

Understanding health and illness: research at the interface between science and indigenous knowledge†

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Indigenous knowledge cannot be verified by scientific criteria nor can science be adequately assessed according to the tenets of indigenous knowledge. Each is built on distinctive philosophies, methodologies, and criteria. While there is considerable debate around their relative merits, contests about the validities of the two systems tend to serve as distractions from explorations of the interface, and the subsequent opportunities for creating new knowledge that reflects the dual persuasions. Maori researchers in Aotearoa/New Zealand have been able to apply the methods and values of both systems in order to reach more comprehensive understandings of health and illness. Two case studies are used to demonstrate how the incorporation of indigenous beliefs into research protocols and measurements can enhance health research and understandings of health and illness.

Permanent Forum on Indigenous Issues

AD 2002 represents an important milestone for indigenous peoples. First, after nearly 80 years of trying to gain access to the League of Nations and its successor the United Nations, the United Nations Permanent Forum on Indigenous Issues commenced its inaugural session on May 13. Second, 2002 marks the 10th anniversary of the launch (December, 2002) of the Year of Indigenous Peoples at the United Nations in New York. The Year, observed in 1993, was the prelude to the United Nations Decade of Indigenous Peoples 1995–2004. Both the Year and the Decade, as well as the establishment of the Permanent Forum represent significant advances in the struggle of indigenous peoples for recognition within their own lands and territories. They have brought global attention to the impacts of colonization, discrimination, marginalization, and the overt and covert policies that led to ethnocide and sometimes frank genocide.

There are significant differences in the circumstances of indigenous peoples in various parts of the world, manifest by varying degrees of dispossession, different health experiences¹ and diverse political relationships. However, there are also fundamental commonalities in experiences and world views. These commonalities may be discussed according to a range of perspectives. For example five levels of argument that characterize indigenous peoples have been proposed, at least for

legal purposes: human rights and non-discrimination, minority rights, self determination, historical sovereignty, and indigenous rights.² Although consensus about universal human rights is sometimes seen as a rationale for regarding a 'rights-based' approach as the most important level, it has not been possible to prioritize them so that all five levels need to be considered.

Nonetheless, a history of colonization is often regarded as the most significant experience that indigenous peoples share. Imperial might, whether emanating from Great Britain or America or France or Germany, arrogantly assumed a right, often on the basis of a claim to a higher order of civilization, or simply on the authority of God, to dismiss, deconstruct, and subjugate the sovereign rights of native peoples. The results of colonization were consistently cataclysmic. A common pattern emerged: loss of culture, loss of land, loss of voice, loss of population, loss of dignity, loss of health, and wellbeing.

Others base indigenous commonalities on the similar socio-economic positions and parallel epidemiological patterns of disease—devastation by infectious diseases, malnutrition and then obesity; cancer and heart disease, diabetes and alcoholism, suicide and depression. Life expectancy generally compares unfavourably with other non-indigenous population groups and disparities are even more obvious when independent life expectancy is measured. In fact on almost all indicators of social wellbeing, whether they measure educational achievement, standards of housing, income levels, unemployment, or lifestyle risks, indigenous peoples fare worse than their non-indigenous neighbours.

However, neither colonization nor socio-economic disadvantage is considered to be the most defining element of indigeneity. Instead, most indigenous peoples believe that the fundamental starting point is a strong sense of unity with the environment.³

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This appears to be the most significant characteristic at least as defined by indigenous writers.^{4,5} 'People are the land and the land is the people.' 'We are the river, the river is us.'⁶

All indigenous peoples have a tradition of unity with the environment and the tradition is reflected in song, custom, subsistence, approaches to healing, birthing, and the rituals associated with death. The defining characteristic⁷ of indigenous peoples is therefore not necessarily premised on colonization or sovereignty or a prior claim to settlement, but on a longstanding relationship with land, forests, waterways, oceans and the air. In this sense, indigeneity can be conceptualized as a state of fusion between indigenous peoples and their accustomed environments.

