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When Two Worlds Meet: An Examination of the Intersection between Scientific Views of Genetic Testing and the Realm of Popular Culture

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Abstract

This thesis explores the variety of ways in which scientific views of genetic testing are portrayed in the realm of popular culture. As a case study, I have used the identification of the gene for hereditary stomach cancer which occurred in New Zealand in 1998, and was the result of a partnership between the affected whanau and scientists from the University of Otago. Both the empirical and theoretical findings of this project have shown how physical processes, such as cancer, are constructed beyond biology, and how such accounts are not neutral or transparent. Rather, they are positioned to represent certain values and ideas, and this is even more evident when those affected are Maori.

However, considering textual representations of the gene and cancer has revealed the importance of taking into account the fact that these ‘things’ are also physical and material. I consider the implications of this and consider the ways in which the whanau health workers negotiate the fetishism apparent in biomedicine. Despite its misgivings, biomedicine has immense benefits, some of which the whanau have manipulated and appropriated for their own good, although they do so on their own terms. Despite the many complexities involved in this case study, this is a positive and hopeful story where those involved in the stomach cancer gene project have emerged with improved solutions.
Acknowledgements

There have been many people who have helped me somewhere along the way in the research and writing of this thesis. First of all, however, it must be mentioned that this project, in its present form, would not have been possible without the participation of those who were interested and kind enough to talk to me about their experiences of working in the partnership which led to the identification of the gene for hereditary stomach cancer. It was a privilege to hear your remarkable stories, and in return, I hope this thesis can contribute something positive to the way you think about all that’s happened in this partnership.

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Chapter One

Introduction

‘the term gene signifies a node of durable action where many actors, human and nonhuman, meet’ (Haraway 1997: 142).

In the past twenty years or so, there has been a plethora of research projects in the area of human genetics, not only in scientific literature, but in the mass media as well (Finkler 2000: 1). My initial interest in examining how genetic testing is portrayed in popular culture stemmed from an awareness of the increasing volume of literature and information about genetics that has appeared in these realms. Anthropologist Kaja Finkler (2000: 1) notes that the mass media portray ‘discoveries’ in genetics as an incredible new frontier, and that such reports present the new trend toward the geneticization of existence as an amazing innovation in scientific achievement. As I came to realise subsequently in this project, the increasing focus and emphasis on the fundamental importance of genetics, notions of the gene and its representation in biomedical and scientific discourse as well as popular culture, has far-reaching implications for how we come to understand and experience these realms.

Anthropologist Paul Rabinow (1992) focuses on the new genetics as a practice of life, believing it to be a potent site for the emergence of new knowledges and powers (1992: 236). He argues that the new genetics will be a primary force for influencing the shaping of society and life because ‘it will be embedded throughout the social fabric at the microlevel by medical practices and a variety of other discourses’ (ibid.: 241). This, he claims, will occur through strategies of medical intervention such as prevention and surveillance as the new genetics becomes an increasingly prevalent and formidable force in our everyday lives, requiring us to be aware of genetic risk and what this could mean (ibid.: 242-243). The focus of my
research thus highlights the complexities of the microlevel of this 'social fabric' by examining the manner in which the worlds of science and popular culture interact and intersect with each other to inform and influence accounts of genetics research.

Background to the Case Study

A central part of examining the variety of ways in which genetic testing is portrayed in popular culture included considering how it is described by the accounts of scientists and other researchers working in this area. In order to effectively elucidate this, I have used as a case study the identification of the gene for hereditary stomach cancer which occurred in New Zealand in 1998. A central focus of this thesis concentrates on the varied popular culture accounts of this groundbreaking work.

The project to investigate high rates of gastric cancer in one particular whanau was initiated in 1994 by the affected whanau (Rankine and McCreanor in press: 10). While the majority of the whanau strongly suspected it was hereditary (members as young as 14 were affected), a small minority of members believed in a historical notion that it was a curse placed upon them for selling a hill to be quarried fifty years ago. This notion was grossly exaggerated in media accounts and the fact that the overwhelmingly majority of whanau members believed it to be hereditary was downplayed. In 1995 the whanau approached the Health Research Council for information about the availability of genetics research teams to investigate the high rates of gastric cancer. They chose to initiate a partnership with researchers from the Cancer Genetics Laboratory at the University of Otago in Dunedin (Rankine and McCreanor in press: 10). In 1998 these geneticists found that this particular form of gastric cancer was caused by a variation in one particular gene. The finding was a world first and thus highly publicised both here and overseas.

Essentially, my project consisted of two phases. In the first phase I undertook an analysis of the popular culture accounts of the finding of the defective gene (including

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1 Rankine and McCreanor note that 'Their experience is unusual as gastric cancer usually occurs in people over retirement age' (in press: 10).

2 While it is a variation in one particular gene (E-cadherin) that is the cause of stomach cancer, media accounts and this thesis refer to it as a gene that causes hereditary stomach cancer for the sake of simplicity.

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newspapers, magazines, internet, radio, and television accounts). I also considered accounts of the work that appeared in children’s literature and scientific literature. Popular culture is an important medium for understanding the importance of genetic testing in contemporary Western society because popular representation is significantly more transparent and accessible than scientific discourse. Sociologists Dorothy Nelkin and Susan Lindee (1995) note that popular culture is a way of accessing the social concerns and popular understandings of the gene that are influencing contemporary concepts, both in science and molecular genetics, as well as culture generally (1995: 10). My analysis follows in a similar vein to these authors who argue that it is not the contrast between scientific and popular culture that is interesting, but rather, it is the intersection (1995: 4). The concept of popular culture is discussed in more depth further in this section in the overview of chapter two.

The second phase of my research involved interviewing key researchers who were intimately involved in the stomach cancer research project. I interviewed three scientists who were involved in the ‘scientific’ research that led to the identification of the gene, and two members of the whanau research team who also played a pivotal role in undertaking research, notably genealogical research and collecting tissue samples for testing. I then embarked on analysing both the similarities and the points of contradiction between the worldviews of these people. This highlighted a myriad of complexities apparent in the labour undertaken by them, and I will discuss this in more detail in the overview of chapter five, which considers the personal accounts of those involved in undertaking the research in the partnership. Throughout this thesis, my stance is against the colonialist notion that objects of study are voiceless and, as stated by Linda Tuhiwai Smith (1999: 61) ‘...do not contribute to research or science’. As considered in chapters three, four and five, this case study proves this claim false.

In terms of methodology, this project is characterised by inductive analysis, whereby ‘analysis is built up from the ground rather than imposed from above’ (Brewer 2000:

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3 All of those interviewed about their experience of the partnership (except for one scientist who resides overseas) are still involved in the partnership in some capacity. The scientists still undertake diagnostic testing and the whanau health researchers still collect samples for testing, and have moved into counselling and advocacy roles as well.

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This kind of analysis requires that the early stages of research be embedded in the data so that the points of interest emerge from the data itself. The advantage of this is that theory emerges from practice, allowing for connections and explanations to emerge that are related to and grounded in the social world they describe (ibid.: 151-152). Part of this empirical research also involved undertaking participant observation. This is beneficial in that it allows one to observe how people understand and experience acts of daily life (Burawoy 1991: 2); and sociologist Danny Jorgensen (1989: 15) notes that it provides ‘direct experiential and observational access to the insiders’ world of meaning’. Other methods I have used in researching this project include discourse analysis and interviewing, which are discussed further in this chapter.

The fieldwork component of this research however, was undertaken in a very short time, as I spent only two days in one research location, and visited the scientists on several occasions, although usually for no longer than an hour. This brings to mind comments put forth by anthropologists Akbar Ahmed and Cris Shore who have argued that social anthropology, as it currently exists, is at risk of becoming both marginalised and redundant unless it adapts to the ever-changing world which poses a threat to its theories, methods and practices (Ahmed and Shore 1995: 15). This entails re-evaluating its usual objects of study and developing novel areas and methods of enquiry that are ‘commensurate with the new subjects and social forces that are emerging in the contemporary world’ (Ahmed and Shore 1995: 15-16). More specifically, they note that time is one problematic area for anthropology’s relevance in the contemporary world. They argue that given the same time and resources as the anthropologist, a competent journalist could produce the same quality of analysis that an anthropologist could, except the journalist could do it more cheaply, faster and in a way that is accessible to a much wider audience (Ahmed and Shore 1995: 23).

In conjunction, these authors argue that anthropology is unable to deal with current affairs, due (in part) to its traditions of lengthy fieldwork (often undertaken alone) and the very slow process of producing results. They note that until recently, students would take from five to ten years to complete their doctorate. Thus, it can take up to ten years before the results of ethnographic studies are printed, and by this time, one
would expect the findings to have lost their relevance and immediacy, not to mention their interest to the public (Ahmed and Shore 1995: 25). Therefore, the short spell of immersion I experienced is more similar to a journalist than an anthropologist. However, unlike a journalist, I have looked deeper by spending many months considering the significance of my research results and consulting large quantities of literature and theories to help elucidate my findings, rather than coming up with a relatively short report that took a few days to write. While this does not bring me any closer to the 'truth', I think the benefits of such an approach are that I have developed a deeper understanding and awareness of the complexities involved in the ways in which scientific views of genetic testing are portrayed in the realm of popular culture, and this is one advantage of a scholarly anthropological approach. Moreover, an assertion made by anthropologist Marilyn Strathern is useful here. She states that: ‘Scientific practice now faces new pressures to take social contexts into account’ (Strathern 2002: xiv). As a large part of this project has entailed the examination of scientific practice, anthropology is better equipped than journalism to identify and illuminate these contexts in order produce a more substantial analysis – bringing an outsider’s rather than an insider’s view of the process of media production.

The ethnographic research I undertook is multi-sited, and the strategies of this methodology include following connections, associations and relationships embedded in the complex webs of interactions of particular research sites in order to come to grips with the myriad of cultural logics that are multiply produced (Marcus 1995: 97). Anthropologist George Marcus, a key figure in refining this type of ethnography, states that:

Multi-sited research is designed around chains, paths, threads, conjunctions, or juxtapositions of locations in which the ethnographer establishes some form of literal, physical presence, with an explicit, posited logic of association or connection among sites that in fact defines the argument of the ethnography (1995: 105).

With this in mind, I have followed connections between Pacific Edge Biotechnology, in Dunedin and the other location of my research, the Kimihauora Health Centre in Mount Maunganui.
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After obtaining ethical approval from the University of Otago Human Ethics Committee, I undertook participant observation and in-depth interviews in these sites with the key researchers involved in the partnership in order to compare and contrast their often different views and untangle some of the complexities involved in this particular case study. Multi-sited ethnography thus helps to define complex and surprising elements of research (Marcus 1998: 13-14). Considering the connections and relationships among these two sites and the people involved in each allows for an organic approach, one in which an argument emerges through the ethnography providing its own contexts of significance (Marcus 1998: 14). In addition, popular culture, particularly the media, can be considered another element in this multi-sited study as it represents a literal and figurative space where an array of cultural logics are both produced and presented (ibid.).

Fetishism and Corporealization: Organizing Threads

A further point to note in this discussion is that this project as a whole is underpinned by the notion of fetishism, a concept which, according to anthropologist Alf Homborg (2001: 474), has been shrouded in ambiguity. This concept has appeared as a tool of analysis in several fields, including the anthropology of religion, Marxism and psychoanalysis (ibid.). More recently, it has been applied in science and technology studies, notably by Donna Haraway (1997) who is an important theorist in relation to this thesis. Two broad notions of fetishism useful here are those propounded by Karl Marx (1981 [1867]) and, more recently, the anthropologist Michael Taussig (1980, 1992) who both take fetishism to refer generally to social relations between people that take on the form of relations between things (Hornborg 2001: 484). The idea of fetishism emerged towards the end of my data collection and analysis as a way of organising the information and highlighting interesting points of analysis, and I would like to spend a little time discussing the concept further because of its centrality to my argument.

Marx defined commodity fetishism as ‘the objective appearance of the social characteristics of labour’ (1981: 176), and this is useful to feminist and scientist Donna Haraway’s (1997) notion of corporeal fetishism (which she also terms gene
fetishism). This notion is about ‘mistaking heterogeneous relationality for a fixed, seemingly objective thing’ (1997: 142) – it is about the ways in which relations and practices get mistaken for things-in-themselves as they are taken for granted as both natural and objective. Building on the work of Marx, Haraway broadens his ideas to include nonhuman actors in acts of fetishism, allowing this concept to be more appropriately applied to the realm of technoscience which includes neutral scientific objects.

In accordance, Haraway argues that fetishism is primarily about denial where a fixed object obscures the relations and labour of human and nonhuman actors, and these things are (mistakenly) understood as the generators of value (1997: 135). In a similar vein, Taussig (1980: 9) argued that exposing fetishism means realising that the social relations symbolised in objects are themselves warped and self-concealing constructs. He states that: ‘Definite social relationships are reduced to the magical matrix of things’ (ibid. 1980: 31-32). For Haraway, the notion of corporealization is central to breaking open this ‘matrix’, as discussed below.

Haraway also draws on the work of Hungarian Marxist philosopher Georg Lukács (1971), who has been pivotal in theorising and illuminating the dynamics of fetishism. The Marxist problem of fetishism comes from ideas expressed in an essay Lukács wrote in 1922 whereby he argued that the concept of objectivity held by capitalist culture was an illusion promoted by capitalist relations of production. He accused Marxist critics of thoughtlessly taking on this concept of objectivity, and by doing so, they were upholding a fundamental element of the very social dynamic they sought to challenge (Taussig 1992: 83). Lukács said of the kind of reification embedded in fetishism that:

Its basis is that a relation between people takes on the character of a thing and thus acquires a ‘phantom objectivity’, an autonomy that seems so strictly rational and all-embracing as to conceal every trace of its fundamental nature: the relation between people (1971: 83).

4 This term refers to the notion of modern science as it is entwined with technological advances (Rabinow 1992: 236), and it is discussed in more detail in the following chapter.

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Haraway’s (1997) notion of ‘corporealization’, which is defined as: ‘...the interactions of humans and nonhumans in the distributed, heterogeneous work processes of technoscience’ (1997: 141-142), exposes the ‘phantom objectivity’ apparent in technoscience. Haraway goes on to state that ‘the term gene signifies a node of durable action where many actors, human and nonhuman, meet’ (1997: 142), and this notion is thus crucial in revealing the objectivity involved in the stomach cancer gene, which has become a thing-in-itself.\(^5\)

I would also, at this point, like to express some reservations, however, about the idea of fetishism – for example, it does not significantly allow for the physical aspects of suffering, which result from, in part at least, ‘the thing’ or ‘the gene’, which fetishism argues is a category in itself. Thus, we cannot put the notion of ‘Cancer’ wholly in inverted commas as it is also material; but in chapter three, however, I have attempted to look beyond its materiality to consider the semiotic and metaphorical portrayals of cancer. As for so many aspects of being in this physical world, metaphor and materiality are intimately entwined\(^6\) and co-constructed.

**Overview of the Subsequent Chapters**

Haraway (1997) argues that belief in an objective and universal notion of science encourages the flourishing of fetishism within the realm of technoscience (1997: 137-138). A key strategy in exposing corporeal fetishism through corporealization is a critique of orthodox notions of science in contemporary Western society. Chapter two thus considers the socially constructed nature of science and how its apparent autonomous and bounded nature can be questioned, revealing science as both a culture and practice. I also consider popular culture here, as science and popular culture both construct the stomach cancer gene. By taking into account various definitions of popular culture and considering the complexities posed by the notion of the public understanding of science, I illustrate how popular culture is an important site for expressing the culture and practice of science.

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\(^5\) Similarly, Hornborg (2001: 490) notes that metaphorically, the stone in the soup (or in this particular context, the gene) can be understood as the prototypical fetish as it moves our attention from the wider context in which it is situated to its imaginary centre.

\(^6\) See E. Grosz (1994) for a discussion of the intermeshing qualities of social construction and materiality in relation to the human body.
In addition, the notion of popular culture is an important site as it is a crucial source of mainstream guidance and information. Nelkin and Lindee (1995) note that the narratives from mediums of popular culture are usually familiar and recognisable, conforming to social expectations, both shaping them and resonating with everyday beliefs and practices (1995: 12). Thus, popular culture is more accessible than scientific discourse, thereby providing a means of access to science, genetics, and culture generally (ibid.: 10); and this has implications for how genetic testing is represented in both popular culture and scientific discourse, and the meanings that emanate from these. However, popular culture is not always transparent, and this highlights the importance of popular culture as a site of anthropological inquiry. In questioning the boundaries that apparently exist between the realms of science, popular culture and the public understanding of science, I reveal these categories as both complex and fluid as they are mutually constitutive constructions.

Having exposed the constructed nature of these domains, I then move in chapter three to a discussion of representations of technoscience and biomedicine in contemporary popular culture, arguing that popular culture accounts of cancer are neither neutral nor transparent. Foucault (1972) argued that discourses wield power and control over their subjects by appearing as both natural and objective, and stemming from this, I have undertaken discourse analysis, which is a useful tool for exposing biases and revealing how ideologies become naturalised within text. Chapter three thus reveals the ideological constructions embedded in the popular culture accounts of the ‘discovery’ of the gene for hereditary stomach cancer.

I then consider prominent metaphors of the body, disease, and cancer that exist in technoscience, biomedicine and popular culture which reveal that masculine and militaristic thinking dominates the construction of these metaphors. I also examine the broader cultural meanings of the gene and consider the implications of the most pervasive metaphors of the gene that exist in contemporary popular culture and technoscience. Generally, the gene is represented in popular culture and scientific discourse as a reductive entity. One exception to this, however, is the Maori view of the gene which differs from that held by mainstream Pakeha society generally.
However, within this Maori view are an array of heterogeneous viewpoints that make essentialising the meaning of gene in Maori culture inappropriate.\footnote{One publication stated: 'Many Maori fear that genetic technology could change whakapapa and for that reason they might oppose it. But there are also Maori families who have sought help from genetic testing services' (Independent Biotechnology Advisory Council 2002: 4).}

Drawing on popular culture for this anthropological project illustrates how anthropology can work in accordance with cultural studies which broadly concerns, as noted by anthropologist Arjun Appadurai (1991: 196), 'the relationship between the word and the world'. Understanding these terms in their broadest sense, so that the relationship becomes one between forms of textualised expression (word) and the organization and relations of cultural reproduction (world) (ibid.), is useful in an anthropological sense as it helps to capture some of the complexity involved in the production of cultural logics (Marcus 1995: 97). Using popular culture as a site of inquiry allows for the exposure of how representations are constructed, and in turn, allows for the questioning of these representations (Appadurai 1991: 208).

In accordance, cultural theorist Paul Willis (1997) has argued for the marriage of anthropology and cultural studies to form what he terms TIES (theoretically informed ethnographic study) because he believes each of these disciplines reflects the others' weaknesses (1997: 183). Willis criticises the emphasis placed on the importance in anthropology of having done fieldwork in order to be considered an anthropologist, as those in cultural studies have similar lines of inquiry, but do not go into the 'field' (Willis 1997: 186). However, he also critiques cultural studies for its lack of ethnography, asserting that it has become excessively theoretical, and this has 'removed it from the engagement from which it originally drew' (Willis 1997: 188). This thesis draws from both disciplines and the ethnography I have undertaken is theoretically informed, as analysis is drawn from both my ethnographic data \textit{and} theoretical literature.

Moving on from an exploration of the ways in which the symbolic, semiotic and textual representations of the body, disease, and the gene in popular culture as well as scientific and biomedical discourse are culturally constructed, chapter four considers
the complexities of medical intervention. Here I take into account the fact that the body is also material, physical and corporeal, and considering these aspects of the body requires a discussion of the notion of embodied suffering, which renders both dichotomous portrayals of the body and contemporary biomedical practice problematic. Here I ask (rhetorically) why the whanau wanted to find the gene and why are they content with genetic testing and surveillance? These questions bring forth many contradictions and complexities, such as a group of indigenous people who embrace genetic testing, workers who criticise many aspects of biomedical practice, yet uncritically take on some interventions offered by this, while ensuring that their beliefs are protected.

