked about the shortages as a barrier to accessing quality care because it resulted in long patient lists each day and limited time with each patient.

In addition, practitioners identified a range of other system barriers, including reference to there being no specialist cardiology service. Since the study interviews, Tai Tokerau/Northland Health has been successful in recruiting a Specialist Cardiologist. Some practitioners also referred to the absence of pre-hospital fibrinolytic therapy in Tai Tokerau/Northland, which, according to guidelines for pre-hospital administration of fibrinolytic therapy by New Zealand general practitioners (The Pre-Hospital Fibrinolysis Guidelines Working Party 2004), should be provided to all patients suffering an acute myocardial infarction who are located over an hour from a hospital. As well, practitioners referred to limited availability of timely defibrillation and advanced life support in some rural areas of Tai Tokerau/Northland and proposed community access to automated external defibrillation and ongoing community CPR training.

There was considerable discussion around the limited capacity for effective, quality chronic care management in general practice, as is necessary for patients with IHD, due to limited time available with each patient under the current model of general practice. There was acknowledgement that the new PHO system with a capitation system of payment to an enrolled population was a step in the right direction but to date was not delivering sufficient funding to allow for substantive changes to the current model of service delivery.

Although a number of practitioners talked about the potential of developing nursing and community health worker services to enhance the model of service delivery to improve chronic care management, they raised criticisms of these services within Māori provider organisations. Their criticisms focussed on a lack of collaboration and effective information sharing, which they described as common throughout the healthcare system – between primary and secondary care and between secondary and tertiary care as well as between Māori providers and general practice. This lack of collaboration and information sharing was considered to be a system barrier to accessing quality effective healthcare.

“What the work that the Māori health providers are doing; it’s not that it’s bad but, sometimes how we measure how effective it is and are we best utilising them, sometimes I wonder. I’ve got two or three people going in to see the same sort of person but are we improving the outcome or where are we doing that, that is such a huge, it’s almost insurmountable to get people to work together instead of in, you know, in competition, instead of collaboration. Clearly room to move. But with a lot of the stuff that we do we have yet to improve an outcome.” Prov6

“I mean communication is always difficult. We just don’t communicate with people we’re dealing with and people change so fast that it’s hard to strike up relationships. I don’t have any great ideas there. The fact that we all have different types of computer programmes, you know the hospital has got another one. The discharge summary might take a month to get to you. I found as a patient actually that I just couldn’t believe how bad it is, you know I wouldn’t believe that it was possible. You know you get home from hospital and see your general practitioner a week later and he doesn’t know that you’re out or dead whatever the case might be. It’s probably worse than it was years ago.” Prov12

Many practitioners qualified their commentary on the system barriers to accessing appropriate care for IHD, as impacting on all their patients without health insurance, not just Māori, and that many of the system barriers were a consequence of the Tai Tokerau/Northland environment; a medium size, high need population, spread over a large geographical area, much of which is rural, thus creating challenges to attracting health professionals and providing adequate services across the region.

Tertiary access – process of care, the provider’s ability to determine patient need and apply requisite clinical knowledge and skill

Generally, Māori participants assumed that the range of services they were advised to consult for treatment of their IHD was appropriate best practice. They expected that, if there were other services and treatments they should access, their GP would refer them. However, there was reference by some Māori participants as to why they had not received a particular investigation or treatment that others they knew of with IHD

had received. Some participants talked about asking their GP if they should be referred for a particular treatment. In one case a patient was referred for and received angiography following her enquiry regarding this procedure.

Other discourses, around how Māori participants perceived the provider's ability to determine their needs and make the appropriate decisions, were evident in talking of their experiences of services across the continuum of care. These were given expression in talk of dissatisfaction with the relationship, poor communication and information sharing in some interactions with the health services. Despite their concerns, Māori participants expressed gratitude for the care they had received. As the relationship with health practitioners and communication was a dominant theme arising from the narratives of both Māori and practitioners we discuss these separately under a section focussed on communication.

Practitioners too, offered accounts of the process of providing care that illustrated access barriers. Sometimes these accounts were of their own practice and process of providing care, others were describing what they observed of other practitioners.

A number of practitioners talked about a range of factors influencing decisions to recommend a care pathway that would not necessarily fit with the clinical guidelines for best practice. For example, a number of practitioners noted that referrals to specialist services would be influenced by perceptions of the length of the waiting list together with the likelihood of the patient attending; so, if the waiting list was thought to be long and the patient a possibility for not attending an appointment, the practitioner would not refer. Similarly, some practitioners reported "holding on to" patients who they perceived as non-compliant, rather than referring them on to other services, because they were concerned they would lose contact with them. Others thought practitioner's assumptions about a patient's tolerance for surgical intervention influenced their decision making about referral.

"Certainly one thing I was going to say is the availability of appointments and exercise testing and that sort of thing puts you off referring I think. There's a lot of evidence that the shorter the waiting list the more general practitioners refer. But once you get up to being sort of six months to see a Cardiologist or something like that. I'll try for a few months to see what happens. There probably are people that should get exercise tests that don't, or probably not referred on for revascularisation until someone wasn't controlled medically, or if they had unstable angina or you know they weren't being controlled with medication." Prov12

"We're more inclined to try and keep things under the one roof and do as much as we can, you know, we're not inclined to refer people until we really, really need to, we'll do everything first, and then when we get to the end of our resources and things, or as far as we can go any further investigation, that's when we send off.." Prov10

A practitioner's currency of knowledge of guidelines for best practice was also thought to potentially create a barrier to accessing care. A number of practitioners referred to observing other practitioners not considering patients for intervention cardiology if they suffered co-morbidities and that this decision making sometimes reflected out dated knowledge of best practice guidelines.

