Māori culture and genetic technology

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Abstract: This article proposes that Māori perspectives and values (tikanga) need to be incorporated when new health technologies become available. The study weaves together the idea of two worlds somewhat like the model of DNA, with two strands moving in parallel, sometimes intersecting and sometimes standing at a distance. Using a kaupapa Māori approach to research, a sample of Māori cultural commentators (pukenga), Māori whānau and health professionals who work with families (interfacers) were interviewed. The results suggest pathways forward in the area of genetic counselling and other services. While these pathways are relevant to Māori and the New Zealand context, the study shows how other cultural groups with alternative world views may seek their own solutions and responses to the technologies available through predictive/pre-symptomatic DNA testing.

Keywords: DNA testing; familial cancer; Māori culture

Introduction

It is now standard health care in most of the Western world to provide genetic services based on the philosophy of informed choice, autonomy and empowerment in an attempt to allow stakeholders to determine their genetic health within a framework of support. Since the 1990s it has been possible to define some genetic disorders by their molecular pathology, which announces a new dimension in health care. The discovery of these genetic mutations which predispose individuals to various forms of cancer, or which predict late-onset single-gene disorders, allows the identification of at-risk individuals before the disease manifests.

The potential for genetic technology to help improve Māori health is, like so many other advances in medicine, a potential that could be denied to people living in marginalised circumstances, with limited access to good health services or with cultural beliefs and world views that are poorly understood by health providers and practitioners. The paper explores the perspectives of Māori and those who work and interface with Māori on one aspect of genetic technologies and services available.

Our right to good health stems from the enjoyment of our land, our forests, our seas, lakes, rivers and whānau. Article II of The Treaty of Waitangi promised for Māori "Te tino rangatiratanga o o ratou wenua, o o ratou kainga me o ratou taonga" (The undisputed control over their land, their villages and their precious possessions). To Māori then, and to Māori now, our good health is a taonga but, as the following statement shows, the promises and hopes that the tūpuna envisaged in signing the Treaty 169 years ago have not been fulfilled. On the contrary, the history of colonisation has been a history of marginalisation which has impacted to shape the major social indices today.

> The extent of that [Māori] marginalisation is clearly reflected in the disproportionate ill health experienced by Māori compared to the general population due to preventable and

> or manageable conditions. The disparity is largely attributed to differences in social, economic, cultural and political determinants of health. (Ratima, 2001, p. 1)

Throughout the world where indigenous peoples have been colonised, a pattern of health statistics similar to those identified by Ratima is often found. Ngiare Brown, an Aboriginal medical educator for the Northern Territory of Australia, explains this in political, cultural and institutional terms:

> Institutional racism, bureaucratic inaction and disconnect between Indigenous people and non-Indigenous Australians [were given] as the underlying reasons behind the so-called "double burden" of disease suffered by Indigenous people. (Lowenthal, Grogan & Kerrins, 2005, pp. 106–107)

If an understanding of the nature and extent of marginalisation of Māori health is possible, it is necessary to understand the nature and extent of the 'disconnect' to which Brown refers.

Looking back

One of the most common impacts of colonisation for many indigenous populations has been in terms of their health and well-being. This was no different for Māori, who were exposed to and laid waste by various diseases from measles to chicken pox, tuberculosis and influenza (Pool, 1977). By the latter part of the 19th century Māori people were in such a poor state of health that a new generation of Māori leaders, who had emerged as the Young Māori Party, set out to visit communities to persuade them to look for new ways to improve their health and well-being. After the Second World War the Māori population began to recover, although there were still major concerns for Māori health. The Māori contribution to the war effort was being recognised and there were major initiatives to improve the conditions of Māori people in New Zealand.

Māori in 1953 were encouraged to move to urban centres for work; education was preparing young Māori for manual work; and the New Zealand government was beginning to tackle areas of Māori health, housing and development. The official government policy for Māori was shifting from total assimilation to one of social integration. In 1953 there was still a separate Māori schooling system, first established in 1867, a Māori Land Court that had been established in 1865 to individualise Māori land so that it could be sold, and various institutions that had been established as the apparatus of a colonial system. Māori people were still a rural population.