Indigenous knowledge

The relationship between people and the environment also forms an important foundation for the organization of indigenous knowledge, the categorization of life experiences, and the shaping of attitudes and patterns of thinking. Because human identity is regarded as an extension of the environment, there is an element of inseparability between people and the natural world. The individual is a part of all creation and the idea that the world or creation exists for the purpose of human domination and exploitation is absent from indigenous world-views.⁸

According to Vine Deloria, 'Most tribes were very reluctant to surrender their homelands to the whites because they knew that their ancestors were still spiritually alive on the land.'⁹ His comments underline the link between the physical and social environments but also emphasize the significance of resources as collective and intergenerational, and the importance of land for health and wellbeing. Similarly the basis for knowledge creation is the dynamic relationships that arise from the interaction of people with the environment, generations with each other, and social and physical relationships. Relationships (whakapapa in Maori terms), form the substrate for indigenous knowledge¹⁰ and the three most distinguishing features of indigenous knowledge are said to be that it is a product of a dynamic system, it is an integral part of the physical and social environment of communities, and it is a collective good.¹¹

By implication, concern about the health standards of indigenous peoples needs to take into account the broader perspective of a world view that has been seriously fractured. Alienation of people from their environment—from the natural world—may be as closely linked to the host of health problems that beset indigenous peoples as the more familiar life-style risks of modern living.

While indigenous knowledge is often valued because of its traditional qualities, a creative and inventive capacity forms the core of an indigenous knowledge system. The perception of indigenous knowledge and culture as applicable only to the distant past misses the thrust for development that is part of the indigenous journey. Arising from the creative potential of indigenous knowledge is the prospect that it can be applied to modern times in parallel with other knowledge systems.

Indigenous rights

Contemporary relevance of indigenous knowledge and culture is made explicit in the Draft Declaration on the Rights of Indigenous

Peoples. The Declaration was presented to the United Nations for ratification in 1993,¹² though may never be formally endorsed. Opposition is expected from some states on the grounds that self determination (one of the 'rights') might be conceived as a right to secede, with the subsequent break up of a nation-state.¹³ The Draft Declaration contains 45 articles covering cultural, spiritual, economic, political, and constitutional rights. It has major implications for the terms under which indigenous people will live within states and requires states to recognize indigeneity by reference to indigenous culture and knowledge, citizenship, the environment and indigenous autonomy. Article 14 for example focuses on the right to 'revitalise, use, develop and transmit to future generations' histories, language, philosophies, and other intellectual pursuits. In article 24 there is a provision for a right to 'traditional medicines and health practices as well as protection of 'vital medicinal plants, animals and minerals.' Importantly, heritage rights are about both the maintenance and the development of culture and resources.

In 1999, the World Health Organization arranged an International Consultation on the Health of Indigenous Peoples in Geneva. Arising from the Consultation a *Declaration on the Health and Survival of Indigenous Peoples* was subsequently prepared and presented to the United Nations Permanent Forum on Indigenous Issues in 2002.¹⁴ Written in five parts this Declaration affirms the basic tenets of the parent Declaration but applies them to health. The links between culture, the wider natural environment, human rights, and health are rehearsed and a definition of health is offered:

'Indigenous Peoples' concept of health and survival is both a collective and individual inter-generational continuum encompassing a holistic perspective incorporating four distinct shared dimensions of life. These dimensions are the spiritual, the intellectual, physical, and emotional. Linking these four fundamental dimensions, health and survival manifests itself on multiple levels where the past, present and future co-exist simultaneously.

In effect both Declarations propose that indigenous peoples should have access to the indigenous world with its values and resources, access to the wider society within which they live, access to a healthy environment, and a degree of autonomy over their own lives and properties. They look forward as well as backward and are as much about development as restoration.

Science and indigenous knowledge

Contests between indigenous peoples and states have been fought in a variety of sites, most obviously around territorial lands, waterways, and oceans. But increasingly the contests are shifting to intellectual and cultural sites and are about the terms under which indigenous knowledge can prevail in modern times for the benefit of indigenous peoples, if not all peoples. Much of the debate is between science and indigenous knowledge and takes three distinct forms: opposition to the promotion of science as the only valid body of knowledge; the rejection of science in favour of indigenous knowledge; and the misinterpretation of knowledge by the use of system-bound criteria.