“I’ve seen here a lot of the co-morbidities being big reasons as to why nothing is followed through, or to why no further investigation, no further treatment management is offered or seen as important to do and I find that very disturbing probably more than anything. Like I said, I’ve come from an experience where we had patients you know that have all the co-morbidities that I see here, that are getting managed and getting treatment for them and getting good results from them so for me it’s hard to understand why that’s happening.” Prov15

“The access issue is both the individual not looking to access these sorts of services and more worrying to me is that the healthcare providers are not facilitating that access. There may or may not be more capacity but tertiary level is not providing a block. There are people out there who under the current criteria would very clearly be accessing tertiary services if we referred to them. Right now those are the ones that concern me most, because that means that we’ve failed them. A number of people who have an assumption that a 65 year old Māori male will have different expectations to a 65 year old non Māori male, and people will change their decisions on, their clinical decisions on the basis of that to a certain extent as well. Something we need to work on. There are, quite clearly there are different decisions being made in different parts of Northland over the same problems, so it will be, if you go to one part of Northland and one health care facility, you’ll get treated differently than going to another part of Northland in terms of accessing services and say tertiary services. I find that a concern” Prov5

A number of practitioners talked about high numbers of locum doctors impacting on patient access to appropriate services due to their limited knowledge and understanding of NZ guidelines for best practice and referral processes.

Additionally there was a commonly held view that some practitioners delayed referring patients out of a concern that they may be seen by their medical colleagues to be unnecessarily referring. This was perceived as a problem across primary and secondary care.

Practitioners also talked of the challenges they experienced in developing a relationship and communicating effectively with Māori patients and expressed concern about the impact communication problems had on accurately determining Māori patient needs and providing quality care. We discuss these issues further in the communication section.

Compliance vs. non-compliance

Māori participants described a desire to be well informed to understand their condition and how to manage it effectively in order to improve their quality of life and prevent further complications from the IHD. Many referred to the major impact the diagnosis of IHD had on their lives and took seriously the need to follow advice and treatment. A number of participants spoke of how they had become high users of health services since an IHD diagnosis. Many made major changes in their life such as changing jobs, moving out of the city and managing stress differently. One participant put her daughters into boarding school following a heart attack. These descriptions of response to their illness were far from ambivalent or fatalistic.

Changing lifestyle habits was talked about as an ongoing challenge and in depth discussion on dietary, physical activity and smoking changes highlighted the seriousness with which they had taken on health practitioners' advice regarding necessary lifestyle changes.

“Those ticks are for certain things, but not the right things, you've got to read it on the side. Going around looking for blasted bread, It's gotta be six ...fibre, the dietary fibre on it, well that's gotta be over six, at least over six. I was having a look at mine but, I found two actually a wholesome one but that's nearly \$2.50 a loaf which that gets expensive. I found this one the other day which is wholemeal split and that's a 6.9 for dietary...now that was \$1.10, at some shops you get it for \$1.00 and you're paying \$2.50 for the other one. I mean you've got to shop around put it that way. Yeah so it's just a matter of working out the dietary fibre and the fat contents and once you get used to it. See even the ones with the ticks on, you still got to look.”
WH14

Not all participants had successfully quit smoking or achieved their goal diet or physical activity regime however, considerable effort towards achieving lifestyle goals were described.

Medication treatment was also found to be challenging for many of the participants who expressed a dislike for pills and suffered unpleasant side effects.

“On a bag of pills...a druggie, yeah I'm a rattler...a real rattler... yeah a bag of bloody pills [laughs] For my own sake I carry one, I've got a spare one, I have one in the office. The other type gave me a headache, the other one, I broke out in bloody hives, yeah with bruises, ...The only thing was that the other type was the spray, this one gave me a splitting headache and that one doesn't, so I take that, if I'm going to do something energetic, I take a zap...if I'm unsure whether I'm having angina or indigestion I take a zap. The doctor, what he actually foresaw that maybe there might be a time where we might be easing off the pill...yeah that's what they said to me...” PPI3

Despite disliking pills and suffering side effects, the talk of participants regarding their medication implied a commitment to adhering to the advice of their doctor; for example strategies to ensure they remembered to take their pills, the cost of medication, negotiating with GPs for medication changes to manage side effects, or managing lipid levels with diet with a goal of coming off statins.

“Like the medication thing has actually controlled it but as I was saying I am very reliant on it. I mean, I have tablets in the car in case I get stuck in the morning and I've had to, because I was never a pill popping person you know, but I have had to buy a little Monday, Tuesday, you know, an everyday thing to make sure and take them.” PPI

Those who had surgical interventions such as angiography, PCI and CABG had readily agreed to follow this advice and were satisfied with the outcome. Some of the participants questioned why they had not been referred for tertiary intervention cardiology, and one participant had received angiography after asking to be referred.

“...When I was recommended to go off to Greenlane hospital, now that also played something in my mind, I had a young family and young grandchildren coming up. That sort of struck me too if I should go, who’s going to look after this lot. So all these things are recommendations from the talk with my doctor, actually that thought in my mind, who’s going to look after the family. That really pushed and prompted me to carry on to surgery. I still remember after my operation that that’s one of the things that I’ve still got in my mind, the doctor telling me... “We’re giving you another fifteen years of life or more, now its up to you to maintain that” again they told me, medication, exercise and food and all that. So every so often that comes up in my mind. I’ve been given another fifteen years or twenty years of life, and could be more if I actually do well with it.” PP20

Although the Māori participants interviewed all spoke of attending their appointments they were aware of the health services’ concerns with patients failing to attend appointments and offered a range of reasons why they thought this occurred; travel difficulties for some rural Tai Tokerau/Northland residents, delays between the initial referral and receiving an appointment meaning people forgot the reason for the appointment, and problems with people sometimes not receiving the appointment letter.

“Might be distance, having a vehicle. The other one is the delay between the doctor asking for it and... it actually happened to me. I had to go to the hospital up here, but by the time that I got up there I had forgotten what the referral was for because it was something like a year before.” PP13

Non compliance on the other hand was a dominant theme in the discourses of health practitioners in describing their experiences of providing healthcare to Māori with IHD. In particular health practitioners referred to their frustration with, what was perceived by them as, limited success in terms of smoking cessation, dietary and physical activity changes and poor compliance with taking medications.