In 1953, when Watson and Crick published their model for the double helical structure of DNA, Māori in New Zealand were beginning to emerge from some of the effects of colonisation that had embroiled them from the time of contact with Europeans. In the 56 years since the DNA model was first published, molecular medicine has developed a large number of applications and potential therapies and interventions which are now delivered as part of public health care. Molecular medicine has advanced knowledge based on the significant discovery of the structure of DNA. In this time, Māori society has become mostly urbanised; the Crown has moved to provide redress for historical grievances; and Māori people have undergone a major cultural revitalisation that is now reflected in multiple initiatives across all sectors of society. Addressing the health disparities of minority groups and indigenous peoples is a significant challenge confronted by all pluralistic societies. In New Zealand that challenge has been dealt with in a number of ways. Māori health has been the focus of attention at political, policy, practice (including service delivery) and research. Māori health delivery, for example, occurs through both mainstream providers and smaller, more culturally focused iwi health providers delivering 'kaupapa Māori' services (Cram, 1999).

Medicine has also advanced. With its implications for the molecular basis of inheritance, genes and genetics have encompassed a revolutionary involvement in all aspects of life. The general public is increasingly aware of the existence and implications of genes. There is a vast supply of information and media coverage, which has stimulated contention and debate on issues ranging from genetically modified crops to recombinant insulin therapy, to human reproductive cloning. Each day brings another research discovery that needs ethical approval and regulatory procedures. Genetic technology in all its facets is running well ahead of humankind's ability to learn, understand and monitor its implications. Debate relating to scientific advances becomes increasingly urgent when human life is at stake. Moreover, while there is a natural desire to improve health, even with new technology, some Māori feel that DNA testing would interfere with their whakapapa.

The abnormal behaviours demonstrated by cancer cells are the result of genetic changes, or mutations, in key regulatory genes. A small percentage of cancers are due to inherited genetic mutation, and a predisposition to cancer develops at an earlier age. In familial cancers, more of the same or similar cancers than would be expected by chance occur within one family. Now that the knowledge of the molecular bases of cancer predisposition is available, diagnostic testing in clinical genetic services can be offered to individuals within susceptible families. Such DNA analysis could then be undertaken in a predictive or pre-symptomatic manner. In this way, at-risk people could be told with certainty whether or not they were carriers of the mutant gene, and thus, whether they had a high inherited pre-disposition risk or probability, or were simply within the baseline population risk (Port, Arnold, Kerr, Glavish & Winship, 2008).

The value of predictive testing is that it facilitates rational cancer surveillance, with early intervention and treatment. These tests cannot be entered into lightly, however, and the ethical, cultural and legal issues arising from pre-symptomatic testing must be carefully considered in collaboration with well-informed representatives of the public, patient groups and relevant professionals.

The discovery of these genetic mutations which predispose individuals to various forms of cancer, or which predict late onset single gene disorders, has facilitated information which may precede the onset of such a disease. The potential for genetic technology to help improve Māori health is, like so many other advances in medicine, a potential that could well be denied to people who live in marginalised circumstances, who have limited access to good health services or who have cultural beliefs and world views that are poorly understood by health providers and practitioners.

Finding a way through research

In 1996, Dr Ingrid Winship, the then new Director of Northern Regional Genetic Services, expressed concern that many Māori were not taking advantage of the services offered by this new service. Health professionals had, in many instances, become aware that many Māori were experiencing a degree of unease in their relationships with the health system. I was invited by Winship to consider research which involved asking Māori their views on DNA testing and more specifically on predictive/pre-symptomatic testing where there is familial cancer.

Before embarking on the larger study I was advised by kaumātua to find out how Māori from different walks of life felt about DNA testing and if they would support further research. The Health Research Council funded the initial research which was in essence, a feasibility study which recognised the need to respect and take account of Māori views as to the acceptability, viability and credibility of the wider research project to follow.

As a result of this study the value of partnership between Māoridom and medical science was supported and encouraged. There was, however, a certain amount of mistrust in the Māori community regarding DNA testing. It is accepted that there are valuable benefits to be gained but they believed that caution and careful study was essential. There was also the belief that the knowledge gained from this study would also contribute to an awareness and understanding of some of the cultural issues that Māori face. This related mainly to the new technologies within the health system, specifically in the area of predictive/pre-symptomatic DNA testing where there was a familial cancer in the family. The report of this research was sent to the Health Research Council and to all participants. An application for funding for the next research project was applied for and granted.