Significantly, the sort of biopiracy critiques of the new genetics from indigenous viewpoints put forth by Vandana Shiva (2000) and Mae Won Ho (1999) are not the case here. In considering these notions, I draw upon a range of literature, as well as my own musings, to elucidate the complexities involved in contemporary biomedical intervention. In addition, uncritical portrayals of medical intervention from within the institution itself are questioned in this chapter through such notions as a post-colonial understanding of medicine, which the whanau can be understood as engaging in.

In chapter five, I consider the personal accounts of those involved in the partnership which led to the identification of the gene for hereditary stomach cancer. This analysis stems from my interviews with three scientists and two whanau researchers who were intimately involved in this project. The interviews were unstructured as I used open-ended questions, allowing the participants to interpret the question and provide as much or as little information as they wanted. This type of interviewing ensures that the content has a degree of depth and ‘attempts to understand the complex behaviour of members of society without imposing any a priori categorization that may limit the field of inquiry’ (Fontana and Frey 2000: 653). My questions centred primarily on themes that emerged from the discourse analysis, as I was interested in the effects of discourses on the key researchers and the complexities

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8 In New Zealand, novelist Patricia Grace (1998) has written on this topic, communicating one widely held view of this issue among Maori in her novel Baby No-eyes.

9 At the request of the Ethics Committee, I have used pseudonyms for the interview participants in order to protect their identity.
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Introduction

that resulted from this. Although several similarities emerged from the interviews, (for example, all of the people I interviewed found the partnership an enriching experience), there were many interesting differences which emerged, especially in relation to the ways in which science and medicine are practised in contemporary New Zealand society. These similarities and differences serve to highlight the complexities involved in such a partnership.

Before exploring such themes further, it is useful at this point to consider anthropologist Lila Abu-Lughod’s (1991) discourse on the self and other in order to situate myself in relation to my ‘objects of study’. She argues that the notion of ‘culture’ in anthropological discourse functions to ‘enforce separations that inevitably carry a sense of hierarchy’ (1991: 137-138), thereby suggesting that anthropologists should write against culture (ibid.). Abu-Lughod puts forward two ways in which the notion of culture enforces separation between the anthropologist and their objects of study: through making these people seem ‘other’, and focusing on the notion of ‘culture’ (1991: 139). This is because the divide in anthropology between self and other rests on the notion of culture, or as Abu-Lughod states, ‘Culture is the essential tool for making other’ (1991: 143). Moreover, anthropological discourse renders such difference self-evident. It is thus apparent that ethnographic representations are ‘truths’ that are both partial and positioned (1991: 142-143).10

It is therefore necessary to position myself in relation to these people. Although I do have iwi affiliations – several older members of my extended family are members of Ngai Tahu and are involved and upstanding members of the Maori community – I was brought up as a Pakeha and consider this to be my primary ethnic label. In relation to the scientists, my exposure to the life sciences at tertiary level has been minimal and I do not consider myself a ‘scientist’. With this in mind, I do not wish to accentuate differences between self/other by casting those I have interviewed into the role of ‘other’, or fall into the trap of simplifying the notion of culture to essentialize difference. Rather, I am aware of the complexities involved in representation and

10 Abu-Lughod also writes about doing ethnographies of the particular (for example Veiled Sentiments [1986]) which stop people being homogenised into a meaningless group in which they lack identity.

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recognise that categories based on notions of culture, self and other are both unstable and fluid.

The point of considering the personal accounts of the labour undertaken in the partnership in chapter five then is to take into account a range of opinions, thoughts, feelings and motives of those I interviewed. I considered their responses in light of anthropologist Emily Martin's (1996: 102) analogy of science as a citadel situated in the city of knowledge production through which we all move. This is a useful analogy for highlighting the complexities of the social reality of technoscience, and I consider how these people move through this bustling centre by comparing and contrasting their views on several themes, including the orthodox notion of science, technoscience and the construction of the gene, embodied suffering, and science and biomedicine in the realm of popular culture. These themes also elucidate the complexities of different cultural worldviews and highlight the notion of science as a cultural construct. For instance, one of the most important findings to emerge from the data was the fact that one scientist is Maori, but leaves his 'Maoriness' at the door of the laboratory, while another, who is Pakeha, is very careful of tissue and blood samples that contain DNA. I also found that the whanau favour genetic testing, and my research thus shows the enormous complexity of the topic and how important it is to do these ethnographies of the particular.

Finally, in chapter six, I conclude the discussion by noting that medical intervention is not passively accepted as the whanau researchers take measures to authorise its intervention. Unusually, this process has found itself entangled with people who are not so much grateful as dynamic as the active recipients of this intervention have their own understandings and ways of undertaking research. This signals that there is scope within science to change and adapt by recognising cultural worth and the need to labour in order to accept each other. In relation to this particular case study, this required a degree of compromise, especially on the part of the scientists. This project has also shown how anthropology can work in conjunction with cultural studies as it takes into account both the word and the world as the constructions I have exposed differ from the 'reality' they seek to portray.
Chapter Two

Defining Technoscience and Popular Culture

'Science is culture' (Haraway 1991: 230).

The purpose of this chapter is to indicate, by using the notions of technoscience and popular culture, how both these realms construct scientific views of genetic testing. I consider the socially constructed nature of science and how its apparently autonomous and bounded nature can be questioned, revealing science as both a culture and a practice. In this sense, the term technoscience is a more appropriate way to conceive of science as it exposes and gives consideration to the social, cultural, economic and political elements apparent in science. Popular culture is also an important site for accessing representations of scientific views of genetic testing as science and popular culture both construct the gene. In considering popular culture in relation to the public understanding of science, this chapter serves to question the boundaries between science, popular culture and the 'public', revealing these constructions as complex, heterogeneous and fluid categories. Thus, neither popular culture nor technoscience are more or less privileged as settings of understanding science as both of these fields are part of the realm of knowledge production, signalling that science and society are mutually constitutive.

Technoscience versus the Orthodox View of Science

Throughout European and European-American history, the notion of science has been critiqued both internally by philosophers of science such as Karl Popper (1959), Paul
Feyerabend (1975) and Thomas Kuhn (1996), and externally, by sociologists, anthropologists and feminists, for example, Laura Nader (1996), Donna Haraway (1997), and Sandra Harding (1998). While critiques of science have most frequently occurred, as feminist philosopher Sandra Harding (1998: viii) notes from within the discipline of the philosophy of science, in recent history there have been several prominent (external) theorists of science who, coming from feminist and post-colonial stand points, have considered the concept of science in unique and different ways. Considering their perspectives allows for a critical survey of the orthodox view of science.

However, before proceeding to a consideration of the critiques of science posed by these theorists, it is necessary to consider of what it is exactly that the orthodox view of science is frequently and popularly thought to consist. Harding (1998: 2) notes that a core assumption embedded in the orthodox view of science is that the success of modern science is due to its internal features. This internalist epistemology, as Harding (1998: 2) refers to it, remains the prevailing theory of scientific knowledge. In the same vein, anthropologist Laura Nader (1996) critiques the notion of orthodox science, which she argues refers to a body of knowledge that is apparently distinguishable from other epistemologies by certain methods of validation. She goes on to assert that in Western society, science is characterised by such features as an institutionalised setting, as well as a set of problems and questions governed by ordered rationality (Nader 1996: 1). Scientific knowledge is therefore knowledge that is considered universal, quantifiable, empirical and predictive (Robinson and Groves 1999: 147). This premise, however, is rendered problematic by the notion of technoscience, as considered later in the discussion.

In addition, Nader (1996) criticises the orthodox view of science by illustrating that the borders of science are not fixed and definitive but rather, are fluid and contentious: contrary to what some scientists believe, science is not a ‘revealed truth’ (ibid.: 1-2). Nader therefore questions the view of Western science as an autonomous activity,

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11 Harding (1998: viii) lists these as:
- Experimental method or scientific method more generally, science's standards for maximising objectivity and rationality, the use of mathematics to express nature's laws, the distinction between primary and secondary qualities in nature.

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removed and distinct from social, political and economic contexts (1996: 3). Understood in this way, she notes that science is a kind of systematized knowledge that is both idealised and privileged and much of its perceived nature is taken for granted, especially its apparent bounded and independent character, as well as its homogeneity.

For example, through proposing that there were four norms of behaviour which characterised 'good' science (communitarianism, universalism, disinterestedness and organised scepticism) American sociologist Robert Merton (1973) sought to demonstrate that 'pure' science was free from political, ideological or economic interests and therefore separate from these contexts. Using these norms, Merton argued that science was separate from society (Fitzgerald and Dew in press: 1-2). Merton's (1973) arguments, however, have been undercut by subsequent social scientists, who, in observing the impact of social influences upon science have concluded that his 'norms' are more the exception than the rule. This is because, as noted by Fitzgerald and Dew, 'Scientists do not operate in a world that is separate from society. In fact, the personal and the political permeate all scientific activity' (in press: 2).

Several elements of what Merton expressed sociologically were also being expressed by Karl Popper philosophically. Popper rejected the orthodox view of scientific method, and in his seminal work, *The Logic of Scientific Discovery* (1934), Popper proposed a falsificationist philosophy of science. Here he criticised the inductivist view that experience can show scientific hypotheses to be highly probable, if not true.

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12 Merton can be considered as part of the Essentialist School of thought on science. According to Gieryn (1995: 393), Essentialists 'argue for the possibility and analytic desirability of identifying unique, necessary, and invariant qualities that set science apart from other cultural practices and products'. Merton's (1973: 270) essentialist leanings are most blatantly expressed in his notion of universalism, in which he states that:

> The acceptance or rejection of claims entering the lists of science is not to depend on the personal or social attributes of their protagonist; his race, nationality, religion, class and personal qualities are as such irrelevant.

13 Popper (1972: 16) defined the premise of falsifiability in terms of: 'whenever we propose a solution to a problem, we ought to try as hard as we can to overthrow our solution, rather than defend it'.

14 Inductive reasoning entails moving from premises moving from premises about objects that have been examined to conclusions about objects that have not been examined. This form of reasoning is considered less reliable than deductive reasoning (if the premise is true, then the conclusion must also be true) in scientific inquiry because inductive reasoning can begin with a true premise and end with a false conclusion (Okasha 2002: 19-20).
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Popper argued that scientific hypotheses are tantamount to broad guesses which experience can disprove, but not justify. Popper thus believed that falsification theory was a logical way of conceptualising scientific procedure, and that scientific theories would always be provisional (Andersson 1994: 1).

Popper, like Merton, also believed that science had an essential nature, arguing that his method was a certain way of distinguishing between science and 'pseudo-science'. This premise is problematic in that it neglects that science is a heterogeneous activity that is comprised of many different disciplines, practices, and theories (Okasha 2002: 16). In terms of observation, what one 'sees' is inevitably influenced by cultural conditioning. Thus, it is difficult, if not impossible, to describe our perceptions objectively. Moreover, in attempting to demonstrate that their theories are true, scientists have to undertake inductive reasoning. Popper's weakness here is that he does not acknowledge that induction is a constant and solid element of scientific inquiry (ibid.: 23).

While certain elements of Popper's theories\textsuperscript{15} have been criticised, they are interesting in one sense with regard to the power of science as they set out the certainty that science can never know all the answers as all scientific theories are open to criticism. His claim that 'Science is not a system of certain, or well-established, statements; nor is it a system which steadily advances towards a state of finality' (Popper 1972: 278) is therefore closer to the notion of technoscience and useful for critiquing the orthodox view of science. Thus, apparent in Popper's work is his belief that no scientific theory could ever be relied upon to be the whole truth, therefore slipping into relativism, which is briefly considered in the following discussion. This

\textsuperscript{15} Further Elements of Popper's (1972) theory resonate with Merton's (1973) notion of universalism as Popper argued that 'Scientific theories are universal statements' (1972: 59). This is compounded by his ideas that science had an essential nature that could be applied universally, and that science could be distinguished from pseudo-science. In addition, Merton's notion of organised scepticism, which involves withholding judgement 'about any research claims until sufficient evidence is available to assess those claims' (Fitzgerald and Dew in press: 1), resonates with Popper's notion of falsification. In terms of Merton's (1973) notion of disinterestedness, this norm 'stipulated that one's self-interested behaviour was not to conflict with the goal of science' (Fitzgerald and Dew in press: 2). This is echoed in the theory of Popper, whose notion of objectivity is used 'to indicate that scientific knowledge should be justifiable, independently of anybody's whim: a justification is "objective" if in principle it can be tested and understood by anybody' (Popper 1972: 44).

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sentiment was echoed (albeit more radically) in the work of one of his pupils, Paul Feyerabend.

That Popper mentored philosopher of science Paul Feyerabend is evident in Feyerabend’s early work, although he did begin to align himself more with Kuhn later in his career. In what is his most important work, Against Method (1975), Feyerabend argued that ‘Science is an essentially anarchistic enterprise: theoretical anarchism is more humanitarian and more likely to encourage progress than its laws-and-order alternatives’ (1975: 17). Thus, the central theme of this book was the non-existence of scientific method, and while this view is extreme, it is useful for questioning the privileged place of science in society.

Several strands of Feyerabend’s thinking resonate with my conceptualisation of technoscience, especially his critiques of the premise that the notion of science can be governed by a fixed set of methodological rules, and that scientific knowledge is not superior to other forms of knowledge. It can therefore be argued that the notion of theoretical anarchism is closer to the idea of technoscience than the laws-and-order of science. In addition, it has also been noted by the philosopher Bala (2001a online) that Feyerabend took seriously the idea of multicultural traditions of science by critically examining the hegemony of modern science. He believed that the status of modern science was due to the belief that there is only one scientific method (ibid.).

In accordance, Feyerabend noted that scientific ‘facts’ are not essentially facts because as they enter our knowledge, we are viewing them in a certain way, meaning that they are essentially ideational. This resonates with the premise put forward by the Frankfurt School which argued that the way we experience the world is essentially conditioned, and this is discussed later in the chapter in relation to popular culture. Feyerabend stated that:

This being the case, the history of science will be as complex, chaotic, full of mistakes, and entertaining as the ideas it contains, and these ideas in turn will

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16 Here, Feyerabend concluded by suggesting that science was an ongoing myth. Radically, he suggested that science should be separated from the modern democratic state, like religion (Preston 1997: 7).

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be as complex, chaotic, full of mistakes, and entertaining as are the minds of those who invented them (Feyerabend 1975: 19).

This resonates with a comment made by sociologist of science and technology Bruno Latour (1987) in relation to technoscience, as he stated that the journey through this culture should not be full of 'microbes, radioactive substances, fuel cells and drugs, but of wicked generals, devious multinationals, eager consumers, exploited women, hungry kids and distorted ideologies' (Latour 1987: 175), highlighting the social, cultural, political and economic aspects of the practice and culture of technoscience. 17

The most prominent philosopher of science was Thomas Kuhn, whose treatment of modern sciences as: 'historical, sociological, cultural, and political phenomena, ones no different in many respects from other social institutions, their cultures, and practices' revolutionised the way science was perceived, especially in the field of science studies (Harding 1998: 1). Harding (ibid.: 24) notes that his 1962 work, The Structure of Scientific Revolutions is credited with spurring the origins of the northern science and technology studies by illustrating a different pattern to the growth of knowledge than had previously been detected by the intellectual histories.

In this compelling work, Kuhn challenged Popper’s progressivist view of science. Like Popper, Kuhn critiqued the inductivist view of science, but unlike Popper, he did so by illustrating that science does not evolve cumulatively; rather, scientific revolutions overthrow established scientific theories (Andersson 1994: 2-3). He considered the history of science, especially in relation to the ways in which communities of scientists practise their branch of science, and consequently, he conceded that particular theories or paradigms 18 are taken for granted as the right and thus only way to consider the world (Robinson and Groves 1999: 152). He believed

17 However, it should also be mentioned that Feyerabend’s extreme assertions that theories are incommensurable and therefore pluralist (Robinson and Groves 1999: 154) were also applied to sociopolitical matters, such as his denouncing of Western imperialism, and this led to his labelling as a cultural relativist. In relation to science, he concluded that objectively, it was not dissimilar to astrology, voodoo and alternative medicine (Preston 1997: 5-6). This highlights the foundations of science (such as biology) as ideological systems, rather than fact.

18 Kuhn (1996) defines his notion of paradigms as 'universally recognised scientific achievements that for a time provide model problems and solutions to a community of practitioners' (Kuhn 1996: x), and he contends that 'each scientific revolution alters the historical perspective of the community that experiences it' (ibid.: xi). Kuhn thus argued that paradigms change and shift throughout history because they take into account new information rather than what is considered the 'truth'.

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that science progresses through sudden (revolutionary) change, rather than by a process of methodical evolutionism (ibid.: 152-3). Kuhn also argued that scientific disciplines are disunited as they are composed of many overlapping disciplines (Sharrock and Read 2002: 13-14). These aspects of Kuhn's arguments thus question some of the many ideological strands of orthodox science that understand science as an isolated practice and a progressive and linear enterprise which moves towards the 'truth'. This notion is discussed in relation to technoscience further on in this chapter.

The notion of the paradigm is pivotal to Kuhn's work, and is important for critiquing the orthodox view of science as he conceptualised this as more than a theory: it is an entire scientific view – ‘a constellation of shared assumptions, beliefs, and values that unite a scientific community and allow normal science to take place’ (Okasha 2002: 81). This premise led Kuhn to question the notion of objective truth, becoming suspicious of the conventional notion that there was a fixed set of facts about the world that were independent of any particular paradigm. He was also against objectivity as he believed that perception is significantly influenced by 'outside' or 'background' beliefs (ibid.: 84).

Applying Kuhn's premises more specifically, cultural theorist Barker (2000: 231-232) illuminates what Kuhn conceived of as the provisional nature of science. Barker speaks of this in relation to the notion of biology as a cultural classification system. In relation to biochemistry and genetics, he notes that this area of science is constructed by a particular kind of vocabulary used as a means for the achievement of certain purposes and gains. A Kuhonian perspective reveals that the arguments and theories put forward by these sciences should be understood as the outcome of agreed procedures.19 This highlights the provisional nature of science and the construction of consensus.

Despite Kuhn's successes in questioning the way we conceptualise science, his work can be critiqued on several fronts. Notably, it has a strong Eurocentric bias, as he ignores the history of science and technology of non-Western cultures by prioritizing

19 For instance, Barker (2000: 231-232) states that: 'These procedures have enabled us to produce levels of predictability which have underpinned a consensus or solidarity amongst the scientific community leading them to call particular statements true'.

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and universalising Western science (Bajaj n.d. cited in Bala 2001b online). This is exemplified by the following statement:

But only the civilizations that descend from Hellenic Greece have possessed more than the most rudimentary science. The bulk of scientific knowledge is a product of Europe in the last four centuries. No other place and time has supported the very special communities from which scientific productivity comes (Kuhn 1996: 168).

Before proceeding to a discussion of role of Eurocentrism in the construction of science, it should be mentioned that like Popper and Feyerabend, Kuhn’s relativist alternative to the traditional view of science was highly problematic for both scientists and social scientists. Paralleling these philosophers, his work encouraged the presence of cultural relativism in both the humanities and social sciences (Okasha 2002: 94). There has been a trend towards cultural relativism\(^{20}\) by some philosophers and how this promotes indigenous categories of science, something anthropologists applaud. However, relativism is problematic, especially with respect to the moral aspects of science in its orthodox view – a point well apprehended by scientists in the critique of scientific understandings of the world. Anthropologists are weary of cultural relativism because it can leave us with no grounds to question the moral enterprise of a group of people, and this is also a negative situation in science as many moral quandaries arise in its practice and purpose.

**Eurocentrism and the Construction of Science**

Considering the Eurocentric basis of orthodox science, however, highlights how it is, and has been in the past, ideologically influenced and constructed. This is also helpful for highlighting the ways in which scientific views of genetic testing might be constructed by technoscience (as considered in the following chapter). Haraway argues that while demarcations between the inside and outside of science, or between the perceived positive and negative accounts of technoscience are important, the lines do not need to appear as if they were created by heroes shrouded in myth (Haraway 1997: 67). (As, to some extent, was the case in the scientific construction of such

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\(^{20}\) For detailed discussions of the complexities of cultural relativism from an anthropological perspective, see Schultz and Lavenda (1995), and Monaghan and Just (2000).
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Eurocentric notions as the Scientific Revolution, Orientalism, and race and gender, which I will now discuss.