“So when I get a chap here... and I know that he's not being compliant and I'm saying “well hey look what are we going to do, why do you come here, I mean you have to pay for the doctor, why do you come here and pay to see us if you are not going to take on board what we’re trying to offer to help you with?” and so you get into sort of discussions and that’s important, compliance yeah, compliance really is such a huge issue because it’s not just the matter of making sure they take their medications, to keep them well, to try and give them an interest, and it’s very difficult sometimes to motivate people for that interest.” Prov14

“It’s a perception problem, a lot of the people are in denial at first, they don’t adhere to the suggestions of diet and exercise and stuff like that because of the way they’ve been brought up. They eat wrong because it’s the way that it is. Get the people active, try to explain to people more from the diabetic side that goes hand and hand with ischaemic heart disease... Really hard! Appalling outcome in terms of green prescriptions you know. I was highly motivated because I really believe that lifestyle changes and diet changes can have a huge influence on the outcome if you stick to it, and it just didn’t work... You get fed up after a while, you know, you put people on these programmes and you bring them in for weekly or two weekly weigh ins, and they actually add on weight instead of losing weight, don’t do exercises

you know. Then you have this whole talk again, you talk over and over, and slowly but surely they take that initiative away from you, you know that you just say “oh I don’t know, you just can’t win here.” Prov19

Talk about mobility of Māori patients across different health providers and failure to attend follow up appointments was also a common theme in the non-compliance discourses of health practitioners.

“Maybe over the years there are patients that have come to see us that we could have had a relationship with, and what they tend to do, they shop around without telling either party that they go and access that they’re shopping around, they almost treat it like a shoe shop. We’ll check out the prices and styles and then in some ways they will actually not do themselves well in that, they could be over-investigated or under-investigated and under treated and nobody will have the full story.” Prov1

“So like, the people that do not turn up for instance for their appointments at Whangarei... to specialists for their heart conditions, we refer them down there and we get a letter back saying “so and so didn’t turn up”. It’s not generally because they don’t want to it’s because they can’t and we’re always trying to get services up here, you know. Well, you have to bring the boom down somewhere along the line, you can take the horse to water but you can’t make it drink. If it hasn’t happened after the third did not attend sort of thing, well there’s got to be a time where you’ve just got to say well “do you just want to get better or not?” I went to a diabetic meeting down in Whangarei and they were telling us for one year, the “did not attend people” for all clinics for all areas could’ve employed a specialist for a whole year.” Prov10

Summary

The preceding accounts of experience with treatment of Māori for IHD illustrate a divergence in perspectives between Māori and health practitioners. On the one hand Māori draw on discourses of compliance with talk of their commitment to treatment and lifestyle change, towards living well with IHD, while on the other hand practitioners draw on non-compliance discourses to describe their experience in providing advice and treatment to Māori.

When Māori refer to the issues practitioners raise as non-compliant, such as mobility between providers, or failing to attend appointments, they describe system barriers to meeting the practitioners defined “compliance” behaviour, as illustrated in the narratives presented on Māori trying to use the same GP but unable to due to GP changes.

Practitioners typically explain their experience of “non-compliance” of Māori patients in terms of cultural norms with expressions such as “because it’s the way they’ve been brought up”, “it’s the way it is”, and “it’s a cultural thing”.

In the next section we present discourses around communication and the relationship between the Māori participants and health practitioners to further explore the impact of the relationship and communication on quality, effective healthcare for IHD.

Communication

While Māori participants expressed gratitude for the healthcare they received, and a general satisfaction with the services, they also raised issues of concern, which commonly lay with the relationship they experienced with health professionals and the nature of communication in consultation. Frequently an experience of an unsatisfactory relationship, poor communication, or a lack of information sharing left the patient and/or whānau feeling they were not understood by the health professional and therefore were not receiving good quality care.

“I just couldn't understand...they didn't explain to me that you know in that time when I was in hospital...I was sort of frustrated the first few days because they did not explain to me what was what and I really felt uncomfortable about that...um but they were just doing test after test with no explanation on the results back from the tests, and I was really getting frustrated but they kept me in for the ten days I think it was.” PP15

Some patients and whānau thought the poor communication may be the effect of cross cultural communication.

“I felt pretty weak a few months ago when I came back from Hawkes Bay and I couldn't get anywhere with the doctor down here. I felt at some stage he didn't believe me, which was disappointing to me. It was on my mind for several weeks and months because there's no other doctor here. The other lady that came from the hospital she was nice. I think she had a better understanding of the culture and people, more so than my GP. I don't think he even concerned himself with... he was more like a traffic cop issuing tickets. He just writes out a prescription.....”

Interviewer: Could you have a good heart to heart conversation with him?

“Well not in my case. Whether he had problems talking to people like myself or not, I don't know. But there was none of that. He might well have with other patients, but certainly not with me.” PP24

Māori participants talked about wanting to have a good relationship with their health care provider, one where they felt they had a voice and would be listened to and valued. The following narrative relates a Māori participant's positive experience with communication, compared with a previous negative experience and illustrates the need to be listened to, understood and given timely information in plain language.

“When we moved up here and I talked to the doctors here and the nurses, they were totally different it was like two separate worlds. They were more, here they're more helpful, they seem to care what you're talking about. I found down in [x town] that there was like a conveyor system, you went in the door, they threw some pills at you and then you end up coming out the other side, non the wiser really. It took ages for me to find out what was wrong and I had huge worries at the start you know where I thought I was gonna die. They just seemed so short and rude pretty much, I just kind of lost faith in them. I only went to them when I needed some more pills and when it got really bad. I've seen a couple of doctors [at the Māori health provider] and they're just totally different you know compared to the ones I've seen in the past. They just seem totally different”

INTERVIEWER: IN WHAT WAY?

“Well friendlier...not stuck behind a desk in a suit you know in a shirt and a tie and they're more like the average person where you can sit down and

actually talk to them and feel like they're actually listening to what you're telling them and you know when they give an answer you actually understand it and you know that's a huge difference." PP6

Māori participants placed considerable emphasis on their need for plain language and expressed a preference for conversation rather than written information, although Māori participants were pleased to receive written information to take away following a discussion. Participants who had been enrolled into the CarePlus programme valued the written information they were given in these consultations, which complemented the longer consultations.