Science has become a dominant global knowledge system and has often been accused of intolerance towards other persuasions. If a conclusion cannot be supported by empirical evidence, if

practice is not evidence based, or if there is an inability to replicate results, then validity is in doubt. Method is all-important and objective measurement is the final arbiter. Systems of knowledge that do not subscribe to scientific principles are afforded lesser status and, if given any recognition at all, run the risk of being rationalized according to scientific principles.¹⁵ While not totally discounted as irrelevant, the non-science knowledge base may be scientifically unbundled and manipulated to coincide with science, even if it is thereby rendered meaningless because it is out of context with other components of the parent knowledge system.

But just as science has either ignored indigenous knowledge or reinterpreted it to fit in with scientific logic, indigenous people have in turn frequently dismissed science as a legitimate knowledge base because it seems incapable of explaining spiritual phenomena or even recognizing the existence of nature as something more than a scientifically-observable construct.¹⁶ Sometimes the rejection is simply related to a rejection of the tools of the colonizer. However, while analysis into smaller and smaller components is a standard scientific method, indigenous knowledge places greater emphasis on the construction of models where multiple strands can be accommodated to make up an interacting whole. Understanding comes not so much from an appreciation of component parts as from synthesis into a wider context.

Indigenous mistrust of science on the one hand and scientific disregard for indigenous knowledge on the other, have in common a tendency to evaluate each other according to limited criteria. Science is one body of knowledge; faith is another; and indigenous knowledge is yet another. It is important that the tools of one are not used to analyse and understand the foundations of another, or to conclude that a system of knowledge that cannot withstand scientific scrutiny, or alternately a body of knowledge that is incapable of locating people within the natural world, lacks credibility.¹⁷

Exploring the interface

Contests about the relative validity of science or indigenous knowledge are usually conducted on the assumption that one is inherently more relevant than the other. Hardly ever does such a polarized debate generate wisdom and seldom does it lead to the generation of new knowledge or fresh insights. Instead positions become more entrenched as proponents defend their ideological positions.

In practice, however, it is not unusual for scientists or indigenous peoples to live comfortably with the contradictions of different bodies of knowledge. Many scientists subscribe to religious beliefs that cannot be explained by science, and many indigenous people use scientific principles and methods in everyday life while at the same time holding fast to indigenous values.

Rather than contesting relative validities, there are an increasing number of indigenous researchers who use the interface between science and indigenous knowledge as a source of inventiveness. They have access to both systems and use the insights and methods of one to enhance the other. In this approach, the focus shifts from proving the superiority of one system over another to identifying opportunities for combining both. Three case studies are discussed below to illustrate how Maori health researchers in New Zealand have

been able to draw on both systems in order to conduct research that has credibility in scientific and cultural terms. The first study concerns a survey of the nutritional status of children under 15 years of age, the second is about the measurement of outcomes resulting from mental health interventions, and the third demonstrates how cultural perspectives of health and wellbeing can be incorporated in research design.

Maori of Aotearoa/New Zealand

Maori are the indigenous people of New Zealand and comprise 14% of the total population. Of Polynesian descent, the first voyagers arrived in New Zealand around 1000AD in a series of planned migrations from Eastern Polynesia (probably Tahiti), by way of Rarotonga. Even though changes to the definition of Maori have made it difficult to make comparisons over time, there is strong evidence of a substantial and sustained increase in the Maori population since 1900 when, at 45 000, extinction had been widely predicted.

For the past three census takes it has been possible to determine the number who are descended from a Maori as well as the number who elect to identify as Maori. Both are valid measures though identity is regarded as the more meaningful measure. In the 2001 census a differential was again present. 604 110 people indicated they were descended from a Maori, though only 87%, 526 281, actually identified as Maori.¹⁸ The difference between the two figures is significant. If self-identification is the only basis for determining ethnicity, then 77 729 people, descended from a Maori, are not regarded as Maori even though their health (and other) problems may align more closely with Maori than other New Zealanders.