Historian of science Steven Shapin (1996) critiques the orthodox view of science by arguing that the Scientific Revolution\(^{21}\) was more a construction over time than an isolated, pivotal event. He believes, instead, that this term was constructed as a conceptual revolution, a reordering of the way in which we think about and understand nature (1996: 2). Moreover, he observes that the phrase ‘the Scientific Revolution’ was not coined until the twentieth century, becoming a book title as late as 1954.\(^{22}\) Likewise, the idea of ‘the Scientific Revolution’ no longer rests easy with other historians as many reject the notion that there was any one united cultural entity called ‘science’ in the seventeenth century – thus, there could not be a ‘scientific’ revolution without a coherent entity of science (ibid.: 3).\(^{23}\) This highlights how science is constructed and portrayed as more unified and monolithic than it actually is.

Another reason to think more carefully about the origins of science, as known by the West, is that there is no general agreement about the apparent causes of modern science. This is implicated by the fact that the search for explanations, and the types of accounts on which progressive Western science theorists settle, more often than not remain fixed to Eurocentric dichotomies (Harding 2001: 196). What did exist, however, was a ‘diverse array of cultural practices aimed at understanding, explaining and controlling the natural world, each with different characteristics and each experiencing different modes of change’ (Shapin 1996: 3).

I will now discuss these notions in relation to the fact that science is constructed in ways that is both gendered and raced, and that these categories are constructions in themselves as Western science has played a crucial role in creating the ‘Other’. I will

\(^{21}\) This term refers to a period of time between the late sixteenth and early eighteenth century when, traditional scholars argue, a series of scientific developments changed what people knew about the natural world and the ways in which they learnt this knowledge (Shapin 1996: 1).

\(^{22}\) This book was by A. Rupert Hall (Shapin 1996: 2).

\(^{23}\) Similarly, Nader (1996) notes that it was not until the late 1700s that a distinction was made between theoretical and practical knowledge, and it was not until 1850 that the idea that scientific knowledge equated to technological power and domination over nature became widespread among both experts and lay persons (Nader 1996: 3).
also make more explicitly the arguments that suggest the notion of science is best understood as a multicultural phenomenon.

Harding (1998) has argued that a sense of highly-valued rationality has played a key role in maintaining a series of Eurocentric contrasts, which may or may not have been intended. According to her, the self-image of the West depends on contrasts, notably between the rational and irrational, between civilization and the savage, the progressive and the backward, dynamic and static societies, developed and undeveloped, the historical and the natural. Through such contrasts, Harding suggests that the European Self has created its Other, thereby justifying its exploitation of various cultures and peoples (Harding 2001: 194). Integral to this project has been the raced and gendered institution of science, and the dichotomous thinking that has become entrenched and normalised within it: masculine, feminine; white, black; expert, layperson; science, non-science, etc.

One outstanding contrast created by the West is that of the Orient, and in looking at literary critic Edward Said's (1995) discussion of Orientalism it is possible to understand how European culture both managed and produced the geographical location of the Orient in many veritable ways, including politically, sociologically, militarily, ideologically, scientifically, and perhaps most profoundly, imaginatively, during the post-Enlightenment period (Said 1995: 3). Specifically, one of the main ways in which the West constructed the Orient was through scientific racism, which I will now discuss.

**Race and Gender**

Science has been used to construct notions of race and gender in ways that make these categories seem natural and 'god-given'. Revealing these categories as constructs illustrates, in turn, the constructed nature of science and how it is influenced by socio-cultural factors. What Said's pivotal analysis of orientalising discourse shows is that as the West went about constructing the Orient as the 'other', it used scientific

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24 In elucidating the work of Said, Cultural theorist Chris Barker (2000: 210-211) states that the Orient is not an inert fact, but a discursive construction which helped to favourably define the West in relation to its perceived 'backward' Other.

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ideologies and tools to do so. One of the main ways in which this was done was through the construction of binaries such as race (white, non-white). Thus, the Orient was constructed (unfavourably) in stark contrast to Europe, as backward, unequal, and inferior. The scientific basis of this stemmed from the notion of the biological bases of racial inequality (Said 1995: 206).

Haraway argues that like sex and nature, race was insidiously constructed as an object of knowledge, especially by the fields of biology, physical anthropology and medicine. This continued from the nineteenth century until the middle of the twentieth century, when these same institutions worked vigorously to disown and dismantle the fruits of their labour. Consequently, states Haraway: ‘All too predictably, the new universals, like the suburbs and laboratories, were all too white’ (Haraway 1997: 217).

Another central criticism of science is that it is, or at least was, an overwhelmingly masculine gendered discipline. As both a scientist and a scholar of feminism, Evelyn Fox Keller (2001) is well placed to question the gendered aspect of science as she has come to understand the popular association of science, objectivity and masculinity as a claim about the social world, rather than the natural (or biological) world. For her, such a realisation refers to a collective consciousness shaped by beliefs which come into existence through language. Thus, thinking about science as a social and cultural construct requires recognition of the social nature of the enterprise known as ‘science’ (ibid. 2001: 61).

Is Science Multicultural?

Having critiqued the orthodox view of science throughout this chapter, to reveal science as a practice and a culture, and questioned its construction as a Eurocentric enterprise, it becomes evident that science does not transcend culture – rather, science...
is entangled within culture, rendering science as both a practice and a culture. Harding (2001: 189) emphasises this point by arguing against the widespread belief that the success of science and its universal validity is due to the assumption that sciences transcend culture. While this premise has been challenged by considerations of race, gender and nature, another central challenge to this assumption are multicultural perspectives, which are useful and necessary tools in re-thinking science (ibid.). Harding’s key point is that modern science does, in fact, have non-Western origins. Modern sciences have borrowed from other cultures, although these ‘borrowings’ have been significantly more important and fundamental than conventional histories will admit. Modern science, then, owes much of its foundations to the ‘complex’ cultures of Asia, such as India and China and the Islamic world, as well as from the ‘simpler’ cultures of Africa and the pre-Columbian Americas (ibid. 2001: 191).27

Thus, embedded within Western science is an attitude which asserts that this enterprise is unrelated to sciences of other civilizations and is superior because their sciences only existed in the past. Harding criticises this view by noting that Egyptian mystical philosophies and pre-modern European alchemical traditions were more important to the development of sciences in Europe than the conventional view (which portrays these elements as irrational and only marginally useful) will admit (Harding 2001: 191-192).28 Modern science can therefore be considered multi-cultural in the sense that it has incorporated components of the knowledge traditions of a myriad of non-European cultures (ibid.: 192). (I will return to discuss the implications of science as a multicultural enterprise in relation to the case study of the gene for hereditary stomach cancer in the concluding remarks of chapter six).

Anthropologists and the Construction of Science

Along with philosophers of science and sociologists, anthropologists have also played a pivotal role in exposing and critiquing the orthodox view of science and its construction. Anthropologist Emily Martin (1996) discusses the contributions of anthropologists and anthropology to the study of science and culture. For example,

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27 This is also expressed by Nader (1996: 1), who observes that contemporary Western science is set apart from sciences of other civilizations, such as those of China, India and Islam, among others.

28 Mathematical developments which originated in India and scientific instrumentation such as gunpowder that were developed in China provide other examples.

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she highlights the important work of Sharon Traweek (1988 cited in Martin 1996: 100) on exposing the culture inherent in physics and how this world is constructed and given different meanings by Japanese and American physicists. Martin also mentions the pivotal work of Rayna Rapp (1988 cited in Martin 1996: 101) and Deborah Heath (1993 cited in Martin 1996: 101-102) who brought to our attention the presence of the varied yet powerful collectives who surround scientific practices, of which non-scientists are one such group (as considered further in this chapter). Through Rapp’s ethnographic account of looking at the role of genetic counsellors and Heath’s ethnography of the boundaries between a genetics laboratory and people with Marfan Syndrome, these scholars have shown that these aforementioned groups are not only present, but that they interact with the domain of science in significant ways. This has implications for the public understanding of science as considered further in this chapter.

Such ethnographic research demonstrates that the borders between knowledge production and the public are not fixed and clean. Rather, these domains are entangled and porous. The significance of this is noted by Martin (1996: 102) who states that:

This means the way is opened for a more complex, less flatly antagonistic attitude toward science than prevailed among some of us earlier. Scientific knowledge is being made by all of us; we all move in and out of the bustling city of knowledge production.

Thus, recent anthropological studies of science have shown that science is not produced in a realm that is both isolated and privileged, ‘trickling out to inform the rest of us about what is “true”’; rather, science is an ongoing process that permeates human culture, which, like science, is historically constituted (Martin 1996: 107-108). Thus, technoscience and popular culture (as considered further in this discussion) are part of this bustling city as these realms both construct the stomach cancer gene, which is discussed in more depth in the following chapter.

The work of physicist and feminist philosopher Karen Barad (2000) highlights why both scientists and non-scientists bustle through the city of knowledge production. She brings our attention to the practice of technoscience as a site of varied
entanglement by putting forward the theoretical framework of agential realism. Using this framework, technoscientific practices are fruitful sites in which many epistemological, ethical, and other issues are intertwined (ibid. 2000: 225).

Barad (2000: 236) states that: 'According to agential realism, reality is sedimented out of the process of making the world intelligible through certain practices and not others'. This notion is important for an understanding of technoscience (as well as popular culture) in that it emphasises that scientific constructions (and accounts of science in popular culture) are consciously made, rather than residing as pre-given facts. (This is exemplified by the discourse analysis I undertook of the popular culture accounts of the identification of the gene for hereditary stomach cancer which is discussed in chapter three).

It is apparent, then, that agential realism is more viable than scientific literacy because as a theoretical framework, it offers an understanding of the nature of scientific and other social practices which acknowledge that both objectivity and agency are entwined with issues of responsibility and accountability. Realizing this forces us to confront that we are partially responsible for what exists because we have a role in shaping it (Barad 2000: 236-237). Barad thus argues that science is not separate from society and the making of these two domains is mutually constitutive. This is because scientific practices are ‘material-discursive intra-actions with intertwined epistemological and ontological significance’ (ibid.: 246).

Defining the Notion of Technoscience

Thus, critiquing the pursuit of scientific knowledge and thinking about science as a social and cultural construct requires recognition of the social nature of the enterprise known as ‘science’ (Keller 2001: 61). I argue that using the term technoscience is helpful for thinking about science in this way, and my stance stems from the work of Haraway (1997: 66) who argues that ‘science is cultural practice and practical culture’. Haraway’s insights on technoscience are especially relevant in that she is trained in molecular and developmental biology, but identifies as a historian of

29 An example to illustrate this premise is Haraway’s (1997: 66) recognition of the laboratory as an ‘arrangement and concentration of human and non-human actors, action and results that change entities, meanings and lives on a global scale’.

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science who has ‘applied for a visa for an extended stay in the permeable territories of anthropology – as a resident alien or a cross-specific hybrid, naturally’ (Haraway 1997: 49). Haraway therefore has the privileged position of understanding both the realms of technoscience and anthropology in all their messy configurations.

The basis of Haraway’s definition of technoscience stems from Latour’s (1987: 174) use of the term. He states that he uses this term to ‘describe all the elements tied to the scientific contents no matter how dirty, unexpected or foreign they may seem’, thereby merging the social and the scientific, and he uses the phrase ‘science and technology’ as a sub-set of technoscience (ibid. 1987: 175).

The notion of technoscience is useful for critiquing the orthodox view of science by revealing science as a practice and culture, and is helpful in highlighting the ways in which scientific views of genetic testing are constructed, as considered in the following chapter. In terms of the meaning of technoscience, Haraway states that she means this term to refer to ‘the implosion of science and technology into each other in the past two hundred years around the world’ (Haraway 1997: 50). Haraway’s (1997) notion of technoscience stands somewhat in contrast to the orthodox view of science and in relation to fetishism, highlights labour undertaken by the human and nonhuman actors entangled in the web of technoscience. However, while Haraway’s definition of technoscience is important for this thesis as a whole, it is incomplete in that she does not consider the personal, embodied experience of being within this realm and does not do justice to the notion of suffering.

Haraway does, however, partly redeem this omission by implicating the notion of impartiality, arguing that we cannot remain neutral in the face of meanings and

30 Anthropologist Bryan Pfaffenberger (1992) brings our attention to the importance of technology to social anthropology through the concept of the sociotechnical system. A central feature of the sociotechnical system, like the notion of technoscience, is that it ‘refuses to deny the sociality of human technological activity’ (Pfaffenberger 1992: 493). The sociotechnical systems model, then, means that each human society is one that is in the process of becoming – one where people are actively engaged in technological advancement and the appropriation of artefacts as the means of self-knowledge and of ‘coordinating labour to sustain their lives’ (ibid.: 511).

31 More specifically, Haraway (1997: 50) goes on to state that she wants to use this term to: ...designate dense nodes of human and nonhuman actors that are brought into alliance by the material, social, and semiotic technologies through which what will count as nature and as matters of fact get constituted for – and by – many millions of people (ibid.).
practices of technoscience which affect us physically and emotionally. She notes that our perspective and understanding is inevitably partial, stating that: 'We must cast our lot with some ways of life on this planet, and not with other ways' (Haraway 1997: 51), suggesting that it is difficult, if not impossible, to be intellectually and emotionally omnipresent and therefore complete in our thinking. While aware of her pragmatic insight, I do attempt a partial redress of this omission in chapter four where I consider the notions of suffering and embodiment which satisfy a personal understanding of the effects of technoscience, and also in chapter five where I consider personal accounts and perspectives of those who are entangled in the web of technoscience.

The World of Popular Culture

Having given consideration to the realm and meaning of science when it is understood as technoscience, it is important to now consider that of popular culture as both these sites construct the stomach cancer gene. Popular culture is also an important part of the bustling 'city' of knowledge production, especially in relation to the public understanding of science.

As argued by van Dijck (1998: 11), the boundaries between the worlds of science and popular culture are constantly shifting, and thus it cannot be asserted that popular portrayals of genetic testing come from 'inside' popular culture, and 'outside' science. Another important point to reiterate in relation to popular culture is that popular representations matter, and historian of science Jon Turney (1998: 201) makes the point that popular culture, especially the popular media, are as important for understanding debates about science as other, more academic records.

Like Turney, sociologists Dorothy Nelkin and Susan Lindee (1995: 10) also bring our attention to the importance of the popular in science. They assert that popular imagery is significantly more transparent than scientific discourse in that it is a means of gaining access to the social concerns and popular understandings that are influencing concepts in molecular genetics specifically, and the culture at large generally. They note that popular culture can take many forms for the consumer, the most common including television programmes, films, mass media generally, and in more recent
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times, the internet. Such vehicles of popular culture, according to Nelkin and Lindee, are a crucial source of guidance and information. The narratives from these mediums are usually familiar and recognisable, conforming to social expectations, both shaping them, and resonating with everyday beliefs and practices (Nelkin and 1995: 12). For example, Turney discusses the myth and presence of Frankenstein\textsuperscript{32} in the popular imagination, emphasising that it is a central and governing myth of modern biology, warning of the potential negative consequences of the 'quest' for knowledge (Turney 1998: 3). Moreover, this story (written by Mary Shelley and first published in 1818) illustrates, according to Turney, that there are important continuities in cultural debates about science from this time to the present (ibid.).

The definition of popular culture is both broad and problematic. Because this term means many different things to a variety of populations, societies, and cultures, there is no definitive definition. In order to arrive at several generalisations about what this ambiguous term encapsulates, however, it is necessary to briefly overview the historical emergence of popular culture. Considering its emergence historically reveals that, as argued by cultural theorist, John Storey (2003: xi), popular culture is a category that was invented by intellectuals. He notes that since the late eighteenth century until the early part of the twentieth century, intellectuals who studied nationalism, Romanticism and folklore 'invented' the first notions of popular culture. He argues that debates over this time about what defined and constituted this phenomenon led to two broad concepts of this term: popular culture was understood as a kind of rural folk culture, or as the low brow and banal mass culture of the newly emergent industrial working class (ibid. 2003: 1).

However, these distinctions became increasingly blurred in the late eighteenth and early nineteenth centuries as traditional socio-cultural relations between upper (dominant) and lower (subordinate) classes began to alter under the far-reaching impact of industrialization, urbanization, and consequently, the emergence of an

\textsuperscript{32} The thematic material of the story focuses on Dr Frankenstein's pursuit of the secret of life. The monster is created after the doctor spends two years collecting and assembling human remains from corpses. When it is brought to life, Dr Frankenstein is at once both exhilarated and horrified by his creation (Allan 2002: 179). The monster becomes the physical embodiment of the doctor's pursuit, and this, argues Turney (1998: 3), became one of the central myths of modernity – the social consequences of the search for knowledge.

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Industrial working class. European and American intellectuals became especially interested in the culture of the ‘folk’, and this culture became an occupation of people from a wide variety of social denominations (Storey 2003: 1-2). In addition, the study of folk culture also helped to establish the notion of ordinary people as the masses, consuming mass culture (Storey 2003: 15). In more recent times, this study of popular culture can be related to the emergence of the discipline of cultural studies, which was considered in the previous chapter in relation to Willis’s (1997) notion of TIES, and I briefly address the emergence of cultural studies further in the subsequent discussion.

There are several tenets that are integral to definitions of popular culture: the popular, class, consumption, and the mass media. In terms of class, sociologist Pierre Bourdieu’s (1984, 1993) work illuminates how actions in the realm of culture help to reproduce and proliferate class inequalities. Generally, he argued that while class rule is essentially economic, its appearance is cultural. Concerning the mass media, sociologist Dominic Strinati (1995: xiii) believes that people’s lives in Western capitalist societies are increasingly affected by the popular culture offered by the mass media. This highlights how the mass media is coming to play a particularly prominent role in the notion of popular culture. Strinati (1995: xviii) emphasises that the difficult task of defining popular culture is also related to how it is explained theoretically. Several of the most common theories of popular culture briefly considered here include the notion of popular culture as a dominant ideology, that popular culture is actively constructed by its audiences, that it is an ideological struggle between classes, and that the popular is political.

The Frankfurt School, for example, argue that popular culture is mass culture which is produced by the culture industry, thereby ensuring the continuity of capitalism (Strinati 1995: xviii). The Frankfurt School is thus influenced by Marxism, and

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33 Cultural theorist Peter Brooker (1999: 197) notes that the most common underlying definition of popular culture equates the popular (including popular attitudes and tastes) with the products of the processes of both mass production and the mass media.

34 Commenting on this dynamic, Storey (2003: 43) states that ‘In this way, the production and reproduction of cultural space helps to produce and reproduce social space, social power, and class difference’. Another theorist to put forward a compelling idea of popular culture in terms of class is Susan Sontag who observed ‘the distinction between “high” and “low” culture seems less and less meaningful’ (Sontag 1966: 296, 299, 302). The cultural valorization of music, among other things, was representative of this ‘new sensibility’ (Storey 2003: 63).

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perceives popular culture as a kind of dominant ideology (ibid.). In addition, this School believes that popular culture is inferior (in relation to 'high' culture). They see popular culture as commodity-based, inauthentic, and banal. Mass culture is perceived this way because it is produced by those with commercial interests and does not enrich its consumers (Barker 2000: 44-45).\textsuperscript{35}

However, in relation to popular culture, the conservative view of the Frankfurt School denies the consumer any agency, as it assumes that textual representations are appropriated by audiences in a manner that is passive and unproblematic. This view also neglects to consider political issues embedded in popular culture (or, popular cultural politics). This position has been convincingly challenged by the arrival of the academic discipline of cultural studies which, in contrast, takes popular culture seriously. More specifically, this discipline introduced the active audience paradigm whereby individuals engage actively and critically with popular culture (Barker 2000: 44-45). Popular culture is thus appropriated by its audiences, and as prominent cultural theorist John Fiske (1989: 8) argues, popular culture is composed by the meanings that individuals take from it and make with it as opposed to those apparent in texts. Consumers are not passive recipients, but discerning and active makers of meaning. Fiske (ibid.: 43) states that: ‘There can be no popular dominant culture, for popular culture is formed always in relation to, and never as part of, the forces of domination’.\textsuperscript{36}

This point also needs to be considered in relation to critical public understanding of science (PUS) studies which demonstrate the ways in which the ‘public’ and ‘laypeople’ do not passively receive information, but actively engage with, and

\textsuperscript{35} It should also be mentioned that the Frankfurt School influenced sociological and anthropological theory and practice in the early to mid twentieth century. This School used Marxist theory to analyse empirical social science research. The approach of this School was characterised by 'critical theory' which takes into account that the way one sees the world is conditioned, especially by political and other ideological structures of society. This had implications also for anthropology as critical theory is self-reflective, taking into account the way in which society shapes perception, recognising the power structures inherent in such conditioning (Edgar and Sedgwick 1999: 150-151).