Participants placed emphasis on the need to involve whānau in consultations and information sharing, and sometimes felt the health services did not appreciate the significance of the role of whānau in supporting healthcare, particularly with respect to giving and receiving information in a consultation. The narrative below illustrates this point and also reiterates the need to be listened to and understood, to be valued for your contribution, whether patient or whānau, in the healthcare consultation.

"I don't think she realized the importance of the person being there as a caregiver or as a spokesperson. I think it's really unfair you know that if you take somebody of her age, and as Māori, we need to be empowered to be able to speak for ourselves and we need to, we know as much as the doctors because we're the ones that are sick, they know professionally how you can cure somebody but we know ourselves you know what's wrong with us. I shouldn't say what's wrong with us but how we feel at that time. To me you know, the system that the doctors work through, they forget about whānau, and how they work through things you know..." WH20

A number of Māori participants talked about poor communication and a lack of information sharing on the part of health providers as a discriminatory experience; that they were being disregarded because they were Māori, and that communication might improve if the health practitioners took opportunities to learn about and understand the Māori communities of Te Tai Tokerau/Northland.

"Perhaps because she was a Māori they didn't want to listen to her... there's no listening from the professionals to the whānau...but I think the whānau knows their patient well." WH16

"Doctors probably especially in areas with Māori people and you know some of the outback areas, country areas, probably need to go in and maybe go along to marae and get to know them all you know better and become a part of them sort of." PP5

Many practitioners turned to talk of communication challenges in describing their experiences of providing health care to Māori. Some were unclear about the success of their relationship and communication with Māori patients; they felt it could be better, but described a sense of frustration and powerlessness to change the situation because it was a problem of cross cultural communication and they did not understand how to overcome it.

"The only thing I understand over the last 15 years is that I don't understand the cultural issues very well at all." Prov5

This narrative below is illustrative of the practitioner's sense of communication not being ideal, and shows how the practitioner views the problem as lying with the patient's communication style being culturally different from his own.

"Yes, because I find that it might be a cultural thing you know, unless I was the same culture, with European decent people you sort of know where they're coming from a bit more. Yeah sometimes more with the Māori men, just the fact that they, you know because they don't engage you in the same way, they don't look you in the eye, you're not quite, you're sort of on the back foot a bit, you're not sure what's wrong. That's not as big a problem as I thought it was going to be, and I think that it's more sort of warming up".
Prov12

Some drew on discourses of non-compliance in explanations of poor communication, contending that Māori patients were not forthcoming with communicating their problems and gave limited accounts of symptomatology in consultation that were difficult to interpret. In this narrative the practitioner claims an understanding of the communication difficulties, particularly Māori patients not fully disclosing their problems. He refers to being experienced at handling consultations to take account of this, but closes with an example of failure to recognise the seriousness of a patient's problem, even though he knew her well.

"You know it's a different way and you've got to handle them differently and I think you've got to be very understanding and know that they're not going to tell you everything. I think handling Māori patients you've got to be aware they tend to be quite stoical about their problems. It really is very dependent on us understanding the patients and being aware of the fact that we don't get told the truth, and we don't get told how bad it is and even though I knew this person very well, and very experienced at it, I didn't get out of her how bad it was until she was better." Prov16

Commonly practitioners referred to passivity of Māori patients; they were unlikely to proactively request a particular treatment and practitioners rely on being prompted by a patient raising questions regarding options for treatment. Practitioners often explained this in terms of a Māori attitude of inevitability that they would suffer poor health.

"What they've accepted for a long time is unacceptable, but they have accepted it and then don't mention it. Possibly because they see it in the generation above or they see it in other people and they think that's the norm within their community but of course it isn't when you compare it with the global picture or with a fit Māori person you know. I do perceive that if you ask you get or at least if you sort of have a tantrum things are probably moved a little bit faster, and patients' expectations of the system they get is often the system they get. Now, I think if somebody raises the question if they're not sat there saying, "do you think I'll benefit from an angiogram, I've heard that there's new angioplasty," you know, doctors as well need to be prompted along to some degree and why it's not offered again I'm not sure." Prov20

The practitioner below talks about the critical importance of effective communication in the management of IHD in being able to provide the appropriate treatment. He refers to Māori patients not necessarily communicating a clear picture and goes on to share his view of the importance of taking time to stress to patients the need for good communication about their symptoms.

“They are potential time bombs and one has to try and judge whether their condition is stable or unstable and that’s a clinical judgment, you can’t always be correct and it does rely in many ways on fairly good communication between patient and general practitioner as to what is happening. In order to change someone’s priority status you’ve actually got to look back on what’s happening, are they having pain, yes, no, are they having it addressed no, are they getting it with a degree of exertion or minimal exertion – all those things become really important. I mean that’s perhaps one area you know where, I mean in theory the way that I manage people certainly at a conscious level is not colour dependent in any way, it never has been, I try to manage people on priority. To gauge a priority you actually have got to have good communication going and then you know possibly in some situations with Māori folk, that feedback may not be coming quite as well as it should. But it’s certainly trying once the diagnosis is suspected or made then I spend quite a lot of time trying to impress on people the importance of keeping us informed as to what they’re experiencing, because it’s often just that it would allow you to intervene before a major catastrophe happens.” Prov17

This narrative presents a view commonly expressed by practitioners that time constraints in healthcare, particularly in general practice and the hospital setting, are a barrier to effective communication.

“With the general practitioners that we have available, it’s really hard for us to you know, if you’ve got 40/50 people to see in a day, to then explain to people. If we have it like when you see twenty five a day, you’ve got twenty to thirty minutes per patient, ideal for doing this type of thing, you can talk to people, you can hear what they feel is a problem, communication is much easier, you can explain things you can hear back from them, that is how we should practice medicine, to have the time for the patient.” Prov19

Summary

Both Māori and health practitioners clearly expressed concern with the quality of their relationship and in particular the effectiveness of communication. Both talked of how poor communication impacted on the ability of health practitioners to provide the right health care at the right time, thus communication is a factor contributing to poor access (tertiary access) to quality healthcare.