Aims and rationale

The primary aim of this research was to study Māori views on predictive/pre-symptomatic DNA testing by testing those who had an inherited form of breast, bowel or stomach cancer and those who, by virtue of their family history, were at risk of these cancers. A second aim was to find out why some Māori found genetic research a contentious issue that expressed attitudes ranging between total rejection to concerned acceptance, and why many Māori were reluctant to avail themselves of the existing services (personal communication, Winship, 1996).

Given that very little has been published on the interaction of cultural issues and genetic technology, the research question for this study focused on how one service can provide for the needs of people in the bicultural and increasingly multicultural society of New Zealand. Because of their cultural background and health status in Aotearoa, it was thought that Māori views about DNA testing as a predictor of familial cancer may differ from the traditional Western model and this might help explain why Māori did not seem to access fully the newly established services provided by the Genetic Service in Auckland (personal communication, Winship, 1996).

The ability to confirm the mutational basis of disease is part of the genetic technology that is available in New Zealand. In the case of familial cancer and other late onset disorders, there is now the ability to test for the presence of a specific mutation where there is a family history of this disorder. In the transfer of mutational analysis to clinical services, the information generated to date has been within a Eurocentric model that favours individual autonomy. It cannot be assumed that this model will transfer to a safe environment for all cultures and may be one reason why Māori are reluctant to take advantage of these services.

It was therefore necessary to ensure that a culturally appropriate methodological framework for the study so the Kaupapa Māori research approach was chosen. This approach emphasises the practice and philosophy of living a Māori culturally informed life (Smith, 1997) and was adopted to guide the cultural aspects of the investigation. A feature of this paradigm is that it takes account of the nature of research, as it has been practiced in a Western model, and integrates that with philosophy and contexts of Māori and other indigenous peoples. It is noted that part of the Kaupapa Māori approach involves the principle of 'tikanga' which is centred on right and wrong in accordance with fundamental Māori values. As Mead (2003) points out, it also involves moral judgments about appropriate ways of behaving and acting in everyday life.

In designing this study and the interview techniques, close attention was given to previous work on how people make decisions about genetic testing; the perceptions of risk; the testing of

children; and the processes of counselling. An overview of these considerations is now presented as part of the rationale.

Decision making

It is under the ethical terms of informed consent that all genetic tests are carried out. The decision about whether or not to take the test was not easy and ways in which each person faced this decision differed greatly. The issues for families at high risk of cancer have been extensively researched in Europe, England and in the United States. It has been found that the individual's readiness to undertake DNA testing is a function of their weighing up the possibilities of whether knowledge of risk will facilitate better management than would a situation of ignorance. Jacobsen, Valdimarsdottir, Brown and Offit (1997) found that when women at risk of breast cancer perceived that the advantages of the knowledge of their gene status outweighed the disadvantage, they opted for testing. Genetic testing readiness was also related to older age as well as a high perceived risk of cancer. It has also been reported that in excess of 90% of women with a first-degree relative with breast cancer would want testing (Lerman et al., 1997).

How do people make the decisions? In this instance, how do Māori participants decide whether or not to have a predictive/pre-symptomatic DNA test where there is a familial breast, bowel or stomach cancer in their whānau? Factors which are taken for granted as supporting decision making in the Pākehā world may in fact be problematic for Māori.

Testing children

The testing of children is another area of concern for the present study. Where the onset of the disease is mainly in adulthood it is generally accepted that testing of children should be left until they are older unless there is a significant health benefit to the child in attaining this information. The testing of children is not usually offered unless there are measurable benefits to the child. For familial adenomatous polyposis, genetic testing is available to 12–15 year olds in the at-risk age group "if a family-specific genetic mutation has been identified at the age when sigmoidoscopic surveillance would normally begin" (New Zealand Guidelines Group, 2004). Issues identified by the participants in the study revolved primarily around the desire to know the risk status for the children, the need to monitor health behaviour and to assess lifestyle options, and the need to gain some reassurance.