\textsuperscript{36} Popular culture can also be considered political especially in light of the concept of hegemony (Storey 1993: 13). Storey (ibid.) draws on Gramsci's political concept of hegemony to conceive of popular culture as 'a site of struggle between the forces of resistance of subordinate groups in society, and the forces of incorporation of dominant groups in society'. Considering a Gramscian view of popular culture illuminates the ideological struggle between dominant and subordinate classes and cultures.

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appropriate, information. Brian Wynne (1995: 385), a sociologist of science, asserts that this field of research has found a wealth of evidence to indicate that laypeople problematise and negotiate their own relationship to 'science'.

While there is no correct answer to the problem of defining popular culture, some ways of doing so are more appropriate than others. For my purposes here, I will generally regard popular culture 'as the meanings and practices produced by popular audiences at the moment of consumption' (Barker 2000: 47). It is fair to conclude then, that while the notion of popular culture is difficult to define, it is always entwined with ideas of social power, especially in relation to socio-cultural categories such as class, race, ethnicity, gender and sexuality (Storey 2003: xii). This is also true of technoscience, which is comprised of these constructions and (unlike the orthodox model of science) problematises them at every turn.

A Consideration of the Public Understanding of Science

If technoscience and popular culture are both present in the city of knowledge production, then the public understanding of science is the result of the intersection of these two fields. Just as the meanings of science and popular culture can be questioned and revealed as constructed, so to can the categories of the public, laypersons and scientists, especially in relation to the public understanding of science. Turney (1998: 5), for example, captures the essence of the complexities involved with the public understanding of science by noting that whether referring to the past, present, or future, we must avoid a simplistic view of this theme. Thus, there is no simple entity called 'science', just as there is no single 'public' – these are both complex and dynamic categories. Other issues which I will consider in this section are the relationship between science, society and the public, public responses to science, and how the term 'public' is defined.

According to Shapin (1990), the past three centuries have witnessed an inversion of the power dynamics between science and the public. He argues that the relations between these two realms have changed markedly since the seventeenth century. In

37 This view stands in direct contrast to the traditional question of how the culture industry transforms people into commodities that serve its interests in favour of understanding how people turn the products of industry into their popular culture, serving their interests (Barker 2000: 47).

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the past, science (when recognized as a separate activity), was influenced by the public and other institutions. Now, however, the scientific community believes itself to be more autonomous, controlling its own proceedings as well as stipulating ‘the nature of proper relations between itself and the public, and even extends its influence importantly into the arena of public affairs’ (ibid. 1990: 992). This view stands in direct contrast to the arguments of Nowotny et al (2001) who suggest that the barriers between science and society are dissolving.

These authors claim science can no longer be considered as an autonomous entity cleanly separated from other realms of society, culture, and economy. They argue that these categories have increasingly become both heterogeneous and interdependent (ibid. 2001: 1-2). They build (as Haraway and I have done) on the work of Latour (1987), who argued that science and society are inseparable as they rely on the same foundation. However, they note that the relationship between these two domains has changed as traditionally, science held an ‘external’ place in society, which could be antagonistic to scientific values and methods. Consequently, scientists understood their task as the ‘benign reconstitution of society according to “modern” principles which they were largely responsible for determining’ (Nowotny et al 2001: 2).

In contemporary society, however, science is now ‘internal’. This means that scientific research is no longer an authoritative and elite project, but a contribution to society as it creates new knowledge and provides degrees of uncertainty and instability (ibid.). This resonates with the aforementioned claim of Martin (1996) that the walls of the citadel of science are porous and permeable. In accordance, Nowotny et al (2001: 260) argue that it is impossible to clearly demarcate between context and core, and therefore, the intrusion of the ‘social’ cannot be viewed as inhibiting scientific novelty. Rather context, or the ‘social’, is a key source of innovation. This statement is also true of technoscience whereby the ‘social’ is embraced as a defining feature of this domain.

**Re-defining the role and importance of the ‘Public’**

Nowotny et al’s (2001) comment about the impossibility of creating clearly defined boundaries resonates with the tenets of the public understanding of science. For
speech communication specialist, Celeste Condit (2001), the distinctions between the categories of scientists and the public are not clear-cut. She argues that the category of the public is messier and has more agency than has been suggested by many scholars (for example Shapin 1996, and further in this section Garvin 2001). Condit observes that in a democratic society, the lay public are influential in terms of the progress of science and the use of science-based technologies. For instance, members of the public can choose which research projects they support morally and intellectually, but most importantly, financially (Condit 2001: 811). She thus embraces a more specific and faceted view of the public and what constitutes this entity, if in fact, it can be referred to as such. These sentiments are echoed by Irwin and Wynne (1996: 9), who state that:

...the public is portrayed as a homogeneous mass which needs to be rendered more receptive to the insights of science. The 'public' exist as an audience for science; they are an object rather than a subject. At this stage, we need to remember Raymond Williams' observation: 'there are in fact no masses, but only ways of seeing people as masses.

Important to consider in relation to the public understanding of science is the role of the citizen as consumer. A common occurrence, for example, is for geneticists and biotechnologists to consult 'lay people' in their role as 'consumers'. While this is important, one potential danger is that the power and force of the market in Western industrialised society might cause those who are acting as individual consumers to be mistaken as the public (Condit 2001: 811). Condit argues, then, that it is important to distinguish between these groups, stating that: 'the public is not a group of individuals who are pursuing their own private advantages and interests' (ibid.).

Instead, the public is a collective concept – one that alludes to shared efforts to gain benefits that transcend limited personal interests, thus affecting the community at large. The nature of the collective concept of the public is also heterogeneous and abstract, and because of this, its thoughts are difficult to capture and identify (Condit 2001: 811). This stands in contrast to the thoughts of both Shapin (1996) and Garvin (2001) who, in their discussion of the relationship between scientists and publics,
overlook the importance of the fact that the concept of the public is both varied and ambiguous.

Public Ambivalence

In considering how the citizens of the city of knowledge production perceive science, it is important to consider Turney's (1998: 3) claim that the general public feel ambivalent and weary about modern biology. While we celebrate the great 'discoveries' of recent times in the mass media, he states that 'we fear that the triumph will turn sour' (ibid.). Although we are eager to benefit from scientific advances, we are also aware of the potential risks of applying this new biotechnology, especially its threat to dissolve and blur boundaries and eliminate taken for granted categories (ibid.).

In relation to how the mass media portray the work of geneticists, Turney (1998: 3) notes that they feel their work is portrayed negatively. This is compounded by the fact that many scientists feel that, in modern Western societies, there is an anti-science movement. Whether this is true or not, it is certain that there is a sense of ambivalence surrounding science and technology. This is especially so in the life sciences, and although modern biologists have perceived this, they relate it to a general anti-science feeling, public ignorance, or media misrepresentation of their work (ibid.: 4). Turney (1998: 5) criticises this rhetorical response to criticism as it dismisses the possibility that 'there may be special reasons why an increase in manipulative power in the life sciences might provoke public disquiet'. In addition, Barad (2000) notes that the notion of agential realism has implications for the public understanding of science as she argues that scientific literacy is problematic in that the 'public' 'no longer considers scientists to be paragons of social responsibility' (2000: 229).

In accordance, Turney (1996) argues that while the public has become more receptive to learning science, there is a feeling of public mistrust towards experts, meaning that a scientific education of the public will involve more than offering simple scientific facts. Scientists thus need to consider the ways in which people are empowered to use the scientific information that is offered to them. The onus, then, falls on the scientist to explain scientific developments and their implications in ways that a diversity of
‘publics’ can use. This has led Turney to assert that, instead of focusing on the public’s understanding of science, we need to improve the scientist’s understanding of the public (Turney 1996: 1087), which would mean redrawing boundaries and redefining the categories of public and science. As previously mentioned, similar sentiments have been made by Martin (1996: 102) and Barad (2000: 246).

Moreover, it can be argued that the ways in which the public construct and define relevant knowledge differs from scientists. However, environment and health policy expert, Theresa Garvin notes that how the public interprets knowledge, just as in the science world, is historically and culturally contextual (Garvin 2001: 450). She therefore argues that there are two main competing models for interpreting risk information: technical and cultural. Lay and expert perceptions contrast because laypersons place importance on the cultural models, while experts usually focus on the technical (ibid.). One consequence of these differences is that there is a degree of conflict because experts believe the public to be scientifically illiterate, while the public accuse experts of technical elitism and oppression. Although this view is simplistic, it is important to acknowledge that the public can evaluate evidence and construct knowledge in ways that are fundamentally different from the scientific community. For example, the public’s access to evidence is derived from sources that are both formal and informal. The public gathers evidence from both scientific assessments and lay sources, (which can include anything from oral histories to personal experience), as well as from the media. Interestingly, Garvin (2001: 450) also notes that the public, in some cases, gives more credibility to these lay sources than to those of a scientific nature.

This discussion has thus set out several important tenets in relation to technoscience, popular culture, and the public understanding of science. I have considered how the orthodox view of science is inferior to the notion of technoscience because it does not acknowledge that society and science are mutually constitutive. The notion of technoscience, however, takes the social and cultural into account and acknowledges that science is not a bounded and homogeneous activity that operates ‘outside’ of the confines of society. This has implications for how information is presented in the realm of popular culture as both technoscience and popular culture construct the
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stomach cancer gene, and how categories are constructed and represented in the public understanding of science. In addition, popular culture is a crucial site for accessing representations of scientific views of genetic testing as it is no more or less privileged as a setting of understanding science – science and popular culture are inseparable as they lie on the same foundation: society. The following chapter will draw on this theoretical basis to discuss the importance of considering the textual and semiotic portrayals of genetic testing, highlighting the various ways in which the stomach cancer gene is constructed by biomedicine, technoscience and popular culture.
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'No object, no thing, has being or movement in human society except by the significance men [sic] can give it' (Sahlins 1976: 170).

The previous chapter considered how the worlds of technoscience and popular culture are both defined and culturally constructed, and having established that both sites exist in the city of knowledge production, I now move on to a discussion of representations of technoscience and biomedicine in contemporary popular culture using the specific example of the New Zealand media handling of the 'quest' for the stomach cancer gene. In doing so, I argue that popular culture accounts of cancer particularly (and interventions to restore health generally) are not the neutral, transparent reporting of one set of facts they appear to be. Instead, these accounts are politicised, culturally constructed and positioned. Moreover, when this cancer is experienced by Maori in a New Zealand historical context, even further cultural shaping occurs.

In this chapter then, I 'lay bare' the constructed nature of popular culture accounts of the identification of the gene for hereditary stomach cancer and consider the consequences of such constructions which have become normalised in contemporary New Zealand society. I also place these findings of the constructions of the cancer gene against the broader socio-historical accounts of metaphorical ways of understanding the body, disease (especially cancer), and genetics, which I will discuss in some detail. As I consider in the second half of this chapter, cancer\(^{38}\) is not a neutral term in the West in that we understand it in terms of military and masculine

\(^{38}\) The meaning of this term is considered in Susan's Sontag's (1978) contested work, *Illness as Metaphor.*
metaphors, as well as in relation to the genre of science fiction. We do this by culturally constructing its meaning beyond biology through storytelling, the use of metaphors and myth. I conclude the chapter by considering the implications of the current and most pervasive metaphors of the gene existing in contemporary popular culture and technoscience and how we understand these in New Zealand.

Assessing Popular Culture Accounts of the Identification of the Gene for Hereditary Stomach Cancer

Considering how technoscientific and biomedical discourses are represented in popular culture is important because, as asserted by Tumey (1998), our perceptions of science and technology and their products are partly influenced by the images of the work which exist outside of the confines of scientific representations and accounts. Bearing this in mind, as part of the empirical research for this thesis I have deconstructed media and other popular culture accounts of the identification of the gene for hereditary stomach cancer by undertaking discourse analysis. This practice is useful for the ways in which it questions assumptions which are taken for granted and upsets what has become naturalised and normalised in the fabric of society. Moreover, discourse, (along with metaphor and myth) is important to cultural life as a way of accepting and resisting meaning.

In conceptualising discourse theory, Foucault (1972: 27) posed a central question in relation to how discourse was able to construct the social world: 'how is it that one particular statement appeared rather than another [?]'. This consideration has informed my approach to this particular topic by highlighting the constructed nature of the accounts I looked at. Foucault argued that the stability of forms of continuity and syntheses embedded in discourse must be disturbed in order to illustrate that 'they do not come about of themselves, but are always the result of a construction the rules of which must be known, and the justifications of which must be scrutinized' (ibid.: 25).

French social theorist Ronald Barthes' (1973) notion of 'myths', which are culturally constructed despite their appearance as pre-given, universal truths, is also useful in highlighting the value of discourse analysis. This is due to the notion that myth 'has...
the task of giving an historical intention a natural justification, making contingency appear eternal’ (Barthes 1973: 155) More specifically, Barthes’ (1973) contentions illustrate how, as citizens of New Zealand society, we ‘buy into’ particular ideas of the stomach cancer gene and how we come to make sense of the broader issues surrounding this gene in the ways that we do. This is considered in the following discussion concerning the outcomes of my own discourse analysis which reveals particular myths as the cultural constructions they are. Furthermore, undertaking this type of analysis reveals which constructions are accepted and resisted, as I will illustrate in the following discussion.

The Case Study in Context

During the course of this research, I analysed twenty seven popular culture accounts focusing on the identification of the gene for hereditary stomach cancer. The purpose of this was two-fold: first, I wanted to deconstruct the ideologies behind these accounts, noting the ways in which certain portrayals were made to seem natural and ‘normal’ by highlighting several prominent themes. Second, I sought to find ways in which the body, disease (especially cancer) and genetics are portrayed in popular culture, and to illuminate the implications of particular portrayals and constructions. The results of this latter inquiry are considered further in this chapter in relation to the broader cultural meanings of metaphors. In terms of the themes that emerged from the discourse analysis concerning the partnership, I found, as did Rankine and McCreanor (in press) in their discourse analysis on the same topic, which corroborates my research, that the whanau are generally portrayed unfavourably in contrast to the scientists. Hence, the themes to emerge from my discourse analysis illustrate that the whanau are marked as ‘other’, and portrayed negatively as ‘traditional’ in relation to the ‘modern’ scientists. I also found that the ideology of modern science and biomedicine is portrayed uncritically, indicating that this is a valued institution in New Zealand society. For ease of reference, seven tables are included at the end of

39 Discourse analysis also reveals how people are positioned in different ways as social subjects (Fairclough 1992: 3-4). Discourses, therefore, encode power relations and specify ‘what relations are possible and valued in specific institutional contexts’ (Schirato and Yell 2000: 103).

40 Although Rankine and McCreanor (in press) focus on media accounts of the identification of the gene for hereditary stomach cancer, I have used accounts that span a wider time frame and accounts that exist in popular culture generally, rather than exclusively print media accounts.
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This chapter: tables one to four show key examples for the accounts of each theme; tables five and six show key examples from my analysis of how the body, disease and genetics are portrayed, and table seven alphabetically lists the accounts I analysed.

Before I commence a detailed discussion of my findings, brief consideration must be given to New Zealand’s history in order to place the discourse analysis in a historical context. It is crucial to the consideration of the emergent themes of my discourse analysis to observe that New Zealand experienced colonialism in the nineteenth century whereby Maori populations were colonised by European settlers. The signing of the Treaty of Waitangi (this country’s founding document) had negative consequences for Maori as their sovereignty was supplanted by British culture, politics and economics. While Maori interpreted the Treaty as confirming and enforcing their sovereignty, imperial Britain understood that the Treaty rendered Maori sovereignty void, thereby paving the way for the British to take legal control and colonise. Although Maori resistance to the negative effects of colonialism has been robust, it has been unable to ward off negative impacts in the areas of culture, health, education and economics of Maori populations (Orange 1992, Rankine and McCreanor in press: 4). Any understandings of contemporary discourses around this case study must therefore be aware of the preceding history.

Before explaining the outcomes of the discourse analysis, several points must also be mentioned about the case study which is itself the subject of this analysis. This medical research differed from most others of its nature in that the whanau team had played a fundamental and active role in the research process. For example, they directed the research, compiled their own genealogy and collected tissue samples. However, the whanau’s active and involved role in the partnership was underplayed in the media accounts, and this led Rankine and McCreanor (in press: 21) to refer to it as ‘Colonial Coverage’, which they state: ‘functions to reinforce and reproduce the

41 Schirato and Yell (2000: 17) emphasise that communication practices ‘are always informed by and produced within cultural contexts’; therefore, considering the wider context of culture in which these texts operate is central to the concept of discourse analysis.

42 More specifically, in partnership with the scientists, the whanau team negotiated: ‘an agreement involving culturally appropriate management and ownership of tissue samples, a shared patent for the genetic test and regular reporting by the genetics team at whanau hui’ (Rankine and McCreanor in press: 10).

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subordinate position of Maori and their position of "other" to the norm of modern Pakeha society’, and this is a finding which my own research supported.

The Notion of Whiteness

Central to the notion of discourse theory is the concept of ideology, which becomes naturalised in the construction of discourse. O’Sullivan et al (1994: 143) note the importance of the concept of ideology in the media because it insists that ‘natural’ meaning does not exist – rather, media accounts are always constructed and socially positioned by notions of class, race and gender, among others.

This argument is significant as it reveals hidden within the texts the notion of ‘marking’, whereby Maori are always the marked category, while the category of Pakeha is always left unmarked because it is assumed (on racist grounds) that the scientists would for the stomach cancer research group, belong to the dominant (white) ethnicity. This, however, is not the case as one scientist is in fact Maori, and this is discussed in more detail in chapter five. Maori are generally, however, relegated to the status of ‘other’ in the majority of popular culture accounts. For instance, in the accounts I analysed, the whanau are always ethnically marked, usually by the term ‘Maori family’ or by the term ‘whanau’, and in none of the pieces I looked at is whiteness marked – there is no mention that the majority of the scientists are ‘Pakeha’, ‘white’, or ‘New Zealand European’.

This indicates that, because Maori are the marked category within these discourses, it is taken for granted that the category which is not marked is assumed to be white, and this is a reflection of the way in which society is ethnically constructed. Statements like the following appeared in the overwhelming majority of articles I viewed: ‘Scientists at Otago University achieved a world first in identifying the gene E-cadherin as being responsible for stomach cancer in five generations of a Maori family’ (The Christchurch Press 27 March 1998: 9). The only exception to the articles I analysed is a short item which appeared in Otago Graduate (1998: 17), which does not mention that the whanau are Maori. Significantly, even specifically Maori
publications have ‘Maori’ as a marked category. However, it should be noted that in these contexts, the marking of this category can be a positive attribute, highlighting the achievements of Maori.

Also related to the notion of Whiteness is the ideology of monoculturalism. According to Abel (1997: 20), this concept refers to the unwillingness to refer to “Pakeha culture” or to recognise that Pakeha might be politically and culturally dominant. Such attitudes position Pakeha viewpoints and values as “normal” and “universal” and force Maori into the position of “other”.

Another possible reason for the consistent marking of Maori is that, according to Abel, most reporters are ill-informed about Maori society and values. Therefore, ‘the importance,” “relevance” and “significance” of a story is inevitably seen through Pakeha eyes’ (ibid. 1997: 24).