From the perspective of Māori patients and whānau, poor communication occurred when health practitioners:

- failed to listen appropriately, and left the patient and whānau feeling misunderstood
- created barriers by using difficult language
- didn’t exchange the usual social discourses or take enough time to build the relationship and develop effective communication
- handed out prescriptions or written information without discussion

- failed to take account of, or appear to value the role of whānau in supporting healthcare particularly through listening and sharing information with whānau

Māori patients and whānau felt the poor communication could be an effect of cultural differences and some talked of discrimination against Māori underlying the poor communication.

The health practitioners' perspectives, on the other hand were that poor communication occurred when Māori:

- were passive about their health and health expectancies
- failed to speak up about particular healthcare options
- were non-compliant by not fully and effectively communicating problems and symptoms
- did not keep their practitioner informed and give feedback on their health

Health practitioners felt that the poor communication was a problem of cross cultural communication and that it was critical to overcome this to have good quality healthcare, however they were not clear about how to overcome the communication difficulties.

Discordance, that is a lack of understanding and agreement between Māori patient, whānau and health practitioner is evident in the discourses of our participants as they talk about pathways into and through healthcare for IHD in Tai Tokerau/Northland, and this is likely impacting on a range of patient outcomes.

Results: phase two change facilitation

The processes involved in conducting phase two of the research project have been outlined in the research methods section previously. Below we elaborate further on the processes and outline actions undertaken in Tai Tokerau/Northland, arising from the research process and findings, towards improved cardiovascular health in the Māori population and improved healthcare for Māori with IHD.

Some of the change projects were undertaken during phase two in 2005. Others were implemented by the research participants, independent of the change facilitation process, but influenced by their participation in the research project. We have also identified change projects that have been undertaken since completion of phase two. Additionally, individual practitioners, patients and whānau talked in phase three interviews about action they had taken as a result of participation in the research.

As a corollary to the research project the researchers were invited to project manage the development of the Tai Tokerau/Northland CVD Strategy between August 2005 and February 2006. The development of a CVD strategy necessarily includes a broader spectrum of conditions than just IHD. However, the findings of this project provided important evidence to support recommendations for improved IHD prevention and management and many of the key themes arising in this project have generic relevance to healthcare broadly. The Tai Tokerau/Northland DHB CVD Strategy and recommendations are reported elsewhere by Tai Tokerau/Northland DHB.

During feedback to research participants and presentations to hui and meetings in phase two of the project, suggestions were offered as potential areas for action, arising from the research findings. They were framed at three levels:

- community and whānau
- health practitioners
- health services

Suggested areas for action - community and whānau level

- raise awareness of the importance of life-course impact on heart disease
- promote understanding of heart disease prevention, early detection and treatment options
- encourage whānau to talk about their family history and protecting the next generation – deal with the myths around genetic causation
- encourage whānau to support each other to get to health services, understand their condition and treatment options and speak up for access to best practice healthcare
- involve GPs, specialists, nurses and community health workers in this process, within a kaupapa Māori context, to enhance communication and the relationships between Māori and health professionals

Suggested areas for action – health practitioner level

- professional development, systems and processes, to ensure all clinicians are familiar with NZ guidelines for management of CVD and are applying them equally across different population groups
- develop understanding of social and economic determinants of health
- develop understanding among health practitioners of assumptions they are making about Māori patients, the potential discord in the relationship and the need to improve communication with patients and their whānau – particularly listening, and information sharing using everyday language
- raise awareness of the significance of whānau in health and healthcare and application to the everyday provision of healthcare

Suggested areas for action – health services

- co-operation between services to share information and co-ordinate their services for the benefit of patients and whānau – making better use of existing services
- development and trialling of new models of service delivery
- emergency response equipment and training to be more readily available in rural areas for advanced life support
- availability of pre hospital fibrinolytic therapy in Tai Tokerau/Northland
- availability of regular medical specialist assessment and investigation services in rural Tai Tokerau/Northland areas
- development of Māori focussed accessible cardiac rehabilitation service in rural Tai Tokerau/Northland areas
- redesign specialist assessment to minimise the number of appointments necessary
- increase availability of specialist cardiology including intervention cardiology in Tai Tokerau/Northland

The following describes the projects arising during phase two of the research process, and since, some of which engaged direct involvement of the researchers, others which were driven by research participants independent of the researchers.

Manaaki Manawa – kaupapa Māori community based cardiac rehabilitation

During the change facilitation phase poor access to and uptake and completion of cardiac rehabilitation by Māori in Te Tai Tokerau was identified as a priority area. The researchers assisted with providing literature reviews, networking with Cardiac Rehabilitation experts and the Waikato kaupapa Māori community cardiac and stroke rehabilitation service. Te Hotu Manawa Māori were also invited to participate in the planning with a view to linking any new kaupapa Māori cardiac rehabilitation service in Te Tai Tokerau to the pending “Heart Guide Aotearoa” trial. Subsequently, the researchers assisted a planning group involving five of the research participants, to develop a proposal for “services to improve access” (SIA) funding for a kaupapa Māori community based cardiac rehabilitation service. The service “Manaaki Manawa” was subsequently funded by Te Tai Tokerau PHO to cover the Mid and Far

North areas and Manaia PHO to cover the Whangarei area. The Manaaki Manawa services are participating in the trialling of the Heart Guide Aotearoa.

Improving systems to support access to outpatient appointments

System issues impacting on access to medical outpatient appointments for Māori, leading to higher rates of non-attendance were identified as another key area requiring action. The researchers supported the development of a proposal for the funding of a project to analyse in depth, the extent of non-attendance, the barriers to accessing outpatient appointments and recommendations for change. A project was subsequently funded through the Elective Services Initiative Fund (ESIF).

Pre-hospital fibrinolytic therapy

The absence of any community pre-hospital fibrinolytic therapy for patients suffering an acute myocardial infarction more than one hour away from a hospital was identified as a system gap impacting on Māori morbidity and mortality. The researchers supported information gathering and initial planning meetings with St John Ambulance services and general practitioners to progress planning towards the implementation of this service.

Te Tai Tokerau PHO strategic planning for CVD prevention and management

During phase two of the project Te Tai Tokerau PHO invited the researchers to work with them on the development of a strategic plan for CVD prevention and management taking into account the findings of the research. This was completed and the PHO has implemented a range of projects to address CVD with their enrolled population.