Most parents from all cultures put the health of their children and grandchildren ahead of their own. When contemplating having children tested, it is anticipated that parents who have been tested and found to be positive would discuss this with a genetic counsellor. It is understandable that parents will be greatly concerned that they will have passed on the gene to their offspring. The testing of minors in high-risk Māori families needed to be considered on a whānau basis, including consultation with whānau, Māori health advisors and a multidisciplinary team.

Counselling

As Harper and Clarke (1997) point out, a crucial point for counselling is that the clients need to understand clearly the genetic disease which has affected their family. Therefore, it is necessary that professionals listen carefully to their clients to establish the level of their understanding, their questions and their anxieties. Harper and Clarke also point out that communication can falter and counsellors may miss or fail to become aware of concerns that their clients need to have addressed. Thus, the ethos of genetic counselling is that the client sets the agenda, and the first rule of the counsellor is to listen.

Counselling does not take the problem away or provide a solution but helps to make sense of the situation by creating a perspective. However, the diagnosis and prognosis of the condition may be

the focus of the client's questions, along with issues related to the reproductive risks and options and how these will be answered. In New Zealand, people are provided with genetic information and test arrangements which acknowledge the fundamental place of emotions and issues as experienced by families with genetic mutations. Counselling is provided before testing so that people understand the inheritance risks, and the information the testing will provide or not provide. The right to ask and have their questions answered is invaluable and informs both the patient and the counsellor.

Procedures

Interviews were conducted with participants who formed three groups. The whānau group consisted of 38 participants from 6 families. All were over 18 years of age and either had an inherited form of cancer (bowel, breast or stomach) or were at risk of familial cancer through family history. They were most important to this research because the information they contributed was crucial to informing society about their condition. There appears to be some intrinsic mistrust or uncertainty about science and, more particularly, about genetic technology amongst the public. Therefore those who have experienced familial cancer and have engaged with the technologies are an important source of information and support for those still coming to terms with their situation and the possibilities the technologies may offer. They also represent a potential source of advice for the health care providers in their attempts to develop more culturally consultative and transparent processes and services. Of the six families, four had familial stomach cancer, one had familial bowel cancer and the other one had familial breast cancer.

The pukenga group consisted of 17 experts from across both worlds who were conversant with both Western and Māori knowledge systems. Their participation was to provide the 'missing voice' (that is, the Māori perspective) that became apparent from my engagement with literature on technological advances in genetics. These participants were able to traverse both worlds at will. Their diversity of work and interest, their wisdom, their glimpses of the cultural view which connects back to traditional Māori views of the world was invaluable in providing perspectives which gave a context to form an opinion about what the whānau were saying.

The 'Interfacer' group consisted of 16 health professionals who were geneticists, surgeons, gastroenterologists, scientists, nurses, a genetic counsellor and a social worker who were all involved with the whānau group in a professional capacity. Although the majority of them (mainly of European descent) were initially unaware of Māori knowledge and belief systems pertaining to health issues, several had become aware that many Māori experienced a degree of unease in their relationships with the health system and thus recognised the value of a collaborative approach.

Some of the interfacers, however, had taken steps to learn about te ao Māori and felt that they had benefited from this engagement. The interfacers were valuable for their insights into te ao Pākehā and the information provided by them could, like that of the pukenga, be used in bridging viewpoints to the benefit of the whānau involved. It was, therefore, important to understand the views of the health care providers so that the process of meeting these two philosophies could be representative of what both have to offer.

Results

The analysis of the whānau interviews has been developed around themes and decision making, which, although in one sense quite distinct, in other ways were inextricably linked. These themes related to concerns about the quality and quantity of knowledge available, the sources of that knowledge; the decision-making process and how those decisions were shaped; the multiple responses to having the illness and to possible engagement in the technologies; and finally, the hopes and aspirations of the whānau to their future and to the future of genetic services for Māori. Where these issues came together most strongly was in the recognition that a mutually beneficial way forward would become possible when the interested parties engaged in meaningful dialogue with one another, rather than past one another.