However, the practice of marking ‘racial’ categories other than white has very real consequences in terms of constructing categories of what is considered ‘normal’ and in contrast, ‘other’. This notion has been theorised in the discipline of Whiteness Studies, and one proponent of this discipline, Richard Dyer (1997: 1), argues that because race is only applied to non-white peoples, white people are not racially marked. Therefore, while ‘other’ people are raced, white people are just people. In the same vein, sociologist Ashley Doane (2003) notes that because Whiteness is a discourse that focuses on the racialised ‘other’, white becomes a category by default. He states that: ‘whiteness is defined through boundaries and exclusion, by being “not of colour”’ (Doane 2003: 8-9). Academic deMello Patterson (1998: 104) argues that Whiteness can be defined by several ideological features including capitalistic society structure, faith in science and progress, family and societal group structures based on

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43 This is illustrated by the following two examples: ‘A unique research collaboration between an extended Bay of Plenty Maori whanau and biomedical scientists in Dunedin into an inherited type of stomach cancer has just been awarded $931,171 in further funding over three years by the Health Research Council’ (Kokiri Paetae February 1998: 6); ‘A unique research partnership between a Maori whanau and University of Otago scientists has identified a world first – a gene for stomach cancer susceptibility’ (Te Maori 14 April 1998: 3).

44 Derek Fox, the creator of Mana Maori Media, a specifically Maori media organization, has stated that ‘Pakeha journalists are generally not aware that in their work they are drawing on their own cultural perspective, since they assume it is universal’ (Fox 1993: 136 cited in Abel 1997: 24).

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the ideology of capitalism (individualism, competition) and 'belief in Eurocentric cultural, philosophical, and economic superiority'.

In other words, Whiteness refers to ways of living that were developed from Western European colonialism (ibid.), and this resonates with the aforementioned conclusion of Rankine and McCreanor (in press: 21), that the media coverage of the identification of the gene for hereditary stomach cancer is 'Colonial Coverage' in that 'It weakens voices that assert an active and positive role for Maori'. Moreover, the construction of the helpful and heroic Pakeha scientists in contrast to the 'problem' Maori whanau appears as both natural and unchangeable (ibid.).

Elaborating on this, Rankine and McCreanor (in press) note that the labour undertaken by Maori in the partnership such as their initiative, research, collaboration and management were considered incompatible with Pakeha 'commonsense'. They assert that this incompatibility was managed by writing Maori out of stories in order to restore the expectation that 'it will be Pakeha excellence and competence in knowledge creation that solves the problem' (Rankine and McCreanor in press: 18). This highlights how, when hereditary stomach cancer is experienced by Maori in a New Zealand historical context, even further cultural shaping occurs.

They also concede that in various yet subtle ways, (such as names, institutional affiliations, photographs and the absence of cultural markers), the conclusion was made that the medical scientists involved were Pakeha. Drawing on the work of Barthes (1973) and his notion of 'exnomination', they elucidate this point. This term refers to the process of identifying the margins in order to naturalise the centre. Barthes cited this as a central way in which dominance (as a social relation) is reproduced (Rankine and McCreanor in press: 16). Rankine and McCreanor argue that in the media accounts, this notion relegates science and medicine as part of the modern (Pakeha) world rather than something belonging to Maori, who are pushed to the periphery as outsiders (ibid.). This point is illustrated by the following example: 'Mr Peters said the project represented a partnership between modern science and traditional Maori culture' (The Dominion 11 Dec. 1997 Ed. 2: 11).
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Resistance to Labelling

Unsurprisingly then, apparent in several of the media accounts is a resistance to labelling on the part of the whanau in order to counter the subtle ways in which they were negatively portrayed as ‘sick, passive and subordinate to Pakeha expertise’ (Rankine and McCreanor in press: 19). The following examples illustrate how the whanau were portrayed as such: ‘A whanau’s cry for help points New Zealand scientists to a world first’ (Perry 26 March 1998b: A1), and:

The project involved a research partnership between the university scientists and a Bay of Plenty extended Maori family group, which suffers from a high rate of aggressive inherited gastric cancer (Gibb 26 March 1998: 1).

Rankine and McCreanor (in press: 14) note that such statements stigmatise the family ‘portraying the disease as a characteristic of the whanau (and therefore perhaps Maori in general), rather than something that happens to some members’. They also note that out of the twenty three stories they examined, only three mentioned positive characteristics in relation to the whanau (such as bravery, courage and optimism) (ibid.). Thus, there is a compounding of the passivity of the cancer victims with the smaller degree of agency associated with non-whites.

In addition, many of the accounts marginalise the central role the whanau played in the project by either downplaying their role, or not mentioning it at all, despite the fact that their part was of crucial importance, especially in terms of initiating and directing the research. Although I found many examples to back this claim, I will mention only the most evident: ‘A team of seven researchers led by Dr Parry Guilford made headlines two years ago when they discovered the gene which leads to inherited stomach cancer’ (Otago School of Medical Sciences n.d.), and ‘Research assistance came from a nurse, Maybelle McLeod, from the Kimihauora Health Clinic at Mount Maunganui, and other helpers in the area’ (Gibb 26 March 1998: 1). In relation to this latter example, Rankine and McCreanor assert that ‘The term “nurse” in this medicalised context is a hierarchical marker of occupation that reinforces the subordinate role implied in “research assistance” for Maybelle McLeod’ (in press: 17). These authors also note that the majority of stories they looked at construct the scientists as active and competent, while the whanau is positioned as passive,
diseased, and dependent on the scientists. Over half of the stories did not mention the fact that the whanau compiled the (very large) whakapapa, or genealogy (ibid.: 13-14).

This is particularly disconcerting in that Rankine and McCreanor (in press), after consulting a Health Research Council press release, were aware of the agency of the whanau in terms of initiating, directing, contributing to and applying the findings of the research. Their discursive analysis of the media coverage is therefore revealing in that this coverage:

...elects to tell the story as if Maori were involved as victims of a terrible disease rather than innovative participants in developing the understanding of and responses to inherited stomach cancer (Rankine and McCreanor in press: 19).

These comments resonate with an assertion made by Abel (1997), who noted that generally, news values are embedded within organisational constraints and routines to 'produce ideological effects which disadvantage Maori ideas and values' (1997: 26-27).

The most outstanding statement (see Table 3 for others) from the whanau in terms of resistance to labelling present in the media came from one involved whanau member, who stated that: 'We are future-looking people who do not dwell on the past. We faced the problem and didn't just sit down and wait for someone else to take the initiative' (Perry 26 March 1998a: A3). Other examples featured in the documentary Gene Hunters (video recording 1998), in which the narrator, Janet McIntyre, introduced it by emphasising the whanau's role in initiating and directing the project.45 This allows the whanau a degree of agency they were not granted in many of the other media accounts, and this portrayal is more accurate in terms of portraying the labour undertaken by some whanau members and the medical research team.

45 McIntyre (Gene Hunters video recording 1998) stated that:
When NZ scientists discovered the gene that causes stomach cancer earlier this year, the international scientific community cheered...What you didn't hear was how the breakthrough came about – how it was triggered by the largest family group in the world afflicted by this cancer. That Mt. Maunganui family was determined to find out why they'd been singled out by this pitiless disease, and as you will see, there were good reasons for their motivation.

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Chapter Three

The Construction of Technoscience and Biomedicine in Popular Culture

**Tradition and Modernity**

Another theme to emerge from the undertaking of my own discursive analysis of media accounts of the identification of the gene for hereditary stomach cancer is the cultural dichotomy between representations of Maori (traditional) and technoscience (modern). The assumption implicit in this is that all Maori people, because they are an indigenous population, are averse to modernity, especially in the areas of biomedicine and medical science. One consequence of this representation is that it serves to widen the perceived gap between modern technoscience and traditional Maori culture such as the previously mentioned quote from Mr Peters (*The Dominion 11 Dec. 1997 Ed. 2: 11*). Comments such as this imply that ‘traditional’ Maori culture is hostile to, and separate from, modern technoscience, which is a misleading and simplistic claim, especially considering that ‘modern science’ is based on its own traditions, as considered in the previous chapter in relation to the notion that science is multicultural.

In addition, the notion of the curse is mentioned in many of the accounts, and this has several negative consequences for the way in which the whanau is portrayed. In some articles, it is implied that there was a firm belief in the curse, and this was the main reason for the whanau not requesting a scientific explanation, or that it was widely believed as the cause of the disease. Examples of this include: ‘A Mt Maunganui family is praying that research soon to be extended to other parts of New Zealand will help lift a lethal curse that has ravaged its members for generations’ (*The Dominion 11 Dec. 1997 Ed. 2: 11*); ‘After losing 25 of its members to stomach cancer in 30 years, a Maori family put aside traditional superstitions and contacted laboratories throughout New Zealand to obtain a scientific explanation’ (Senior 1998: 276); ‘A family cursed? That was the Maori belief for many years, that a maketu had been put on the whanau. But this “curse” they would be told in 1997, had a scientific reason’ (Coddington 2001: 77). These statements also serve to further reinforce the construction that the whanau and traditional Maori culture generally, is hostile to modern technoscience, thereby enhancing this dichotomy.
However, the fact that one whanau member stated that the belief of the curse did not come, for the most part, from the whanau highlights how the media exaggerated the significance of the curse in order to create a ‘good story’. Thus, this member stated that this belief was ‘mostly promoted by people outside the whanau, that a makutu or Maori curse was responsible for the deaths’ (The Dominion 11 Dec. 1997 Ed. 2: 11). Significantly, all those I interviewed reiterated that the notion of the curse was simplified, exaggerated, and overemphasised in the media, becoming a means to make ‘good press’ and portray the whanau in a negative light. For instance, the whanau health workers whom I interviewed said the curse was a ‘misconception’, and the scientists also noted that they tried to downplay the curse as it was exaggerated and taken out of context in order to make the media accounts more interesting to the detriment of the whanau. (This will as discussed in more detail in chapter five).

Moral Qualities of Technoscience and Biomedicine

Another issue apparent in the accounts I analysed was the unanimously positive portrayal of technoscience and biomedicine, especially in relation to the moral qualities of these institutions. Before embarking on this discussion, it is important to consider a comment made by Kleinman (1995: 23), who notes that: ‘There is...no essential medicine. No medicine that is independent of historical context’. This helps to locate biomedicine as just one of many health systems, and opens it to criticism. Another healing system, for instance, is that of ethnomedicine and anthropologist Mark Nichter (1992) notes that while this healing system is negatively presumed to be complacent and irrational, biomedicine is, in contrast, portrayed as ‘logical and self-correcting through the deployment of standardized, replicable procedures which test for the falsification of hypotheses’ (ibid.: xii).

Although biomedicine is generally privileged in Western society and the mainstream media, this medical system is deeply flawed in that it takes a disembodied approach to illness and healing. However, in consideration of my own findings, sociologist Alan

46 Ethnomedicine is:
...the study of how well-being and suffering are experienced bodily as well as socially, the multivocality of somatic communication, and processes of healing as they are contextualised and directed toward the person, household, community and state, land and cosmos (Nichter 1992: x).
Petersen (2001), in his investigation of how the newsprint media ‘frames’ stories on genetics and medicine in articles appearing in several Australian newspapers in the late 1990s, stated that: ‘Gene stories were found to be prominent in each of the newspapers, and to emphasise the medical benefits of genetic research’ (2001: 1255). I also found that such positive portrayals of biomedicine were especially apparent in the ‘human-interest’ story.\(^47\) Such stories emphasise the personal experience and suffering of the individual. One example of this is an article titled ‘Errant gene cut family members down’, subtitled ‘Wondering each day who would be next was the hardest part’, whose lead sentence is: ‘Everyday of his adult life, Rangi McLeod felt like a soldier going into battle’ (Knight and Perry 23-24 May 1998: A3). Such portrayals serve to bolster the positive effects of science and medicine as they are seen as the sole mechanisms for the alleviation of suffering.

A further point to note is that in none of the accounts I analysed, is there any mention of the negative aspects of monitoring, surveillance and medical intervention generally. This is interesting in that the tendency in biomedicine to reduce persons to objects through these means is dehumanising (Kleinman 1995: 31). However, this is not surprising considering the relatively uncritical relationship between the media and the institutions of biomedicine and medical science (as will be discussed in more detail in the following chapter). Biomedicine is therefore privileged and taken for granted as the only possible system of healing. Practices such as endoscopy and surveillance programmes are hailed as being life saving, or having great preventative power,\(^48\) and many of the accounts frame monitoring as a privilege. For example: ‘Christchurch oncologist Bridget Robinson said the discovery was “really exciting”. It would allow people with familial risk of stomach cancer to be monitored through screening’ (The Christchurch Press 27 March 1998: 9); this example brings to mind a comment made by Rankine and McCreanor (in press: 17) who state that in much of the media coverage, the whanau are seen ‘only as passive targets of the genetic screening programme’, and is also exemplified by this statement: ‘Dr Guilford said Otago

\(^{47}\) These particular types of stories are ‘a powerful way of both universalising and personalising human experience, which is portrayed as beyond the reach of social, political and economic factors’ (Karpf 1988: 101 cited in Petersen 2001: 1259).

\(^{48}\) References to screening through a simple blood test, monitoring through endoscopy, and/or general surveillance are mentioned in 14 of the accounts I analysed.

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researchers had already developed genetic blood tests which could be used to screen members of the three Maori families involved in the study' (Gibb 26 March 1998: 1). I will consider the social complexities of this kind of genetic testing in the following chapter.

Another associated pattern to emerge from the texts I analysed was the altruistic construction of scientists in relation to the whanau. Notably, the leader of the team of geneticists, Dr Guilford, is always portrayed as the person responsible for most of the ground-breaking work, and as being solely responsible for saving lives: 'With a one in three billion chance of success, gene research scientist, Parry Guilford, has identified the mutant gene – saving the lives of thousands of people' (Cancer Gene n.d.). The same account also stated that: 'The lives of thousands of people will be saved because of the co-operation of Hira's whanau and Parry Guilford's amazing discovery' (ibid.). Here there is a notable contrast in which the whanau are noted for their co-operation, while Guilford is credited for his 'amazing discovery'. This serves to reinforce other media portrayals of the whanau as passive and needy. Moreover, it is apt that in this context, it is a scientist who is focused upon as, as previously mentioned, the media has a relatively uncritical relationship with the institutions of technoscience and biomedicine.49

In conjunction, Rankine and McCreanor note that in the articles they studied, the scientists are attributed with 'active, controlled, expert actions – the descriptors of the scientists' agency and purpose are unequivocal' (in press: 11). Such descriptors included: the scientists 'identified' a gene, 'developed a test', 'saved lives worldwide', studied the whanau, tackled the cancer, 'monitored', 'patented' and 'achieved' (ibid.). In contrast, they note that references to the whanau are more 'mixed', and that the current affairs story (Gene Hunters video recording 1998) was the only one that mentioned that the whanau recruited the scientists after 'rigorous scrutiny', that they wanted control over the process, that a group of women from the

49 This observation echoes the work of other scholars who have argued that 'Newspapers rely heavily on geneticists' own discourse about their practice and tend to neglect uncertainties in scientific knowledge and the social context of science and practice' (Cunningham-Burley, Kerr, and Amos 1998: 20-22, cited in Petersen 1999: 164).
whanau 'footslogged' through cemeteries, constructed a whakapapa, convinced members to give DNA samples, and compiled a database (Rankine and McCreanor in press: 11). Such contrasts in the portrayals of the same event highlight how popular culture accounts of genetic testing generally, and this case specifically, are culturally constructed to reflect certain values, emphasising the importance of considering discourses.

Metaphors in Technoscience, Biomedicine and Popular Culture

In undertaking discourse analysis I also considered how the body, disease and genetics are portrayed in the popular culture accounts of the case study. The findings reinforce the fact that representations of these physical entities are culturally shaped beyond biology. For example, discourse analysis revealed that it is common to use masculine and militaristic metaphors in technoscientific and biomedical discourse, as well as popular culture. The rest of this chapter, then, will focus on the role of metaphor in these discourses because the use of metaphor is a central way in which they are constructed. It is also appropriate to discuss at length the role of metaphor here because of the great deal of literature written on this topic.

My findings parallel those of Flannery (2001: 628) who, coming from a feminist standpoint, argues that metaphors used to describe technoscience and its processes are overwhelmingly masculine. Petersen (1999: 169) has also asserted that metaphors in technoscience are masculine, noting that science is often represented as a quest to find the gene. This is reinforced by the common use of hunting and sporting metaphors to describe the work of the researchers or the processes of research. Examples that illustrate this point are the titles of two accounts of this particular case study: Gene Hunters (video recording 1998), and The Gene Seekers (O'Brien 2001).50 These examples demonstrate that scientific and biomedical discourse filters through into popular culture, which uncritically appropriates and proliferates such constructions. This is compounded by the fact that the family involved is indigenous, therefore conjuring images and connotations of tribalism, primitivism and depicting a sort of

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50 Refer to Table 5 at the end of this chapter for more examples of this particular theme.
hunter-gatherer organisation. Another noteworthy example is the following headline, which states that ‘Cancer find “like scaling Everest”’, followed by a comment by an involved professor who stated that: “It was like scaling Everest for the first time” (26 March 1998a: A3). This comment is masculine in tone in that it resonates with the idea of discovery, of conquering nature and the unknown; it also plays on the idea of a major discovery in a linear and progressive fashion (i.e. climbing a mountain). It is an appropriate metaphor in New Zealand society as it refers to Sir Edmund Hilary’s victory of ‘conquering’ Mount Everest (which is generally not understood to be the achievement of Tenzing Norgay).

In terms of war and military imagery (see Table 6) in the accounts I analysed, I will mention only the most obvious and notable examples: [Whanau member] “It’s similar to going to war, not knowing if they were going to die or when a bullet’s going to hit them. We all felt the same fear” (Knight and Perry 23-24 May 1998: A3). While this particular quote was from the affected person, the reporter chose to select and emphasise it, placing it at the beginning of the article. This phrase is an obvious metaphor of going to war, and is reinforced by the accompanying photo of three female members of the McLeod whanau standing, looking into the distance. However, this metaphor is interesting in that the person using it is provided with a way of articulating what the illness experience is like, a way of communicating both the fear of being surrounded by illness and a sense of foreboding as one is fearful and uncertain of the future. Therefore, there are positive aspects of using militant metaphors in communication about disease. 51

Other negative examples include: ‘A $330,000 marae-based clinic to fight a cancer-causing gene has opened near Te Maunga’ (New Zealand Herald 17 March 2001 online), and ‘Researchers battle family curse’ (The Dominion 11 Dec. 1997 Ed. 2: 11). It is evident then that cancer is perceived as something to be feared and fought. Both

51 It is important to bear in mind that the experience of cancer can be like this, and it is not surprising that such metaphors are frequently used in relation to this disease. One possible reason for this is that it speaks to the overwhelming sense of actual attack that we might feel. Therefore, it is important to point out that such views of the body can often have a positive effect on those who are ill. As Arthur Frank (1995: 105) states: ‘Where life can be given narrative order, chaos is already at bay’. Thus, war imagery is a way of giving narrative as well as physical order to life in the face of disease.

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of these examples illustrate that masculine thinking is entrenched and naturalised in contemporary popular culture in relation to technoscientific and biomedical discourse. Moreover, such use of language suggests that the audiences of these newspapers are familiar with this kind of language, and that not only is it accepted, but also expected. One scientist I interviewed was also critical of this language for the way in which it negatively portrayed and misconstrued the processes and effects of cancer, and I will discuss this later in the thesis.

In considering representations of the effect of cancer on the whanau, then, it becomes apparent that language imbued with references to violence and war are pervasive in the media accounts. In conjunction with this, the whanau are portrayed as passive victims of this disease. The following phrase illustrates this point: 'The family...had been plagued by stomach cancer' (Perry 26 March 1998b: A1), and the following statement goes further by conjuring images of uncontrollable destruction, as is sometimes the case with news reports of tornadoes and hurricanes: 'The disease has ravaged generations of the McLeod family...' (New Zealand Press Association 28 Oct. 1999 online). The effects of cancer are thus portrayed as having a violent and forceful effect on those who have it, both physically and emotionally.

George Annas (1995: 745), an academic of public health, has noted how medical metaphors draw on military images for their substance. He draws on the practice and financing of medicine in the United States, asserting that: 'Military thinking concentrates on the physical, sees control as central, and encourages the expenditure of massive resources to achieve dominance' (ibid.). More specifically, he asserts that this thinking encourages viewing the human body as a battlefield, which is perceived as appropriate by many male physicians, who, until recently served in the American military (ibid.). Despite the fact that the notion of the body as battlefield has come under criticism from many critics of scientific and biomedical discourse, this metaphor is still apparent in these discourses.52 One key reason for its prevalence is

52 Scientist Scott Montgomery (1991: 347), for example, concedes that in Western culture, the reigning image-system for all diseases is war as the language of militarism represents its users as an occupied people.
that fact that military metaphors have historically played an important role in technoscience and biomedicine, as discussed by Sontag (1978).