Improved angiography booking system for Tai Tokerau/Northland patients

Poor access to intervention cardiology was identified as a significant issue in the observed Māori IHD morbidity and mortality disparities. Subsequently, at the beginning of 2005, the Coronary Care Service of Tai Tokerau/Northland DHB collaborated with Auckland DHB Angiography Services to implement a new angiography booking system for Tai Tokerau/Northland patients. Northland DHB report that reserving a set number of beds each week for Tai Tokerau/Northland patients for angiography services at Auckland DHB has significantly improved access for Northlanders to this service.

Māori focused audio visual resource providing information on the development and management of IHD

The Tai Tokerau/Northland DHB Coronary Care Service is planning the development of an audio visual resource to improve information sharing and support to Māori with IHD.

Marae based Automated External Defibrillation (AED) and CPR

Poor access to emergency life support for some rural Northlanders, including significant numbers of Māori, was considered an important factor contributing to Māori IHD disparities. Marae were suggested as an appropriate location for the placement of AED equipment in many rural communities in Te Tai Tokerau and as a venue for training community members in AED use and CPR. Recently a funding proposal was presented to the Te Tai Tokerau PHO from a Māori provider to support this initiative.

Reported change by individual research participants

Some health practitioners, during phase three interviews reported having new insights into the issues impacting on healthcare for Māori with IHD, since participating in the research project; in particular, issues around how they may be characterising Māori as non-compliant, and consideration of how they might improve communication. One practitioner also talked about how he might initiate Māori male focussed weight watcher type groups, which he noted Māori research participants had expressed interest in. Another practitioner talked about new relationships developed with a local hapu through a marae weekend organised for the general practice team. Although this had been initiated as part of the general practice accreditation activity, the research practitioner noted that developing relationships with the local Māori community was one of the suggestions raised by Māori and practitioner research participants. Other practitioners covering remote rural areas talked about taking steps towards facilitating the availability of pre-hospital fibrinolytic therapy in their area.

Discussion

Previous sections outlined the background epidemiology of ischaemic heart disease in the Māori population nationally and in Te Tai Tokerau/Northland; the methodology of the study; the findings of in-depth interviews with Māori patients, whānau and health practitioners about their experiences of receiving or delivering healthcare for IHD; and action for change that arose through the course of the project. In this concluding section we comment on the findings in light of the research questions; discuss ways that the findings build on, or depart from, the understandings that have emerged from past studies relating to Māori health and healthcare generally; and discuss the value of our research approach in addressing Māori disparities in health and healthcare.

Māori disparities in morbidity and mortality from IHD are evident and the gap between Māori and non-Māori has widened over the last two decades (Ajwani et al 2003). Most studies to date with respect to Māori and IHD have focussed on quantifying the outcome gap in terms of mortality. Some have examined the difference between Māori and non-Māori use of healthcare such as revascularisation procedures. This study has explored Māori and healthcare practitioners' experience of receiving and providing healthcare for IHD in Northland - what happens in the provision of healthcare, in seeking explanations for the observed disparities in Māori IHD morbidity and mortality.

Māori and health practitioners' experiences

Māori participants demonstrated knowledge and understanding of the range of causal associations with IHD in the Māori population, however consistent with other studies (Newman 2003; Meischke et al 2000; Mosca et al 2000; Gans et al 1999) we found they sometimes struggled to apply their knowledge to their own personal risk and illness and most commonly talked about stress as the main contributing factor to their IHD. There was as well, considerable emphasis on the impact of family history from a genetic causation perspective. This is a concern, firstly given limited evidence for genetic causation of CVD specific to the Māori population, and secondly given a hopelessness that sometimes arises from this perspective out of misunderstanding the complex dynamic of genetic and environmental factors. There is clearly a need to improve the quality of information provided to the Māori population on causal associations with CVD towards effective prevention.

Our findings show Māori described varied pathways to and through healthcare for IHD, covering the full range of possible pathways. While the Māori participants expressed anxieties about heart disease and the use of health services, they demonstrated considerable effort to make full use of the services and follow the advice of health professionals despite evident barriers to accessing quality, effective healthcare.

Barriers to accessing the right healthcare at the right time were identified by Māori participants related to their confusion with and perception of seriousness of symptoms, as well as perception of appropriateness of seeking healthcare at a particular time. Patient delays in seeking healthcare for IHD for these reasons have been widely reported in other populations (Ruston et al 1998; Ottesen et al 1996;

Dracup et al 1997; Dracup et al 1995; Norris et al 1998). It is noteworthy that many of the participants described symptoms other than what is commonly communicated to and understood by the public to be indicative of IHD, that is, classic severe chest pain. As Ruston et al, (1998) concluded, in order that people may recognise symptoms of ischaemia, the messages communicated by the media and health services need to be revised.

Māori participants in this study also described barriers to accessing healthcare related to availability of services, geographical distance, and cost, as have been reported previously (Cormack et al 2005; Crengle 2000; Baxter 2002).

System barriers were also reported by the Māori participants, in terms of waiting times to receive referred services and limited information provided in correspondence relating to a given outpatient appointment; poor continuity of GP care due to a high turnover of locums and new PHO arrangements; inconvenient hours of availability of services; and the centralisation of most specialist services to Whangarei or Auckland.

While discontinuity of primary health care provider is understood to be a barrier to quality primary health care, most commonly it is reported by health care providers that the barrier occurs because of patient mobility. As far as we are aware other Aotearoa/New Zealand studies have not reported Māori patient perceptions of difficulties accessing their chosen GP, and that this barrier occurred for some patients in our study as a result of new PHO arrangements, seems antithetical to the goals and objectives of PHOs.

Barriers to accessing the right healthcare at the right time described by Māori participants also related to the way services were delivered by individual health practitioners. Experiences of lack of information sharing and poor communication led to Māori participants feeling misunderstood, uninformed and dissatisfied with the quality of healthcare provided at times. This observed discordance in the relationship and communication between Māori and health practitioners concurs with Jensen (2006). Our findings are of significance given the evidence that good outcomes in healthcare are in part dependent on effective relationships and communication between patient and health practitioner (Kearse et al 2004; Stewart 1995; Levinson et al 1997; Ferguson and Candib 2002; Rosenberg et al 1997). We discuss this further under practitioners' perceived barriers.