Provision of context-sensitive options

The most important request from Whānau and Pukenga was for marae-based services, including clinics and counselling services. The reason for this is that the marae space belongs to Māori and validates their tikanga and mātauranga. It is a place in which they can experience cultural comfort, safety and support, and feel free to speak, seek advice and information. Marae are, moreover, sites in which Māori are able to express their apprehensions and anxieties, their doubts and their fears, and their hopes and dreams, with unquestionable acceptance. Within the marae setting there is greater potential for developing a whānau-based approach to consultation, where there is ready access to the kaumātua to whom the people may look for holistic advice and support. As the leaders of whānau, hapu and iwi, the kaumātua not only provide access to wider Māori educational networks, but are also able to act as conduits of wisdom and respect with the healthcare officials in issues so deeply embedded in whakapapa. It is appropriate and a responsibility for those with the knowledge, both of genetics and tikanga, to create a context which will enable Māori to engage with genetic technology and clinical practice with confidence.

Access to information

Many of the participants asked that the information should be at a level they could understand, and be delivered by a sympathetic and skilled educator. To have educators from within the whānau adds a further dimension to cultural comfort. Health promotion material should ideally be presented in a variety of ways to address the diverse audiences across the age groups. Because children are implicated in the impacts of the illness, one suggestion is that children's books relating to whānau-based health issues should be available.

Collective decision making

Māori cultural beliefs favour collective decision making and conflicts strongly with the approbation in which the rights of an individual are paramount. Within iwi, but mainly hapu, whānau groupings, participation in the organisation, and sharing in the decision making is the responsibility of all. One of the significant factors that a number of participants noted was the collective nature of decision making in the Māori world.

Consensus is not always attained. Metge (2001) draws attention to the effects of time constraints and the resilience of some speakers who do not discard their individual views; she also notes that it is accepted that unanimity does not always produce the best solution. Although some Māori are part of a collective decision-making process, individuals are, she believes, free to make their own decisions about testing. For the most part, however, the decision-making process reflects the fact that at the heart of Māori philosophy is the concept of whānau, a collective group working together towards a common purpose for the good of all. When significant decisions have to be reached, whānau, hapu and iwi gather, under the leadership of kaumātua, to work through the particular *take* which has to be discussed and resolved. Genetic testing for cancer predisposition

is in this sense a *take* and, as the interviews demonstrate, these processes were observed, especially where uncertainty and lack of knowledge impacted on the decision making.

An example of this process of collective decision making is the instance when an individual appeared for his consultation with the surgeon, accompanied by 15 members of his whānau. This represented an important opportunity for the interfacers to learn from the whānau and in their learning contemplate appropriate changes in the way in which services may be provided. These contexts provide the potential to establish the foundations of mutual trust and respect on which such services could be developed.

Māori view of counselling

Some participants suggested that, because the decision was one that depended on whānau agreement, counselling became irrelevant. For other participants, however, a collective decision with much discussion and support from the whānau/hapu (before and after the testing), combined with skilled counselling from genetic services staff, would offer the best preparation to those seeking testing. For some participants, there was an expectation that pre-test genetic counselling to facilitate decision making should be a joint venture between the health services and the whānau. Some were unsure about taking the test but were influenced by kaumātua or other relatives who were being tested.

For Māori the issue of counselling and whether or not it would, or should, be part of the decision-making process, was also one which pivoted around contested notions of knowledge and expertise. The notion that counselling was an extraneous prerequisite for testing was expressed by one of the whānau who were interviewed for the study. In this instance, the reluctance stemmed from a belief that, because they had for decades shared this experience of hereditary gastric cancer, whānau members were their own best counsellors. This was resolved after a time by the whānau having their own trained nurse present while being counselled. Lipmann's (1999) concept of embodied knowledge, which incorporates an understanding that information provided regarding testing becomes interwoven within one's own instincts, beliefs and personal experiences, offers some explanatory potential here. Embodied knowledge involves drawing on 'feelings' or 'instinct' or 'insider' information in decision-making processes. Life decisions, she continues, are based upon this embodied knowledge, and this means that sometimes the process of genetic counselling is simply a validation of a decision already made**.**

Disclosure of results

The results of genetic tests are usually provided in person by a clinician who is able to interpret and explain the implications of the result. Many Māori requested their results to be sealed on receipt, so that the clinician and whānau learned the outcome simultaneously, allowing no prejudice of feeling from prior knowledge for either parties.