The Cultural Construction of Cancer and the Body

It is evident, then, that there is cultural labour involved in the use of metaphor to describe science which we often tap into unthinkingly and uncritically. Concerning cancer specifically, Sontag (1978: 61) asserts that cancer is the metaphorical barbarian within. The dominant metaphors used to describe cancer are drawn from the language of warfare, highlighting how cancer is constructed beyond biology in the West, and this was the case in my own discourse analysis of the popular culture accounts of the identification of the gene for hereditary stomach cancer. Both physicians and patients, argues Sontag, are familiar with such military terminology. So, rather than perceiving cancer cells as simply ‘multiplying’, they are considered ‘invasive’. Cancer cells, then, are seen to ‘colonise’ from the original tumour to other sites in the body, and the body’s ‘defences’ are not strong enough to destroy a tumour that consists of countless destructive cells (ibid. 1978: 64). However, Sontag’s work has been criticised for her assertion that diseases should be relieved of metaphorical associations. This is paradoxical in that she was one of the first critics to argue that disease becomes meaningful through using metaphor (Lupton 1994: 57-58).

In accordance, war imagery is especially prevalent in portrayals of the physical dynamics of cancer. Such portrayals connote violence as power dynamics between cells victimise the body as the variations and processes of cancer are constructed as both invasive and aggressive. The following examples (see Table 6 for others) from one article about the identification of the gene for hereditary stomach cancer illustrate this point: ‘suppress cell invasion’, ‘the E-cadherin was mutating, leading to

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53 Sontag (1978) argued that the military metaphor in medicine became both pervasive and popular in the 1880s as a result of the identification of bacteria as ‘agents of disease’ (1978: 65-66), and the bacteria was understood to ‘invade’ and ‘infiltrate’. However, she also states that the use of war imagery to describe disease, especially cancer, is now strikingly literal and authoritative as medical treatment is overwhelmingly described this way (ibid.). Sontag elaborates on the origins of military metaphors in technoscience and biomedicine, claiming in a later work that it was when the ‘invader’ was perceived as the micro-organism that causes the illness (rather than the illness itself) that medicine became particularly effective, resulting in the credibility and precision of military metaphors (ibid. 1990: 97).

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extremely aggressive forms of tumour...’ (Perry 26 March 1998a: A3). This brings our attention to the fact that how we understand cancer is culturally shaped.

Breast cancer specialist Musa Mayer (1998) argues that common metaphors of cancer can contribute to the stigma associated with the disease. For example, when cancer treatment fails or is particularly harsh, biomedicine’s mechanistic view of the body as a fixable machine lead easily to the use of metaphors of war whereby disease becomes the invader that must be counter-attacked by biomedical treatments. Mayer concedes that ‘Warlike imagery plays a role in eliciting fear when cancer is conceived of as an invincible enemy, mindlessly mowing down victims in its path’ (Mayer 1998 online: para. 6). So, the way in which cancer is constructed can have very real consequences for those who live with it.

The use of the term ‘mutant’ in reference to the defective gene E-cadherin which causes familial gastric cancer (see Table 5 for notable examples) also has negative connotations and illustrates how, in the West, cancer is constructed beyond biology and associated with the genre of science fiction. The use of this term in this context ensures that cancer is portrayed as unnatural, out of control and ceaselessly threatening. The great majority of articles I studied mentioned that the gene is ‘mutant’, for example: ‘Seven out of ten people with the mutant gene are expected to develop cancer’ (New Zealand Herald 17 March 2001 online), ‘The Maori family has lost at least 30 members in 30 years to gastric cancer because of a mutant gene passed on by an ancestor’ (The Dominion 11 Dec. 1997 Ed. 2: 11). Journalist Jenny Rankine has made a crucial point in relation to this case. She stated that:

In scientific terms, mutation simply means a change, but its lay associations of deformity, freakishness and serious innate disease contributed to the media construction of the whanau as diseased. This is something scientists don’t realise, I think, and contributes to problems with media coverage of genetic issues more generally (Rankine, J. 2003, Pers. Comm. 14 May).
Sontag (1978: 68) also notes that cancer is considered as 'the disease of the Other', and in science fiction, 54 'mutant' cells are seen as an invasion of 'alien' cells, which are considered stronger than normal cells. Thus, the process of cancer has affinities with the standard science fiction plot of mutation. This theme is usually expressed either by mutants arriving from outer space or by accidental mutations occurring among humans. Cancer, then, can be described as a victorious mutation, as mutation has become a central image for cancer (Sontag 1978: 68). Thus, it is apparent that one prominent way in which we understand cancer in the West is by associating the physical process with particular elements of science fiction: the unknown, the undesirable and the uncontrollable.

The body has also been likened to a machine, especially in the field of genetics. I found this to be the case, particularly in reference to DNA, as the following statement from one article illustrates: 'They plan to reverse the existing mutation using the cells' inherent DNA repair machinery' (Senior 1998: 276). This phrase resonates with the notion of the body, and its workings as a machine, and portrays processes associated with DNA as a kind of industrial factory – it’s repairing is seen as automatic, immediate, and technical. In addition, Nelkin and Tancredi (1989) have argued that the metaphor of body as machine has shaped how diagnostic tests are interpreted, and how their results are employed; and while metaphors of the body have changed through time and in response to technoscientific and medical developments, they have always reinforced the notion of the body as a mechanical system, highlighting how the body is culturally shaped. 55

**Metaphor As Strategy**

Having established that metaphors which exist in technoscience, biomedicine and popular culture are culturally constructed, notably as masculine and militant as well as

54 Here Sontag (1978: 68) is referring to such science fiction films as *Invasion of the Body Snatchers*, *The Incredible Shrinking Man*, *The Blob*, and *The Thing*.

55 For example, Nelkin and Tancredi (1989: 15) cite the developments in the area of organ transplantation during the 1960s, which projected an image of the body as a set of replaceable parts. Earlier, in the 1930s, another metaphor emerged whereby antibiotic medications created the representation of the body as a chemical system. They (1989: 15-16) suggest that this metaphor became increasingly apparent and pervasive as advances in molecular biology in the 1960s and 1970s, as well as the chemical basis of cellular activity became illuminated.
in terms of science fiction, I will now briefly consider the strategic use of such metaphors in the communication of science in order to further elucidate how representations of disease, the gene and the body are culturally constructed.

Petersen (2001) offers a compelling argument on the strategic role of metaphor in newsprint stories about genetics. He states that scientists have 'employed particular metaphors and rhetorical strategies to help convey complex ideas to a broad lay public and to communicate the excitement and the benefits of their work' (Petersen 2001: 1257). He concedes that while genetic researchers and the professional journals that publish their work strive to promote research as objective and value-free, scientific descriptions depend on metaphors and other imagery that circulate in the broader culture and also mirror social biases (ibid.). For example, Petersen observes that the use of military metaphors help to convey the significance of the research for the development and advancement of new preventive techniques, drugs or therapies. In articles that use this technique, it is also apparent that researchers appear heroic as defenders and guardians of the public’s health (ibid.: 1264).

In addition, as sociologist Deborah Lupton (1994) notes, both the linguistic and visual representations of medicine, illness, disease and the body in popular culture as well as medical and scientific texts, play a significant role in the construction of lay and expert knowledges and experiences of these domains. The metaphors used to describe illness, disease and the body are choices which are telling of deeper social feelings of both the body politic and the corporeal body (Lupton 1994: 78). It is significant, then, that common portrayals and understandings of these phenomena incorporate imagery that has connotations of war, violence and control (ibid.).

It has been argued that the use of metaphor in communication about technoscience is always strategic (Nelkin 1987, Bono 1990, Nelkin 1994, Nelkin and Lindee 1995, Keller 2002, Brown 2003). Therefore, the use of particular metaphors and not others signals that particular values of certain institutions are more prominent than others, and in relation to the identification of the gene for hereditary stomach cancer, metaphors explaining the notion of whakapapa are at best, sparse. Bearing these points in mind, I will now discuss several prominent metaphors of the gene, giving
consideration to their broader cultural meanings in the realms of technoscience and popular culture.

**Cultural Constructions of the Gene**

By examining some of the most prevalent metaphors of the gene\(^{56}\) to exist in contemporary popular culture, I consider how the broader cultural meanings of these metaphors offer a limited and partial understanding of the complex socio-cultural relations embedded in technoscience. The metaphors discussed here are those of the blueprint, the map, and the ‘master molecule’, and are important to consider for the way in which they construct and reify the gene as an entity, at the cost of ignoring complex socio-cultural factors. The broader cultural meanings of the gene therefore offer a limited and partial understanding of the complex socio-cultural relations embedded in technoscience. Contrary to these portrayals is the notion of whakapapa which questions the reductive portrayal of the gene in popular culture, and this holistic concept is considered further in the following discussion.

Condit (1999: 205) notes that the end of the twentieth century saw the emergence of the blueprint metaphor, which, during the 1990s, became the dominant metaphor for genetics. This metaphor was influenced by a refocusing of scientific views and possibilities from the individual genes to the ‘genome’, and consequently, a more holistic perspective was adopted when looking at the complex role of DNA in animals and cells (ibid.: 20). In this new era, the blueprint metaphor represented a more holistic portrayal and was also understood as more materially connected to the environment (ibid.). One role of the blueprint metaphor is that it orchestrated the different parts of the code into a whole and particular text (Condit 1999: 219). However, this portrayal of the gene as a deterministic entity lacks a sense of socio-cultural context, especially when considering other definitions of the gene, such as that put forth by Haraway (1997) in relation to the notion of corporealization, as considered further in the discussion.

\(^{56}\) Considering metaphors of the gene must also necessarily entail considerations of DNA and the genome as generally, these are all the same thing. The genome consists solely of DNA, and the genome contains genes, which are finite pieces of DNA embedded within the genome (Khan, A. 2004, Pers. Comm: 2 March).

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Another metaphor of importance as to how the gene and genome are constructed in the settings of technoscience and popular culture is that of the map. Haraway (1997) argues against the standard view put forward by many geneticists, which argues that their work is simply an objective representation of reality. She reveals the way in which the gene is appropriated and fetishised, noting that for gene fetishists (scientists and geneticists) maps and scientific objects generally are simply objective technical representations which are entrenched in a process of neutral and objective discovery.57 Arguing against this view, Haraway draws on the work of Latour (1987) to emphasize her point. She focuses on the way in which he emphasises the movement of worlds through practices of mapping. Latour concedes that cartography is both a metaphor and technology of central importance to technoscience (Latour 1987: 215-257 cited in Haraway 1997: 163), and this leads Haraway (1997: 163) to assert that ‘Cartography is perhaps the chief tool-metaphor of technoscience’. Nelkin (1994) also notes the importance of the map as a cultural construction in relation to genetics. She asserts that maps represent cultural choices and are, as a form of knowledge, tools of persuasion. She states that: ‘As a curator put it: “Every map is someone’s way of getting you to look at the world in his or her way”’ (Nelkin 1994: 29).

Along with the blueprint and map metaphors, the ‘master molecule’ is another central metaphor apparent in popular discourses about genetics. The discourse surrounding this particular metaphor has encouraged notions of genetic determinism to flourish, especially in the realm of popular culture, as noted by Nelkin and Lindee (1995). Even geneticists have critiqued the notion of the ‘master molecule’; for instance, Richard Lewontin (1992: 48), an internationally renowned geneticist and philosopher of science, states that: ‘Isolating the gene as the “master molecule” is an…unconscious ideological commitment, one that places brains above brawn, mental work as superior to mere physical work, information as higher than action’.

Haraway (1997) also critiques the idea of the gene as ‘master molecule’ by offering a complex definition of the gene which consciously takes into account its place in

57 To illustrate her point, she paraphrases the attitude of denial inherent in corporeal fetishism: Scientific maps could not be fetishes, fetishes are only for perverts and primitives. Scientific people are committed to clarity; they are not fetishists mired in error. My gene map is a non-tropic representation of reality, that is, of genes themselves (Haraway 1997: 137).
socio-cultural relations. She states that: ‘A gene is not a thing, much less a “master molecule” or a self-contained code. Instead, the term gene signifies a node of durable action where many actors, human and nonhuman, meet’ (Haraway 1997: 142). This understanding of the gene highlights its multifaceted and heterogeneous nature, as well as its embedded position within dynamic social and cultural beliefs and practices. Moreover, this understanding of the gene is illustrated throughout this thesis, especially in chapter five where I consider the labour undertaken by the key researchers involved in the stomach cancer gene project.

**Gene Fetishism: Separation of the ‘Natural’ and Cultural**

Considering the broader cultural meanings and metaphors of the gene that exist in popular culture illustrate how the gene has become fetishised, not only in popular culture, but in technoscience as well, highlighting how the gene is culturally shaped. Haraway’s notion of corporealization\(^{58}\) exposes the myths and metaphors of the gene prevalent in both the practice of genetics and the realm of popular culture, and this notion reveals the constructed nature of the gene and frames it less as an object and more as a web of action made up of human and nonhuman actors (Haraway 1997: 142).

Haraway notes the original site for the construction of the gene is the sphere of technoscience, or more specifically, biotechnology. Drawing partially on the work of Freud, who argued that ‘a fetish is an object or part of the body used in achieving libidinal satisfaction’ (Haraway 1997: 144),\(^{59}\) Haraway argues that the dynamics of gene fetishism obscure the sociotechnical relations among humans, and between humans and nonhumans that create two things essential to commodity fetishism: objects and value (ibid.: 147). The notion of corporealization thus renders such entities as ‘natural-technical objects of knowledge and practice’ (ibid.: 141-142),

\(^{58}\) As previously mentioned in chapter one, Haraway (1997: 141-142) defines corporealization as ‘...the interactions of humans and nonhumans in the distributed, heterogeneous work processes of technoscience’.

\(^{59}\) In relation to this point, Haraway states that:

Only half jokingly, I see the molecular biological fetishist to be enthralled by a phallus-substitute, a mere “penis” called the gene, which defends the cowardly subject from the too scary sight of the relentless material-semiotic articulations of biological reality, not to mention sight of the wider horizons leading to the real in technoscience (Haraway 1997: 146).

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highlighting their constructed nature. Considering this point in relation to the stomach cancer gene highlights how it has become fetishised in the realms of technoscience, biomedicine, and the media.

Popular culture (especially the media) often mirrors the ideology of gene fetishism in that it separates the 'natural' from the cultural by focusing on the gene as a physical entity that is both fixed and objective. Petersen (2001) for example, argues that stories about genetics in the newsprint media portray the gene as 'all powerful, reinforcing the view that nature is separate from culture' (ibid.: 1266). This point becomes especially evident when considering that the role of DNA is reified (as the 'blueprint' of life, among other things), at the cost of ignoring socio-cultural factors. This has significant ramifications not only for how we understand genetics and the gene, but how we perceive technoscience generally. For instance, the stomach cancer gene has become a thing-in-itself: as noted in the Introduction of this thesis, the familial gastric cancer is not caused by a 'mutated' gene, but rather, a variation in one particular gene. Standing in contrast to the way in which many metaphors of the gene separate the 'natural' from the cultural are some Maori views of the gene, especially the notion of whakapapa. Interestingly, the Maori notion of whakapapa was not considered in most of the popular culture accounts of the identification of the gene for hereditary stomach, highlighting how discourses are produced to represent certain values and views and not others.

Before discussing the significance of this term in relation to genetics, it is important to place this term in the cultural context of Maori belief, although it should be mentioned here that not all Maori adhere to this worldview, and opinion of how this worldview should be adapted by Maori in contemporary New Zealand society also differs. Ethnologist Percy Smith (1913 cited in Mead 1998: 23) translated teachings of Maori religion, cosmology and history, which made the Maori worldview of creation accessible to a New Zealand European (or Pakeha) audience. From this translation, it

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60 For example, the South Island iwi of Ngai Tahu has been particularly opposed to technologies that interfere with genetics, such as genetic engineering and modification. One member of this iwi, scholar Tim Rochford, has argued (in an article entitled 'D.N.A.: Do Not Alter') that DNA, because it is the physical manifestation of whakapapa, should be regarded as tapu, or sacred, and therefore should not be interfered with (Rochford 2000: 12).

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is understood that the Earth grew out of waters, and this Earth became Papatuanuku (earth mother) who became the wife of Ranginui (sky father). The next creation was minor vegetation, then trees were created to clothe the earth. Reptiles and insects came next, followed by animals and birds, and the creation of the moon, sun and stars. Finally, the first woman and her daughter were created ‘from whom mankind in the world sprung’ (ibid.). Thus, every living being is descended from Papatuanuku and Ranginui (Mead 1998: 23).

Stemming from this are the numerous ways in which Maori describe the human genome. For instance, the term *Iratangata* (the life force of mortals) describes the genome, while the notion of *whakapapa* is used to refer to what is contained in the genome (Independent Biotechnology Advisory Council 2002: 4). This latter notion is fundamental to the Maori view of genetics because it is the physical and spiritual embodiment of their genealogy. The notion of *whakapapa* entails the following elements:

Spiritually, it includes notions of orderliness, sequence, evolution and progress which are ‘embodied in sequence of creation stories, traditions, genealogical succession and tribal histories which trace the lineage of human beings and the development of culture and human institutions (ibid.).

Academic Bevan Tipene-Matua (2000) notes that while the English equivalent of the term *whakapapa* is genealogy, the notion of *whakapapa* differs from its English counterpart in that the traditional Maori worldview holds that *everything* has a *whakapapa*. This notion explains the relationship between people and other living entities, and it is the interference with these relationships that causes concern among many Maori (Tipene-Matua 2000: 100). Similarly, Aroha Mead (1995), who has written widely on issues concerning Maori and the environment, notes that the notion of *whakapapa* differs from the Western tradition of separating the physical from the metaphysical, such as isolating the (physical) human gene from any broader (metaphysical) identity. In contrast, Maori culture promotes the notion that the human genome is the physical embodiment of both the metaphysical and generational *whakapapa*. Mead goes on to assert that *whakapapa* is not something that can be owned. It is inherited from previous generations, and the individual contributes to this
and then passes it on to future generations. Mead (cited in Dixon et al. 1995: 34) therefore asserts that the human gene is both collective and cultural property.

Although the concept of whakapapa has been considered as a template for knowledge, especially in the way the notion of reality is understood as a continuous, unfolding of generative processes, it is seen as being incompatible with most of modern science. However, as Roberts and Wills (1998) argue, the Maori worldview harbours the potential of ‘a more sustainable relationship between humanity and the world that science studies’ (ibid. 1998: 43). They argue that the assimilation into science (especially biology) of notions such as whakapapa and mauri (life principle) would make it impossible to separate issues of science and ethics (ibid.).

Collectively, these views of the gene break open the fetishism apparent in the previously mentioned metaphors as the notion of whakapapa is a more holistic way of describing the human genome – one that stands in stark contrast to conventional (Pakeha) notions. Such Maori views of the gene, especially the spiritual and metaphysical aspects of this definition, make conventional notions of the gene and genome problematic by exposing the fetishism apparent in these more reductionist and physical notions. However, it is important to bear in mind at this point that neither Maori nor Pakeha are monolithic entities, and these views are shared by some members of each group, but not all.

Quilting and Ecology: More Appropriate Metaphors

It is evident, then, that metaphors employed in contemporary scientific and biomedical discourse and portrayed in popular culture are culturally constructed. The metaphors of disease and the body are often reductive, but there are some benefits to such portrayals. While the use of masculine and militant metaphors and imagery to describe scientific inquiry and the body and disease, create a reductive and rigid understanding of these complex areas, understanding disease in military terms can be

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61 Roberts and Wills (1998: 43) state that:

The continuity of relationships and processes that constitute whakapapa carry intrinsic obligations, manifest not only in tribal society as mores of kinship but in the responsibilities of humans to all other living and non-living descendents of Papatuanuku (Roberts and Wills 1998: 43).
helpful to the sufferer as they attempt to regain control over their body and their life. However, due to the many negative aspects of such portrayals, less aggressive and more holistic views of science and medicine have also been theorised.