Māori participants were aware of the establishment of PHOs however were not aware of their organisational structure or the specific role and function of PHOs or their goals and objectives. They were aware of the impact they have had on lowering general practice consultation fees and saw this as a significant benefit. Apart from this the only other comments regarding the PHO related to difficulties accessing a chosen GP since the establishment of the PHO. This had arisen as a result of competition between providers for capitation funding and was also reported by practitioners.

CarePlus, a chronic care management programme implemented nationally through PHOs was the only systematic patient centred clinical care pathway programme provided to our study participants. A limited number were enrolled onto the CarePlus programme at the time of phase one interviews and others had been enrolled by phase

three interviews. Not all participants eligible for CarePlus were enrolled. Those who were, found the longer consultations with Nurses and the information provided were of value. They typically referred to their CarePlus folder of information during interviews.

While CarePlus does facilitate communication with the patient regarding a pathway of care this predominantly relates to the patient's goals and does not necessarily facilitate communication with the patient regarding a gold standard clinical care pathway from the practitioner's perspective so that the patient can participate in the clinical decision making process. Other clinical care pathway programmes do communicate to the patient the best practice treatment pathway and this has been shown to be beneficial (Wellingham et al 2003). Given the importance practitioners place on the need for patients to raise treatment options with them, it would seem reasonable that these are communicated to the patient by health professionals in the first instance. As Wellingham et al. (2003) identified based on earlier evidence and their own findings, for patients with chronic disease to have better health outcomes they need to feel understood, respected and empowered by the general practice team to share in clinical decisions. The "expert patient" model of care is based on these concepts and provides a good example of patient centred clinical care pathways that involve communicating the best practice treatment pathways to patients as well as discussing patient goals (Moscrop 2001; Thomson et al 2001).

In explaining the cause of Māori disparities in IHD morbidity and mortality, health practitioner's discourses focussed on Māori lifestyles, risk factors and non-compliance with healthcare recommendations. While some health practitioners acknowledged the impact of the socio-economic position of Māori on health status, they did not comment on the historical and political processes that have led to the over representation of Māori in the most deprived deciles of Aotearoa/New Zealand, neither did they discuss structural change as a factor in addressing the social and economic position of Māori towards health improvement, despite significant discussion of the importance of this strategy in the Aotearoa/New Zealand health literature over the last five years (Ajwani et al 2003; MOH 2001; MOH 2002b; MOH 2002c). Rather, they focus predominantly on interventions to change individual patient behaviour as the most important solution to Māori disparities in health. There is no doubt that reducing risk factors will have some impact on CVD disparities experienced by Māori, however recent analyses have shown that socio-economic factors play a much more significant role in the gaps between Māori and non-Māori health status (Blakely et al 2006).

Describing Māori pathways to and through healthcare for IHD, health practitioners talked about Māori typically presenting late with established multiple health problems. This was explained by health practitioners as a result of Māori delaying help seeking because Māori are either ambivalent or stoic about poor health and are fearful or reluctant to use health services, as has been described previously by McCreanor and Nairn (2002).

In addition to the above barriers to Māori initially accessing healthcare for IHD, health practitioners also described barriers to optimum pathways through healthcare, related to how Māori utilise healthcare and how the system and individual practitioners deliver healthcare. Firstly, the dominant discourses of health

practitioners relating to how Māori utilise healthcare, focussed on non-compliance. Non-compliance with attendance for ongoing healthcare and poor adherence to medication regimens and lifestyle changes, were highlighted as significant factors contributing to Māori disparities in IHD, and this “non-compliance” was commonly described as a cultural trait.

These non-compliance discourses of health practitioners, talking about Māori health have been presented previously (McCreanor and Nairn 2002) and fit within a general non-compliance literature internationally, that tends towards victim blaming as an explanation for limited success in the management of chronic disease generally.

The explanation by GPs of non-compliance as culturally determined or as described by Nasreen (2006) as “problematising of ethnicised patients on linguistic and cultural grounds” has also been shown elsewhere. For example Ahmad et al. (1991) in the United Kingdom, found GP perceptions of non-compliance of ethnic minorities leading to a less positive attitude towards patients of Asian origin compared to their non-Asian patients.

We contend that the observed divergence in perspectives between health practitioners and their patients is likely to set up a climate of discord in the patient practitioner relationship. This discord may be further compounded by the pre-existing unequal power dynamics between the patient with limited health knowledge alongside the “qualified” health professional who, in the Aotearoa/New Zealand context is likely to be of the dominant European culture.

Furthermore the stereotyping of Māori as non-compliant denies the diversity of the Māori population. We concur with Nasreen et al. (2006) who contend:

“The danger of cultural determinism, to view culture as a thing that causes thus explains the behaviour of patients may lead to stereotyping and the effect of stereotyping is as detrimental to good healthcare as the neglect of cultural factors. Both positions produce situations in which important information about the patient is distorted thus risking diagnostic distortions“.

There was concordance between health practitioners and Māori with respect to system factors that acted as barriers to healthcare, for example long waiting lists, shortage of health professionals, centralisation of specialist services, and inconvenient hours of availability of services for some people. In addition health practitioners referred to non-availability of specialist cardiology services in Northland, pre-hospital fibrinolytic therapy for management of acute myocardial infarction, and appropriate emergency first response in some areas of Northland. Health practitioners also viewed poor information sharing and collaboration between different parts of the health sector and outdated models of primary health care that largely impede effective chronic care management, as system barriers to effective healthcare for Māori with IHD. Commonly they talked about these system barriers affecting all Northlanders not just Māori, and that holding a private health insurance policy was the only sure way of receiving timely, gold standard treatment for IHD. McLeod et al. (2004) in New Zealand, exploring clinicians’ perceptions of equity of access to elective surgery, also found clinicians felt access was poorer for people unable to access private care.