Although accounting for some 14% in 2001, by 2051 the Maori ethnic population will almost double in size to close to a million, or 22% of the total New Zealand population. Even more dramatic, by 2051 33% of all children in the country will be Maori, and Maori in the working age group, 15–64 years, will increase by 85%.¹⁹

Like many New Zealanders, Maori are mobile. Following World War II urbanization resulted in major migrations from country areas to towns and cities and by 1976 more than 80% of Maori were living in urban settings, a quarter in the greater Auckland area. Emigration overseas has also become a significant trend, some 30 000 Maori now being recorded as residents in Australia. More recently still, there has been a shift in internal migratory patterns away from urban areas where unemployment is high and back to tribal areas such as Northland, from where grandparents had moved some 30 or 40 years earlier.²⁰

Over the past two decades, in addition to demographic change there has been a dramatic revitalization of Maori language and culture with a renewed sense of commitment to indigenous values and knowledge. It has been accompanied by a demand for increased autonomy and a parallel rejection of policies of assimilation and dependency. Maori providers of health and education services have been part of the trend and their emergence has resulted in pressure for theoretical and methodological frameworks that can incorporate Maori perspectives as well as scientific practice.

Two consequences of the Maori demographic and cultural renaissance are evident. First, the developments have made a significant impact on the political and cultural life of the

country and second there has been a significant shift in academic and service domains to reflect a Maori world-view. The trend has seen the use of Maori methods alongside conventional approaches. Leadership in exploring the science/indigenous interface has come largely from Maori academics and professionals in medicine, health sciences, law, education, natural sciences, business, and the arts, but there has been a corresponding readiness by other researchers to endorse the process. The three case studies that follow both reflect the new mood and are indicative of a coming together of two bodies of knowledge without undermining the credibility of either.

Case study 1—Research protocols

Researchers from three New Zealand universities are undertaking the Child Nutrition Study. It involves 3000 children aged 5–14 years and contains 1000 Maori children. Although making up only 20% of the age group, over-sampling of Maori was justified to ensure that a statistically valid sample of Maori children could be included. Twenty-four hour diet recall, a qualitative food frequency questionnaire, questions on physical activity, dental health, and food security form the basis for interviews with children and /or parents. In addition body measurements are taken and blood and urine sample collected for estimates of iron, zinc, lipids, and iodine.

Maori participation in the study was initially threatened partly because the food frequency questionnaire did not recognize indigenous foods but mainly because there was opposition to the collection of blood and urine samples. Two concerns were expressed by Maori communities. One was related to a Maori world-view that people are vulnerable if their body parts, including fluids, fall into the malicious hands. Underlying that fear is a widespread conviction that the mistreatment of body parts including even a human shadow, can result in mental or physical harm to an individual. The other concern was linked to the growing anxiety among many indigenous peoples that the promotion of genetic modification might lead to DNA experiments on blood samples collected for other purposes. There was a lack of trust in the ability of the researchers to safeguard human property.

The research team included a group of Maori researchers who had understanding of both qualitative and quantitative methods and who had wide experience in health research with Maori people. On their advice a Maori advisory group made up of eight elders, the kaitiaki group, was established. The elders recommended changes to the research protocols by extending the food frequency questionnaire to include foods that had some special cultural value to Maori.

In addition, two elders were designated as spiritual guardians for the blood and urine. Along with the senior Maori researcher they travelled with the specimens to the laboratories and having satisfied themselves that the handling of samples was consistent with the principles of respect and dignity, conducted a ceremony to render the laboratory 'safe'. Once analyses were completed, the blood and urine remnants were then buried in the earth, again with the approval of the elders. Some samples were sent to an Australian laboratory for analysis. Again, an elder acted as guardian and followed the same routine. In this way, the beliefs of participants were endorsed and anxieties about future misuse of bodily fluids were minimized.