Flannery (2001: 628), for instance, suggests that a feminist view of technoscience calls for the introduction of new metaphors that are less aggressive and alienating. She argues that the quilting metaphor ‘may assist in the reconstruction of scientific inquiry to be more inclusive, responsive and human’ (ibid.: 642). She notes that most of the metaphors in technoscience have masculine connotations, such as hunting, discovery, penetrating, control over nature, and conquering the unknown. This is damaging she argues, because these ways of acquiring scientific knowledge ‘miss the nuances of context, the subtleties that become apparent through intimate conversation rather than through conquest’ (ibid.: 630-631). Flannery concludes that feminist approaches to science emphasise a more holistic view of this enterprise, taking into account the complexity of nature and exploring the relationships and processes of this domain (ibid.: 639). In addition, Annas (1995: 746) has also opted for a more holistic way of thinking about metaphors in medicine and proposes an alternative to military thinking through the metaphor of ecology, which has connotations of integrity, balance, diversity, sustainability and renewal.

Sontag (1990) has vociferously argued that the prominence of the military metaphor is perilous, and is eager for its demise. This is due to its effects on the social body as she argues that it justifies authoritarian rule and compounds the view that state-sponsored repression is necessary. She also notes that military thinking about the body is dangerous in that ‘It overmobilizes, it overdescribes, and it powerfully contributes to the excommunicating and stigmatising of the ill’ (Sontag 1990: 182).62

62 However, Sontag has been critiqued for this position; for example, Levin (1999: 107) believes that because of her focus on the physical causes of cancer, the hegemony of Cartesian dualism is reinstated. Consequently, disease becomes known to us as solely physical through reductive analyses, of which subjective meanings are absent (ibid.). Levin also argues that Sontag’s reading of cancer does not allow for critical self-reflection as her view seems to claim that cancer is nothing more than a material disease (ibid.).

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This chapter has illustrated how portrayals of the body, genetics and disease (specifically cancer) are culturally constructed in technoscientific and biomedical discourse, as well as in popular culture. This was also the case for the New Zealand accounts of the stomach cancer gene research, and examining these accounts highlighted how they are culturally shaped and politicised to represent material in a particular way that is to the detriment of the whanau. While this signals that discourses matter, it also brings to our attention the tension between considering not only the importance of textual and semiotic representations of cancer and the body, and the meanings that emanate from these, but also the material aspects of the body and disease. This, then, is the subject of the following chapter in relation to the whanau’s experience of medical intervention.
Table 1 Key examples from Media Accounts illustrating the theme Notion of Whiteness

<table>
<thead>
<tr>
<th>The Notion of Whiteness</th>
</tr>
</thead>
<tbody>
<tr>
<td>'A unique research collaboration between an extended Bay of Plenty Maori whanau and Biomedical Scientists in Dunedin into an inherited type of stomach cancer has just been awarded $931,171 in further funding over three years by the Health Research Council' (Kokiri Paetae 1998: 6).</td>
</tr>
<tr>
<td>'This project was driven by a western Bay of Plenty Maori family with a history of gastric cancer stretching back eighty years' (Morning Report 26/3/98).</td>
</tr>
<tr>
<td>'The Maori family has lost at least 30 members in 30 years to gastric cancer because of a mutant gene passed on by an ancestor' (The Dominion 11 Dec. 1997: 11).</td>
</tr>
<tr>
<td>'The research project was initiated in 1994 by a Bay of Plenty Maori family affected by a high rate of an aggressive inherited gastric cancer' (The Dominion 26 March 1998: 7).</td>
</tr>
<tr>
<td>'The disease has ravaged generations of the McLeod family and led to a unique, Government-funded collaboration between the whanau and Otago University scientists to find out why' (NZPA 28 Oct. 1999 online).</td>
</tr>
<tr>
<td>'Scientists at Otago University achieved a world first in identifying the gene E-cadherin as being responsible for stomach cancer in five generations of a Maori family' (The Christchurch Press 27 March 1998: 9).</td>
</tr>
<tr>
<td>'Lives are being saved around the world, thanks to a team of New Zealand doctors who discovered a mutant gene causing stomach cancer in one Maori family' (New Zealand Herald 31 Dec. 1998: A13).</td>
</tr>
<tr>
<td>'The project was instigated by a Maori family of Mt Maunganui who had lost 25 members to the cancer over 25 years' (New Zealand Herald 27 March 1998: A16).</td>
</tr>
<tr>
<td>'And while much fanfare greeted the study's findings, the Maori family which made the discovery possible is staying quietly in the background - at its own request' (Sunday Star Times 5 April 1998: 10).</td>
</tr>
<tr>
<td>'Otago University researchers Dr Parry Guilford and Professor Toney Reeve announced in March they'd discovered the gene mutation after a two-year study involving 121 members of the Maori family' (Sunday Star Times 24 Oct. 1999: 9).</td>
</tr>
<tr>
<td>'After losing 25 of its members to stomach cancer in 30 years, a Maori family put aside traditional belief superstitions and contacted laboratories throughout New Zealand to obtain a scientific explanation' (Senior 1998: 276).</td>
</tr>
<tr>
<td>'A unique research partnership between a Maori whanau and University of Otago scientists has identified a world first' (Te Maori 1998: 3).</td>
</tr>
<tr>
<td>'New Zealand scientists have identified a genetic mutation which makes people prone to stomach cancer. The discovery happened as a result of action by a Maori whanau from the Bay of Plenty' (Rankine 1999: 35).</td>
</tr>
<tr>
<td>'The team of doctors who discovered a mutant gene causing stomach cancer in one Maori family have confirmed their findings with a similar breakthrough among sufferers overseas' (McEneaney 1998: A6).</td>
</tr>
<tr>
<td>'A whanau's cry for help points New Zealand scientists to a world first' (Perry 1998: A1).</td>
</tr>
<tr>
<td>'Gene isolated with help of Maori family' (Perry 1998: A3).</td>
</tr>
</tbody>
</table>
Table 2 Key examples illustrating the theme Tradition and Modernity

<table>
<thead>
<tr>
<th>Tradition and Modernity</th>
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<tbody>
<tr>
<td>'Mr Peters said the project represented a partnership between modern science and traditional Maori culture’ (<em>The Dominion</em> 11 Dec. 1997 Ed. 2: 11).</td>
</tr>
<tr>
<td>'Waiariki MP Mita Ririnui congratulated the whanau for opening their doors to scientists to enable research to being on the disease. Kimi Hauora Trust chairman Petera Ririnui thanked doctors and scientists for showing sensitivity to Maori culture during their involvement' (<em>New Zealand Herald</em> 17 March 2001 online).</td>
</tr>
<tr>
<td>'A family cursed? That was the Maori belief for many years, that a maketu had been put on the whanau. But this &quot;curse&quot;, they would be told in 1997, had a scientific reason' (Coddington 2001: 77).</td>
</tr>
<tr>
<td>'At their Bay of Plenty marae, atop a hill overlooking glorious Papamoa beach and the vast sweep of the Pacific Ocean, a whanau coming to terms with the fact that traditional culture can accommodate genetic modification was just what the good doctor needed' (Coddington 2001: 80).</td>
</tr>
<tr>
<td>'John Fraser was the second family member after Rangi McLeod to undergo a gastrectomy. The success of his operation - a life saved - has vindicated the actions of those whanau who trusted scientific technology, often upsetting others in their family who opposed genetic research' (Coddington 2001: 80).</td>
</tr>
<tr>
<td>'After losing 25 of its members to stomach cancer in 30 years, a Maori family put aside traditional superstitions and contacted laboratories throughout New Zealand to obtain a scientific explanation' (Senior 1998: 276).</td>
</tr>
<tr>
<td>&quot;'Many people from the family started out with quite a high level of suspicion about genetics but they are equal partners in this project and most are now very well educated in the science and the ethical issues involved’&quot; (Senior 1998: 276).</td>
</tr>
<tr>
<td>&quot;'In Maori culture, body parts represent the embodiment of the family tree and so are sacred. The family’s requests were easy to accommodate: we stored all their body samples and DNA in a specially designated area; we agreed never to send samples or DNA overseas; and we promised complete confidentiality,&quot; explains Guilford’ (Senior 1998: 276).</td>
</tr>
</tbody>
</table>

Table 3 Key examples illustrating the theme Resistance to Labelling

<table>
<thead>
<tr>
<th>Resistance to Labelling</th>
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</thead>
<tbody>
<tr>
<td>'Ms McLeod said there had been barriers to the project, including &quot;a belief, mostly promoted by people outside the whanau, that a maketu or Maori curse was responsible for the deaths’’ ( <em>The Dominion</em> 11 Dec. 1997 Ed. 2: 11).</td>
</tr>
<tr>
<td>&quot;'[Maybelle McLeod] We are future-looking people who do not dwell on the past. We faced the problem and didn’t just sit down and wait for someone else to take the initiative’” (Perry 1998: A3).</td>
</tr>
</tbody>
</table>
### Table 4 Key examples illustrating the theme The Moral Qualities of Science and Biomedicine

<table>
<thead>
<tr>
<th>The Moral Qualities of Science and Biomedicine</th>
</tr>
</thead>
<tbody>
<tr>
<td>&quot;Today, family spokeswoman and researcher Maybelle McLeod confirmed that screening since then had uncovered 32 carriers of the mutated gene, and that they would now be monitored for the first signs of stomach cancer. She said the figures were “disturbing” and confirmation of the gene “frightening” for the individuals identified. But it was also exciting to be able to tell people one way or the other and arrange for monitoring aimed at early detection of any cancers that developed” (NZPA 28 Oct. 1999 online).</td>
</tr>
<tr>
<td>&quot;The project will now focus on screening people who have the defective gene, and scientists hope other families, who have a high rate of stomach cancer will also come forward” (Morning Report 26 March 1998).</td>
</tr>
<tr>
<td>&quot;Now the family could be blood-tested for the gene and if they tested positive then close monitoring, including annual endoscopies, meant the disease could be detected before it became terminal” (Coddington 2001: 80).</td>
</tr>
<tr>
<td>&quot;‘We have now screened 55 people in the whanau and have identified some family members who have the mutant gene. They will now be regularly monitored for warning signs and in 90 per cent of cases we think we can prevent them getting the stomach cancer’” (New Zealand Herald 31 Dec. 1998: A13).</td>
</tr>
<tr>
<td>&quot;Sometimes the excitement in a scientist’s eyes is easy to share. Yesterday was one of those times. The scientist, eyes wide with triumph in the photograph on our front page, was Dr Parry Guilford of the genetics laboratory of Otago University. He and his colleagues had isolated a gene that, when mutated, causes cancer of the stomach. The discovery opens a door that could save many thousands of people every year and, who knows, could lead to that elusive cure’ (New Zealand Herald 27 March 1998: A16).</td>
</tr>
<tr>
<td>&quot;With the knowledge so gained, the researchers can identify the cancer gene with a simple blood test and people found to harbour it can be monitored and treated if necessary, in good time’ (New Zealand Herald 27 March 1998: A16).</td>
</tr>
<tr>
<td>&quot;The scientists also developed a simple blood test which identifies the gene and so far 80 family members have been tested. Those with the gene have 70% risk of getting stomach cancer. Guilford said those with the mutation had been enrolled on a clinical surveillance programme to watch their conditions. [Guilford] “That will ensure we pick up any tumour development. The sooner we catch it, the better chance we have of successful treatment”’ (Alexander 24 Oct. 1999: 9).</td>
</tr>
<tr>
<td>&quot;In the short term, family members are being offered clinical surveillance every six months. If the cancer is caught early, before it spreads to other tissues, the prognosis is better. The next step is to look at ways to delay the onset of cancer in mutation carriers’ (Senior 1998: 276).</td>
</tr>
<tr>
<td>&quot;Identification of the gene enables the cancer to be detected early, and greatly improves treatment options’ (Te Maori 1998: 3).</td>
</tr>
<tr>
<td>&quot;People with the gene are having six-monthly surveillance endoscopies at Tauranga Hospital. Early this year these people also started to attend regular clinics at the marae for other tests. This monitoring enables the cancer to be detected early, and greatly improves treatment options and the survival rate of whanau members’ (Rankine 1999: 37).</td>
</tr>
<tr>
<td>&quot;The whanau are now being individually screened to identify who is at risk, using a simple blood test researchers developed...The project manager, nurse Maybelle McLeod, said whanau members were now desperate to be screened because the fear of the “unknown killer” had been removed’ (McEneaney 5 Nov. 1998: A6).</td>
</tr>
<tr>
<td>&quot;The lives of thousands of people will be saved because of the co-operation of Hira’s whanau and Parry Guilford’s amazing discovery’ (nzoom.com n.d. online).</td>
</tr>
</tbody>
</table>

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Table 5 Key examples of how the Body, Disease and Genetics are portrayed in my analysis

<table>
<thead>
<tr>
<th>How the Body, Disease and Genetics are Portrayed in my analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gene Hunters</strong> (video recording 1998).</td>
</tr>
<tr>
<td>‘Seven out of ten people with the mutant gene are expected to develop cancer’ (<em>New Zealand Herald</em> 17 March 2001 online).</td>
</tr>
<tr>
<td>‘They have identified genetic mutations in the E-cadherin gene in the 16th human chromosome, which predisposes some people to develop stomach cancer’ (<em>The Evening Post</em> 26 March 1998 Ed. 3: 2).</td>
</tr>
<tr>
<td>‘Their project involved a unique research partnership between the university scientists and a Bay of Plenty whanau, which has a high rate of aggressive, inherited cancer’ (<em>The Evening Post</em> 26 March 1998 Ed. 3: 2).</td>
</tr>
<tr>
<td>‘New Zealand scientists have identified a genetic mutation which makes people prone to stomach cancer’ (Rankine 1999: 35).</td>
</tr>
<tr>
<td>‘They had expected the gene hunt to take five years but it took only 18 months’ (Rankine 1999: 36).</td>
</tr>
<tr>
<td>‘The Bay of Plenty whanau, which is affected by a high rate of an aggressive inherited gastric cancer, initiated the research project in 1994’ (<em>Te Maori</em> 14 April 1998: 3).</td>
</tr>
<tr>
<td>‘They plan to reverse the existing mutation using the cells’ inherent DNA repair machinery’ (Senior 1998: 276).</td>
</tr>
<tr>
<td>‘Thirty-two members of a Mt Maunganui family have been diagnosed with the gene mutation which causes stomach cancer, a disease which has already killed at least 25 of their relatives’ (Alexander 24 October 1999: 9).</td>
</tr>
<tr>
<td>‘By comparing each person’s DNA, they identified a single gene, named E-cadherin, mutating, leading to aggressive forms of tumours’ (Alexander 24 October 1999: 9).</td>
</tr>
<tr>
<td>‘The research project was initiated in 1994 by a Bay of Plenty Maori family affected by a high rate of an aggressive inherited gastric cancer’ (<em>The Dominion</em> 26 March 1998: 7).</td>
</tr>
<tr>
<td>‘This suggested there could be an environmental trigger setting it off among the McLeods, such as a bacteria or something specific in their diet,’ said Dr Guilford, of the university’s genetics laboratory’ (<em>New Zealand Herald</em> 31 Dec. 1998: A13).</td>
</tr>
<tr>
<td>‘The project manager, nurse Maybelle McLeod, said that for the whanau the fear of the unknown killer had now been removed’ (<em>New Zealand Herald</em> 31 Dec. 1998: A13).</td>
</tr>
<tr>
<td>‘The Maori family has lost at least 30 members in 30 years to gastric cancer because of a mutant gene passed on by an ancestor’ (<em>The Dominion</em> 11 Dec. 1997 Ed. 2: 11).</td>
</tr>
</tbody>
</table>

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Table 6 Key examples of statements with connotations of War and Violence in my analysis

| Examples War and Violence in my analysis                                                                                                                                 |
| 'By comparing the DNA of each relative they identified a single gene, E-cadherin, which is important to a process called cell adhesion and structure and is thought to suppress cell invasion' (Perry 26 March 1998a: A3). |
| 'E-cadherin is a protein which helps cells stick together and is also thought to stop cancer cells invading healthy tissue' (Rankine 1999: 36). |
| 'The mutations, which can be inherited, inactivate the gene, which is important in cell adhesion and structure and is thought to suppress cancerous cell invasion' (Gibb 26 March 1998: 1). |
| 'The breakthrough came after a Maori family approached the scientists to help to tackle the disease which had claimed 25 of their loved ones in 30 years' (Perry 26 March 1998a: 1). |
| "It means we can put these people on a monitoring programme and tackle the cancer before it gets a hold" (Perry 26 March 1998a: 1). |
| 'The flow-on effect of a company commercialising research like Guilford's discovery of the gastric cancer gene could be hugely beneficial in New Zealand's fight against cancer' (Coddington 2001: 81). |
| 'The disease has ravaged generations of the McLeod family and led to a unique, Government-funded collaboration between the whanau and Otago scientists to find out why' (NZPA 28 Oct. 1999 online). |
| 'Every day of his adult life, Rangi McLeod has felt like a soldier going into battle..."It's similar to going to war, not knowing if they were going to die or when a bullet's going to hit them. We all felt the same fear"' (Perry 26 March 1998a: A3). |
| 'A $330,000 marae-based clinic to fight a cancer-causing gene has opened near Te Maunga' (New Zealand Herald 17 March 2001 online). |
| 'Researchers battle family curse' (The Dominion 11 Dec. 1997 Ed. 2: 11). |
### Table 7 Alphabetical List of Accounts Analysed

<table>
<thead>
<tr>
<th>Source</th>
<th>Date</th>
<th>Title of Account</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Kokiri Paetae</strong></td>
<td>February 1998</td>
<td>Whanau and scientists work together on ground-breaking cancer research project</td>
</tr>
<tr>
<td><strong>Molecular Medicine</strong></td>
<td>1998</td>
<td>Maori family initiates successful search for stomach cancer gene</td>
</tr>
<tr>
<td><strong>Today</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>National Radio</strong></td>
<td>26 March 1998</td>
<td>Morning Report</td>
</tr>
<tr>
<td><strong>New Zealand Herald</strong></td>
<td>26 March 1998</td>
<td>Cancer find 'like scaling Everest'</td>
</tr>
<tr>
<td><strong>New Zealand Herald</strong></td>
<td>26 March 1998</td>
<td>Gene research leads to cancer breakthrough</td>
</tr>
<tr>
<td><strong>New Zealand Herald</strong></td>
<td>27 March 1998</td>
<td>Profits from Science</td>
</tr>
<tr>
<td><strong>New Zealand Herald</strong></td>
<td>23-24 May 1998</td>
<td>Errant gene cut family members down</td>
</tr>
<tr>
<td><strong>New Zealand Herald</strong></td>
<td>5 November 1998</td>
<td>Foreign cases confirm cancer finding</td>
</tr>
<tr>
<td><strong>New Zealand Herald</strong></td>
<td>31 December 1998</td>
<td>Cancer-Gene Link A Saviour Abroad</td>
</tr>
<tr>
<td><strong>New Zealand Herald</strong></td>
<td>17 March 2001</td>
<td>Clinic targeting stomach cancer gene opens</td>
</tr>
<tr>
<td><strong>New Zealand Press Association</strong></td>
<td>28 October 1999</td>
<td>32 Members of Whanau Identified With Cancer Gene</td>
</tr>
<tr>
<td><strong>New Zealand Science Teacher</strong></td>
<td>1999</td>
<td>Partnership acts on inherited stomach cancer</td>
</tr>
<tr>
<td><strong>North and South</strong></td>
<td>December 2001</td>
<td>The Big C: What do we really know?</td>
</tr>
<tr>
<td><strong>Nzoom.com</strong></td>
<td>n.d.</td>
<td>Cancer Gene</td>
</tr>
<tr>
<td><strong>Otago Daily Times</strong></td>
<td>26 March 1998</td>
<td>Cancer Breakthrough</td>
</tr>
<tr>
<td><strong>Otago Graduate</strong></td>
<td>1998</td>
<td>Otago scientists have identified a gene linked to stomach cancer</td>
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<td><strong>Otago School of Medical Sciences</strong></td>
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<td><strong>Sunday Star Times</strong></td>
<td>5 April 1998</td>
<td>Cancer Families Come Forward After Discovery</td>
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<td>24 October 1999</td>
<td>Cancer Gene Afflicts 57 Relatives</td>
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<td><strong>Te Maori</strong></td>
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<td>Maori whanau key major cancer research discovery</td>
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<td><strong>The Christchurch Press</strong></td>
<td>27 March 1998</td>
<td>Cancer Gene 'Excites' Doctors</td>
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<td><strong>The Dominion</strong></td>
<td>11 December 1997, Ed. 2</td>
<td>Researchers battle family 'curse'</td>
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<td>26 March 1998</td>
<td>Stomach Cancer-Causing Gene Identified</td>
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<td>26 March 1998 Ed. 3</td>
<td>Stomach cancer breakthrough for Otago Scientists</td>
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<td>11 August 2001</td>
<td>Cornering Cancer Calls for Cold, Hard Cash</td>
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<td><strong>60 Minutes</strong></td>
<td>24 May 1998</td>
<td><em>Gene Hunters</em> (video recording)</td>
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Chapter Four

Medical Intervention

Janet: Yeah, well we agree that that’s how they describe it, but when they talk to us, or any of our people, they have to put it in lay people’s terms. They have to be down to earth, telling them exactly, none of that medical rubbish. If you’ve got cancer, then that’s what you’ve got. It’s not “carcinoma something something” (field notes 7/10/03).