Management of specimens

To Māori, a specimen is still a part of the self and the whānau and contributes to spiritual well-being in a holistic way. The provision of blood or other tissues for testing needs consideration in light of this view. While it is now standard practice that participant's blood specimens be returned after test results if desired, if the specimen is not returned, the method of storage or disposal should be explained, discussed and agreed upon. Essentially the needs are to answer questions like: why, how, where, and for how long? In addition, details of the respect afforded to that specimen need to be ascertained. A further change which has allayed Māori fears is in the standard consent form for DNA testing which now states: "I am able to obtain the sample or have it destroyed on request. Testing will/will not require sending the sample overseas."

Discussion

The Genetic Service here in New Zealand is robust and on a par with international standards of best practice. It was, however, recognised that these practices may not be sensitive to the Māori world view, and that adaptation would be required to create a service that catered to the needs of the indigenous people of Aotearoa. Clinical genetics is an entity within the provision of health care, distinct from other branches of medicine. It is the ability to redefine genetic disorders by the molecular pathology that creates an additional dimension to traditional clinical genetics. Because many of the consultants are not sick, there is a particular recognition of duty of care to the family and to the individual.

Firm understandings and guiding principles need to be established which accommodate the unusual nature of the professional/consultant relationships and which take account of the requirements and expectations of the stakeholders, for whom service delivery will be a key component of their health programme.

It is of course predictable that many of the intangible issues are the same for all people. It was an important part of the study to examine the reported issues, and compare and contrast with the issues which emerged as significant for Māori. A principal aim has been to open up spaces for new perspectives to be presented in a focused way, so that a culturally safe service for Māori people may be developed.

Workforce development as a result of research

Because Māori do not yet have enough scientists and staff in Genetic Services, they have to depend on non-Māori staffing in all areas of technological transfer. As one of the pukenga argued, it is necessary to look for Māori who have credibility and technological expertise or to look for the best technological services available. What is crucial is that there have been some shifts in the nature of services available to Māori, in relation to genetics, to match the country's demographics.

Actions have already been taken within Genetic Services in response to the research in that Māori clients may have a Māori person present who has some knowledge of genetics. Previously this had been permitted, but the healthcare worker had to come from the general hospital service and did not have knowledge of genetics. The first step taken was to meet with genetic staff on best practice, arranged by the Chief Advisor Tikanga for the Auckland District Health Board (ADHB). This meeting began with an explanation of the spiritual and cultural domain of a Māori world view pertaining to health, before engaging more specifically on the nature of the services to Māori.

In addition, a new position for a Kai Arataki (Cultural Advisor) was established within the Genetic Service and was invited to become a member of the Kaunihera Kaumātua which is a council of senior Māori ADHB staff. This council meets once a month to support the Chief Advisor Tikanga about Māori concerns within the ADHB.

The next step was to employ a Māori genetic counsellor. To facilitate this, the service made provision for funding the appointment of a Māori educator to be employed whilst being trained as a genetic counsellor. Although two trainees were appointed in 2003 and 2005, both subsequently left because of family relocation. While the desire is to find a prospective Māori genetic trainee, the Kai-Arataki maintains liaison with clinicians and whānau that are seeking genetic services in

the meantime. In 2009 this liaison work has included visits with clinicians to Huntly, Waikato, Kawerau, Gisborne and South Auckland, to help Māori whānau with Genetic Services.

The clinics are often not places where whānau and supporters feel comfortable and as a result the clinical geneticist agreed to meet a Māori whānau, who had a hereditary genetic mutation, at an elder's home. Upon arrival, he was surprised to see over 40 people of all ages gathered, eagerly waiting to hear from him. After he had spoken to the attentive audience and answered their questions, the whānau served a delicious meal and chatted with the geneticist and the Kai Arataki. This event was a defining one, for it showed overwhelmingly, that through accommodating the participants at a time and space that was more conducive to them, a better service was achieved with Māori whānau.

Partnership approaches and future

A 'partnership approach' is modelled in the whānau who sought university scientists to help them in using technology to manage their illness. This model is likely to be supported by communities of those involved in, or affected by the illness. The present research has drawn upon a wide variety of personal and professional expertise and demonstrates the richness of perspective and understanding that such a community could provide.

With such an approach, based on the trust between Treaty partners, there is considerable promise for extending the bounds of existing knowledge, through a process of systematic enquiry. Such enquiry can combine the best of both cultures in order to attain excellence that would benefit the health and well-being of all.

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