Although non-Maori members of the research team were divided about the necessity for making special arrangements for Maori blood and urine samples, after explanations about Maori world views and systems of knowledge, there was unanimous support and even interest in participating in the ceremonies. Moreover, once the protocols had been formally amended, Maori participation in the study was enthusiastic and recruitment opportunities were expanded. The changed attitudes of both the scientific and Maori communities owed much to the key roles played by Maori researchers as they worked to synchronize the interface between science and indigenous knowledge.

Case study 2—Health measurements

A shift from output measures to outcome measures has been recognized as a more meaningful way of measuring effectiveness in health services. In the mental health field, outcome measures have typically focused on an absence of symptoms. However, an increasing recognition of the goal of wellbeing as distinct from the absence of illness has led to the development of a range of measures that go beyond the presence or absence of symptoms. In this approach much depends on how health is conceptualized.

Maori perspectives on health have favoured a holistic interpretation; good health is seen as a balance between mental (hinengaro), physical (tinana), family/social (whānau), and spiritual (wairua) dimensions.²¹ Because all four are regarded as essential there is little support for a uni-dimensional outcome measure such as HONAS (which records mental symptoms only).

In response to Maori dissatisfaction with existing measures, the MMHO framework was developed by Maori researchers to measure mental health outcomes for Maori.²² It is based on Maori perspectives of health and depends on the views of consumers, clinicians, and family who are independently asked to rate the effect of a particular intervention on wairua (spirituality), hinengaro (mental/behavioural domain), tinana (physical health), and whanau (family/social health). Ratings are recommended at the end of defined clinical endpoints such as inpatient care or a period of community care.

The underlying premise in the framework is that wellness, not simply the removal of symptoms, should be the aim of an intervention. While this approach is consistent with a holistic framework, it should be noted that wellness depends on many more variables than can reasonably be expected of a treatment or care service. Clinicians may argue that their field of expertise addresses only one aspect of wellness (such as the removal of symptoms) and that they are insufficiently resourced or skilled to address the wider social, economic, and cultural issues which, together, lead to wellness. Models of disease remission focus on the signs and symptoms of disorder, rather than the capacity to function in a dignified and meaningful way. The principle of wellness reflects consumer interest in being able to enjoy a meaningful life, with or without symptoms. Symptom removal may be a less important goal than simply being well.

It has already been emphasized that mental health outcomes should take account of the views of clinicians, consumers, and families. An outcome measure is not the same as a patient satisfaction measure, or a clinical rating scale, or a family

opinion about a treatment process. Although the tension between these sometimes conflicting views may not be easy to reconcile, the MMHO framework allows for a global picture of outcome requiring at least consumer and clinical views and preferably family views as well. While clinical views will inevitably focus on a particular diagnostic grouping, clinicians must also exercise judgement about the relationship of the disorder to other aspects of healthy living.

Although the immediate focus might be on mental health, outcomes should not be confined to narrow measures of mental health but should acknowledge the interaction of the various components of health. This holistic paradigm also recognizes that the separation of mental and emotional health from physical health and social functioning introduces an artificial divide that is inconsistent with modern notions of mind/body interaction, and Maori views on health. The domains of outcome encompassed in the MMHO measure include biological, psychological, behavioural, spiritual, social, and cultural domains. For each domain four dimensions have been identified and questions have been shaped around them.²³

Of all domains, *wairua* (spirituality) is probably the most difficult to measure. It has many connotations including the experience of mutually rewarding encounters between people, a sense of communion with the environment, access to heritage, and cultural integrity but at the heart of spirituality is the cultural ethos within which a person's identity unfolds. In the MMHO study, two approaches have been taken to measure spirituality. The first asks whether, as a result of a particular intervention, consumers have become 'stronger as a Maori' and responses are rated on a five-point scale. The second is more concerned with feeling valued and 'healthier from a spiritual point of view.' Clinical trials are encouraging enough to suggest that the measure, constructed around Maori perspectives of health, will provide a useful outcome measurement tool.