With respect to how individual practitioners may create barriers to quality effective healthcare for Māori with IHD, health practitioners talked about differential referral practices which departed from best practice pathways. This was thought to be due to variable knowledge in current best practice guidelines; locums not familiar with local referral guidelines; practitioner perceptions of the length of waiting lists; the practitioner's perception of the likelihood of a patient taking up scarce appointments in an overloaded system and the patient's tolerance of specialist interventions. As well, health practitioner's talked about referral practices being influenced by a concern for not wanting to be perceived by their colleagues as inappropriately referring and less likely to refer patients who did not proactively ask to be referred.

Previous studies internationally, of variability in GP referral rates and the reasons for variability, show remarkably similar findings (O'Donnell 2000; Langley et al 1997). Our findings are consistent with McLeod et al. (2004) who also reported New Zealand GPs perceptions that access to elective surgery was inequitable for socio-economically disadvantaged people whom they viewed as less likely to advocate for themselves. Whether or not the GP would advocate for them was dependent on the value the GP perceived the patient would receive from the surgery (McLeod et al 2004). McLeod et al. (2004) concluded subjective decision making by clinicians has the potential to advantage or disadvantage patients. Our findings and those of McLeod et al. (2004) may provide some explanation for the lower referral rates of Māori than non-Māori by general practices across the country, observed in the National Primary Medical Care Study 2001/02 (Crengle et al 2005).

Communication was identified by health practitioners as well as Māori participants as a barrier to Māori accessing quality, effective healthcare. As previously discussed, Māori at times felt poor communication with health professionals left them feeling misunderstood, ill informed and dissatisfied with the quality and effectiveness of care. Some expressed feeling the problem was one of cross cultural communication and others described feeling discriminated against in an experience of poor communication.

Health practitioners felt poor communication with Māori patients impeded effective assessment, diagnosis, and treatment, and their explanations focussed on Māori not providing a full accurate picture of symptomatology or change in condition. Further, that Māori are passive recipients of care, generally unlikely to raise options with them for particular IHD management strategies. Time constraints across primary and secondary care were identified by health practitioners as a barrier to more effective communication. Many practitioners explained the problem of communication with Māori as a result of cultural differences which they found difficult to understand but critically important to overcome, particularly in the provision of chronic care management. Crengle et al. (2005) also found doctors reported a lower level of rapport with Māori patients than with non-Māori patients, and the mean length of consultations (13.7 minutes) was lower than that for non-Māori patients (15.1 minutes).

Ample evidence is available that highlights the importance of health professional-patient relationships and effective communication (Stewart 1995; Levinson et al 1997) and that achieving these delivers improved outcomes such as patient

satisfaction, adherence to treatment and disease outcomes (Ferguson and Candib 2002; Rosenberg et al 1997; Stewart 1995). The largest factor in patient dissatisfaction has previously been reported to be communication (Hawken 2005; Levinson et al 1997). Evidence has also previously shown a key factor in patient dissatisfaction with communication is not being listened to and understood by the health practitioner (Stewart et al 2000). Kearsse et al. (2004) recently found in a Aotearoa/New Zealand study that the particular aspect of the physician-patient relationship significantly associated with medication compliance was practitioner-patient concordance, measured by understanding and agreement between the patient and practitioner.

Previous analyses internationally of how ethnicity influences the quality of the practitioner-patient relationship have found minority patients are less likely to engender empathic response from physicians, establish rapport with physicians, receive sufficient information and be encouraged to participate in medical decision making (Ferguson and Candib 2002). Jansen (2006), in a study exploring Māori consumers experience with health services, also found communication was a significant barrier to effective healthcare for Māori.

It is clear considerable investment needs to be applied to improving communication between Māori, their whānau and health practitioners in the pursuit of equitable, quality, effective healthcare.

With regard to the impact of PHOs on the delivery of good primary healthcare, particularly in the context of chronic care management for IHD, health practitioners felt the new PHO system was a step in the right direction but to date was not delivering sufficient funding to allow for substantive changes to the current model of service delivery. The governance structure of Te Tai Tokerau PHO, with fifty percent Māori governance, was considered to be supporting improved relationships between Māori providers and general practice. As well the health practitioners felt the lowering of general practice fees had improved access to GP consultations for some people.

The research process

Closing the research, policy, practice gap remains a challenge in all fields. As can be seen in the health sector, positive change does not necessarily follow sound evidence. Studies have shown for example, that up to half of the patients in the United States and Europe are not receiving care according to the best scientific evidence (WHO 2004). Effectively communicating research findings is a challenge for researchers, and creating an environment that facilitates access to research based evidence and then facilitates positive change based on the evidence is a challenge for policy makers and practitioners.

Consumers of healthcare are commonly cautious in considering participation in research and often dubious of whom if anyone, will benefit. Indigenous and other marginalised minority groups internationally have particular concerns about the agenda of research that involves them and who will benefit or indeed be disadvantaged as a result of the research findings (Battiste and Youngblood Henderson 2000). Māori have clearly articulated dissension to being researched

without a central role in clarifying the research agenda and the research process including how research findings are interpreted and brought to bear on policy and practice (Moewaka-Barnes 2000; Smith 1999).

The kaupapa Māori framework for this project, and change facilitation phase, were designed to take into account these issues. Although kaupapa Māori and action research have become more prevalent in the health and social science fields generally in Aotearoa/New Zealand, action research methods in primary care are relatively uncommon. Our experience with this project, involving key stakeholders in the project from conception, through planning, implementation and action on the findings has been positive, and demonstrated that these methods are workable within the health sector generally and the primary care sector specifically. Our findings show potential for action at the level of patients and whānau, the health system and individual practitioners, towards improved prevention and management of IHD in the Māori population. Unintentionally, the focus of action arising during phase two of the project was predominantly on health system changes. As discussed earlier the prioritising of areas for action during phase two came from the wider stakeholder community rather than the researchers. That the actions prioritised were predominantly system oriented may be explained by the capacity and readiness for change among health planners and funders working at a system level. For patient, whānau and individual practitioner change, we contend more time and support than we had available in phase two is required. As well, the number of participants and different groups – patients, whānau and health practitioners, was possibly a barrier to in-depth action research methods.

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