Case study 3—Health perspectives; the Kaumatua Study

A survey of 400 Maori participants over the age of 60 years undertaken by Maori researchers in 1996, assessed standards of health and wellbeing.²⁴ The assessment was based on Maori health perspectives and also recognized the roles and functions of older people within Maori society. Generally older Maori are regarded as the carriers of culture and are expected to perform a wide range of duties in relationship to tribal affairs as well as the cultural life of family and community. Wellbeing is seen to be a function of participation in the Maori world, and lack of the necessary skills is associated with diminished wellbeing. A hallmark of wellbeing for older Maori is the capacity to provide leadership and direction, despite advancing years, and regardless of socio-economic position.

In addition to economic and social considerations, wellbeing for older Maori was therefore conceptualized as an interaction between personal health perspectives and participation in certain key elements of Maori society e.g. land, language, *marae* (tribal gathering places). Methods of estimating personal health were required as well as measures of the quality and quantity of interaction with Maori cultural heritage. The objective was met by using a cultural index devised in a longitudinal study of Maori households, *Te Hoe Nuku Roa*. The index is capable of

measuring use of Maori language, access to customary lands, participation in tribal activities, and inclusion in family celebrations. It has since been used as a proxy measure for 'Maoriness' and has enabled correlations to be made between spirituality, cultural affinity, material wellbeing, general health status, and disability.

In the study of older Maori, those participants who scored lowest on the cultural index scale were likely to have the worst health. While the relationship between the two measures is complex, older people who had lower cultural index scores, reported lower levels of wellbeing, even in the presence of similar standards of health. In other words a Maori view of wellbeing is closely linked to an ability to fulfil a cultural role. Measures of wellbeing that do not capture cultural identity will not be able to convey the nature of wellbeing, as it applies to Maori.

Conclusions

The interface between science and indigenous knowledge need not be a site of contest. Rather, it can provide opportunities for the expansion of knowledge and understanding. In case study one for example, although medical researchers, including epidemiologists were not always comfortable with the performance of cultural ceremonies in a laboratory, nor necessarily able to appreciate the significance of treating blood and urine samples with a degree of reverence, there was respect for the indigenous view point and a willingness to modify research protocols accordingly. For Maori participants, the modifications were critical for maintaining confidence in the study, while for Maori researchers, recognition of the two systems of knowledge was an important step in the validation of their own intellectual and cultural realities. Importantly, no attempt was made to fuse the two knowledge systems; instead the integrity of each was acknowledged and the dual contributions led to more sophisticated understandings of health research.

Fundamental to research into health and illness are perspectives about health itself. Misleading conclusions could result if the conceptualizations of health held by a population were not adequately appreciated. Case studies two and three illustrate the point. By using a four-part Maori framework, an outcome measure was devised that accorded with Maori views on health and wellbeing. It proved problematic with some clinicians who argued that their task was not to improve spiritual, or even physical health but to treat mental illness. But for the most part, clinicians, consumers, and families welcomed the opportunity to measure outcomes using criteria that made sense to the target population. The Maori researchers who developed the instrument had been able to draw on two distinct bodies of knowledge to create a measure that had scientific robustness as well as cultural validity.

Indigenous researchers have a crucial role in straddling the divide between science and indigenous knowledge, acting as agents at the interface. Not only do they have access to indigenous populations, an important consideration in case study three, but they also have access to two systems of knowledge and subscribe to both. At the same time they face criticism from two fronts. In the three case studies, for example, indigenous groups may feel that the Maori component has simply been added on to standard scientific practice, without

any fundamental shift in method. Researchers on the other hand may complain that unnecessary variables have been introduced which limit cross-population studies. For their part the Maori researchers concerned have been encouraged by the possibilities that two world views, two bodies of knowledge, can be brought closer together. They have recognized that in developed countries most indigenous peoples live at the interface i.e. they are informed by science and by indigenous knowledge. The challenge is to afford each belief system its own integrity, while developing approaches that can incorporate aspects of both and lead to innovation, greater relevance, and additional opportunities for the creation of new knowledge.

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