Allison: Straight up the guts (ibid.).

The previous chapter explored the symbolic, semiotic and textual constructions of the body, disease, and the gene in popular culture as well as in scientific and biomedical discourse, particularly in relation to media accounts of the identification of the E-cadherin stomach cancer gene. This revealed that these representations are culturally constructed as their meanings have significance beyond the boundaries of biology. However, such analysis into the state of the body and disease in these realms is incomplete as the fact that the body is also material and corporeal must be acknowledged.

The opening statements of this chapter made by the whanau health workers I interviewed deserve consideration in that they set the scene for the following discussion on the complexities of medical intervention in relation to this specific case. Their words illustrate that the health workers resist the fetishism apparent in biomedicine by emphasising the importance of communication that makes sense to lay people, without all the trappings of jargon and other symptoms of the fetishism evident in biomedical discourse. The holistic and straightforward approach of the whanau health workers lessens the degree of fetishism as it emphasises the social aspect of the medical encounter. It can thus be argued that their weariness and mistrust of some health professionals previously stems from the tendency in
biomedicine to fetishise the patient through objectifying the disease in a very particular and disembodied way at the cost of obscuring the important social relations and meanings of that disease. The interviews I undertook with these health workers indicate a strong interest from them to avoid such concealment in the practice of science and medicine.

It should also be stated that at this point, what I am talking about are my own musings, and there is a risk in this of abstracting the corporeal aspects of suffering from the health workers' accounts. I therefore do not purport to be speaking for the whanau in considering the importance of the material body. Through my involvement with them and the scientists, as well as the literature I have consulted, I consider how I can make sense of the complexities of my research as well as highlight not only the presence of fetishism in biomedicine, but the ways in which it is perhaps negotiated by the whanau health workers.

The Conundrum

The whanau are happy with the health centre which was erected specifically for their use, and they are satisfied with the surveillance programmes in place to screen for those who have the defective gene and those who have, or are at risk of developing cancer. It struck me that while they were focused on people, they quickly appropriated medical science and its negative aspects, such as its tendency to reduce people to objects and its invasive nature, especially surveillance. While it may appear that the whanau are appropriating biomedicine somewhat uncritically, this is not the case as they do criticise and challenge the way practitioners of this institution go about their work, as discussed in the following chapter. This indicates that they have manipulated biomedicine for what they want, which questions some social science critiques of biomedical practices. This leads to a conundrum, therefore, in how they have presented what they have done, especially in terms of critiquing the way in which practitioners of biomedicine relate to and communicate with people.

It is also important to bear in mind that people suffer and search for meaning of their afflictions, indicating that socio-cultural notions of illness and disease are other crucial factors to consider in the experience and construction of disease. However, the
tendency in biomedicine to treat bodies as simply physical is limited in that it ignores
the notion of suffering which is experienced not only physically, but also, and perhaps
more profoundly, emotionally and socially. Michael Taussig argues (1992) such
suffering is disguised in biomedicine as this ideology objectifies the body and focuses
on the physical and material aspects of suffering at the cost of fetishising the social
relations embedded in biomedical practice.

Bearing these implications in mind, then, the rhetorical question I pose in this chapter
is: why did the whanau want to find the gene? This leads us to other questions such as
why were they so active in their quest, and why do they want genetic testing and
surveillance? The answers to these questions may seem obvious – in short, they are
helping to save lives and alleviate physical suffering. However, when considering the
complexities surrounding the corporeal body and the embodied self, many issues arise
which problematise conventional notions of the body, suffering, and the taken for
granted altruistic nature of the social relations embedded in contemporary
biomedicine.

The Implications of Genetic Testing

In order to explore the complexities of medical intervention and how the whanau
negotiate these, brief consideration must be given to the premises of genetic testing
and why the whanau sought this procedure. I will also consider other physical
procedures involved in alleviation of hereditary stomach cancer, such as endoscopy
and gastrectomy. Genetic testing procedures allow scientists to examine genetic
information contained inside an individual's cells in order to determine if that person
has, or is at risk of developing, a particular disease or could pass a disease to his or
her offspring (Nordenson 1999: 1274). In this particular case, it is hereditary stomach
cancer (or familial gastric cancer), which is a disease where the cells that form the
inner lining of the stomach become abnormal and divide uncontrollably, forming a
tumour (Niendorf 2002: 1097-1098).

Predictive (presymptomatic) genetic testing is used on individuals known to be ‘at
risk’ for a genetic disease because other members of their family are affected. The key
advantage of this type of testing is that the effects of the disorder can be better

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managed if identified early. In relation to hereditary stomach cancer, the introduction of treatment in response to early detection improves the individual’s chance of survival (Clarke 2001: 134). A blood or tissue sample from the individual at risk is necessary for the genetic test in the context of detecting cancer, and if the individual tests positive for the defective gene, molecular probes are used to identify defections in certain genes that have been associated with particular cancers (Cherath 1999: 571). Of those who test positive for the defective E-cadherin gene, not all will develop cancer, although they could be at greater risk of developing cancer compared to an individual who does not posses the defective gene (Niendorf 2002: 1102).63

Those who test positive for the defective gene will undergo surveillance whereby the use of an endoscope shows whether or not the carrier has developed tumours. Presently, endoscope is the most effective and commonly used detection tool available for stomach cancer, allowing a diagnosis in about 95% of cases. In this procedure, the endoscope, which is a thin optical instrument containing a minute camera and light, is put down the throat, allowing the oesophagus, stomach, and upper small intestine to be viewed. If there are any suspicious areas visible, a biopsy is taken. The tissue from these samples is then examined, indicating whether or not it is cancerous (Niendorf 2002: 1102).64

Those who do have stomach cancer can opt for gastrectomy (the only cure for stomach cancer), which is the surgical removal of all or some of the stomach, depending on the severity of the cancer. Most commonly, however, this operation is performed to remove a malignant tumour. After gastrectomy, the digestive tract is reconstructed in order for it to function, and while there are several different surgical techniques, the surgeon generally attaches any remaining parts of the stomach to the small intestine (Helwick 1999: 1247). While endoscopy and gastrectomy are undertaken at a hospital, the whanau have their own health centre which was erected specifically for the purposes of dealing with issues relating to the testing, prevention

63 Seventy percent of those who test positive for this defective gene will develop stomach cancer in their lifetime; currently, there are investigations into why thirty percent of those who carry this gene do not develop stomach cancer (Kimihauora Health Centre 2003 online).
64 While it is a straightforward process, it is laborious, as after the procedure (which takes approximately thirty minutes), the patient is expected to stay in hospital for up to four hours to allow the sedative to wear off (New Zealand Consumer Health Information 2001 online).

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and treatment of stomach cancer. The clinic is ideally positioned on the top of a hill at
the whanau's pa where it sits next to their marae and is surrounded by an avocado
orchard and a plant nursery. It was designed by several members of the whanau, and
its structure mimics that of a marae. The first floor has consultation rooms, a
reception, and a staff room, and the second floor is a boardroom where their trust
meets to discuss issues to do with the clinic, such as finance.

More specifically, the centre has several varied purposes, which include the collection
of samples for genetic testing (which are then sent to the Cancer Genetics Lab at the
University of Otago for testing), and the offering of genetic counselling and advocacy
to those who have tested positive for the gene. In addition, the roles of the staff
include driving those undergoing gastrectomy to the hospital in Auckland where it is
performed and comforting them before and after the surgery, as well as sorting out
financial aid for patients who are unable to work or support their families. One
possible reason why the whanau are content with the testing is because they have a
large degree of control over the procedures and can thus do things on their own terms,
in their own way (albeit within reason).

As discussed in more depth in the following chapter, the manner of the whanau health
workers I spoke to was relaxed and informal – they have little time for tedious
bureaucracy and incomprehensible medical jargon. They are straight-talkers who
emphasise a more holistic and personal connection with the patient than one would
generally expect from a strictly biomedical context. In order to consider the contrasts
and implications from these different approaches, it is necessary to point out that
while I am speaking theoretically, they are not. This is because they are living through
the reality of the implications of hereditary stomach cancer, while I am merely
theorizing the complexities of this.

The dilemma I will now discuss concerns the implications of biomedical intervention.
While biomedicine works to alleviate physical suffering by naming and controlling
(and often curing) disease, it does little to acknowledge the embodied experience of
suffering. The following discussion highlights both the positive and negative aspects
of biomedicine and considers the role of fetishism in this practice. In doing so, I am pursuing my own interests, not those of the whanau health workers.

**Taussig and Biomedical Fetishism**

Although I will consider in depth the implications of medical intervention and the material body further in the discussion, I begin with the work of Taussig (1992) who has revealed the ways in which biomedicine fetishises social relations as disease. He highlights that in biomedicine, the emphasis is on the body and disease and the ‘how’ of disease, while biomedical practitioners cannot offer insight to the social and moral meaning (the ‘why’) of the disease. This is somewhat ironic in that the ‘how’ of disease and disease itself, is socially constructed. His central thesis is that the physical body is fetishised at the cost of obscuring or disguising the social nature of the medical encounter. Taussig states that:

...things such as the signs and symptoms of disease, as much as the technology of healing, are not “things-in-themselves”, are not only biological and physical, but are also signs of social relations disguised as natural things, concealing their roots in human reciprocity (1992: 83).

This premise brings our attention to both the positive and negative aspects of biomedicine as discussed by Taussig. In relation to fetishism, he builds on the aforementioned work of Lukács (1971) and is concerned with the ‘phantom-objectivity of disease and its treatment in our society’ (Taussig 1992: 84). Taussig observes that we mystify human relations embodied in symptoms, signs and therapy which are consequently denied, thereby reproduce a political ideology masked as a science of ‘real things’ – what he terms ‘biological and physical thinghood’ (ibid.). Therefore, the objectivity embedded in biomedicine is culturally constructed, and I will consider this premise in relation to my experiences with the whanau health workers and scientists throughout this chapter.

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65 Lukács said of the kind of reification embedded in fetishism that:

Its basis is ...is that a relation between 'people takes on the character of a thing and thus acquires a 'phantom objectivity,' an autonomy that seems so strictly rational and all-embracing as to conceal every trace of its fundamental nature: the relation between people (1971: 83).

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Taussig (1992: 84) applies these abstract concepts to the material aspects of sickness. He notes that conceptions of the body are fluid and dynamic, changing over time and through cultures. This is echoed by feminist theorist Elizabeth Grosz (1994: x) who also contends that bodies are the products and effects of the social constitution of nature. Historical, social and cultural demands produce 'the body as a body of a determinate type' (ibid.). In contemporary times of modern capitalist culture, the body is considered dualistically: as a thing and a being, or a body and a 'soul' (Taussig 1992: 84). This is especially the case in scientific and medical discourse where the body is considered as a dichotomy of mind and body. This separation of the mind from the body is attributed to French philosopher and mathematician Rene Descartes who, in the seventeenth century, argued that the mind and body worked not in unison, but separately.

The historical construction of Cartesian dualism has been widely criticised in the social sciences and humanities for the way it disembodies the corporeal body. For example, Grosz (1994: 7) states that: 'To reduce either the mind to the body or the body to the mind is to leave their interaction unexplained, explained away, impossible.' Another feminist theorist, Young (1997), expresses a similar view. She notes that in the realm of biomedicine, the body is inscribed into a discourse of objectivity: the self is ignored as the material body becomes the focus of biomedical attention. This disjunction is the core of biomedical discourse: the separation of the mind from the body. Thus, although one experiences one's self as embodied, in the realm of biomedicine, the body becomes an object of scrutiny at the cost of the embodied self (Young 1997: 1). I will consider this premise in relation to the complexities of medical intervention in relation to the case study further in the discussion.

Revisions to the mind/body dichotomy have been made by Grosz (1994: 7) who argues against the notion of dualism which, she notes, 'is responsible for the modern forms of elevation of consciousness (a specifically modern version of the notion of soul, introduced by Descartes) above corporeality'. Cartesian dualism separates the body and mind, and Grosz argues that to reduce either component to the other renders their interaction both unexplained and unexplainable (ibid.). However, this is
somewhat paradoxical in that Cartesian dualism in medicine and science is attributed as elevating the body over the mind. It was this privileging of the body over the mind that allowed biology to pursue the extremely materialist thinking that is characteristic of biomedicine (Schep...201). Schep-Hughes and Lock (ibid.) go on to state that Cartesian dualism 'caused the mind (or soul) to recede to the background of clinical theory and practice for the next three hundred years'.

**An Embodied Approach**

Grosz (1994: x) brings our attention to the way in which the body in the natural sciences has been, and continues to be, colonized through the powerful discursive practices of these disciplines, especially the discourses of biology and medicine. Likewise, Schep-Hughes and Lock (1998: 209) argue that:

A singular premise guiding Western science and clinical medicine (and one, we hasten to add, that is responsible for its awesome efficacy) is its commitment to a fundamental opposition between spirit and matter, mind and body, and (underlying this) real and unreal.

As I will consider throughout this chapter, the whanau health workers mitigate the degree of fetishism in biomedicine, and one reason for this is the Maori belief in whakapapa, as discussed in the previous chapter. This worldview lessens the degree to which the mind and body can be separated as its metaphysical elements link the body to a wider metaphysical identity. Maori culture promotes the notion that the human genome is the physical embodiment of both the metaphysical and generational whakapapa (Mead cited in Dixon et al 1995: 34). The way in which the whanau health workers demanded that their tissue be stored separately and not used for any other purposes other than testing highlights how they are mindful of the mind/body split in biomedicine, and how, under normal circumstances, their tissue would have been treated as a physical entity, separate from the wider context in which the whanau’s beliefs locate it. (This point is discussed in more depth in the following chapter).

Furthermore, Grosz (1994: x) maintains that bodies are the products and effects of the social constitution of nature, and as previously mentioned, historical, social and cultural demands produce and shape the body in a certain way. This points to her assertion that bodies are embodied as she argues against the body as dichotomous –

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that is, in terms of the physical, material body on one hand, and its many cultural and
historical representations on the other. Rather, she claims that such 'representations
and cultural inscriptions quite literally constitute bodies and help to produce them as
such' (ibid.).

Grosz (1994) uses the model of the Möbius strip as a suitable way of
(re)conceptualising the relationship between the mind and body. This model illustrates
the merging and inversion of the mind and body whereby one side becomes another.
This model is thus a useful way of questioning and rethinking the relations between
the exterior (corporeal) and interior (psychical) of a person by illustrating 'the torsion
of the one into the other, the passage, vector, or uncontrollable drift of the inside into
the outside and the outside into the inside' (Grosz 1994: xii). Using this model, Grosz
warns that fresh analysis of the body must avoid dichotomous views of the person
whereby the subject is divided into the apparently mutually exclusive categories of
mind and body. She believes that we must create understandings of what she terms
embodied subjectivity, and psychical corporeality (ibid.: 21-22). Materialism therefore
needs to be conceptualised as more than corporeality as this has implications for how
we conceive of the body in terms of embodiment and the notion of suffering. It also
highlights that while the body is textual and semiotic, it is also corporeal and material,
and all of these components of the body have interrelated consequences for both the
experience of suffering and the notion of embodiment, especially in the context of
biomedical discourse. The model of the Möbius strip thus acts as an antidote to the
argument put forth by Schepet-Hughes and Lock (1998: 211) who state that:

Ironically, the conscious attempts to temper the materialism and the
reductionism of biomedical science often end up inadvertently recreating the
mind/body opposition in a new form.

However, their point that categories of illness and disease have both been claimed by
physicians for the medical domain, and consequently, that illness has become
medicalised (ibid.) is a valid one.

The Phenomenon of Fetishism in the Realm of Biomedicine

Having considered how Cartesian dualism is responsible for the objectification of the
body in biomedicine and consequently, its disembodied approach, I now consider

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more specifically the phenomenon of fetishism in the realm of biomedicine, of which this dualism is a part. I will illustrate throughout the following sections how, in my own opinion, the whanau negotiate this. Taussig (1992: 86) notes that such physical entities as bodily organs are considered mere things in biomedicine, even though there is a personal need to understand the social significance and meaning of dis-ease. Thus, as argued by Taussig, the master paradigm of biomedicine in modern capitalist culture dichotomizes mind from matter, morality from physical determinism and “things” from the social context and human meaning in which they inhere (ibid.: 90). Herein lies the fetishised nature of the body in biomedicine – it is removed from any sort of social context, thereby disguising the constructed nature of biomedicine itself.

This element of Taussig’s argument parallels the thought of Haraway (1997: 67) concerning technoscience. As discussed in chapter two, technoscience renders science as a culture and a practice, and attempts to maintain boundaries become a more visible, overt practice as the labour of the human and nonhuman actors who partake in its constitution is exposed. Medical innovations (such as genetic testing) are one strong area for the operation of technoscience, and the labour involved in constructing not only its boundaries, but also the way in which it objectifies people as they, and the social relations between them, become represented as things.

Because modern science (including biomedicine) focuses on the physical aspects of disease, this discourse is unable to adequately explain the human significance of physical effects. However, one central advantage of biomedicine is that it can, in many cases, explain the ‘how’ of disease, and such naming is extremely powerful (Finkler 2000: 194). The ability to name and understand the physicality of disease can have a profoundly positive impact in relation to the alleviation of not only physical, but emotional and social suffering as well. In relation to the identification of the gene for hereditary stomach cancer, the naming of disease, and the understanding of its ‘how’ has been an immense psychological and emotional comfort, not to mention life-saving. One whanau health worker I interviewed stated that the whanau were ‘Elated’ at the finding and naming of the physical cause of the illness (field notes 7/10/03).
Where biomedicine subsequently fails, however, is in its ability (or lack thereof) to explain the social significance of disease and acknowledge the embodied aspect of suffering. Because biomedicine focuses on the corporeal body and disease at the cost of ignoring the embodied self, it does not consider an embodied approach to disease. This is noted by Kleinman (1995: 31) who argues that the experience of suffering is given little consideration in biomedicine because of biomedicine's insistence on materialistic dichotomies, such as body/mind. The nature of biomedicine therefore encourages the practitioner to construct disease as both the object of study and treatment. This leaves little, if no room for the patient's experience of suffering.

This sentiment is reiterated by Cassell's (1991) notion of suffering which helps to illuminate the effects suffering has on people, and emphasises that suffering is not confined to physical symptoms. He states that: 'Suffering must inevitably involve the person – bodies do not suffer, persons suffer' (Cassell 1991: vii). This notion of suffering is therefore important to consider in relation to this particular case study in that the whanau are more emotionally involved and invested in the project because they are directly affected by the incidences of illness among their people and have a close, 'hands on' relationship with those (physically and emotionally) affected.

In accordance, Cassell (1991: 23) states that: 'The promise of scientific medicine is that the knowledge does the work'. This premise is echoed in biomedical practice, as the emotional labour and social suffering involved in illness and disease is usually not considered. Stemming from Cassell's observation, I would argue that in scientific medicine, the knowledge does some of the work. For instance, the scientists and doctors involved in the partnership with the whanau health workers undoubtedly played a pivotal role in identifying the 'how' of the disease, but in terms of managing the illness, the whanau health workers have also had an important role in restoring health by undertaking many varied and additional roles related to specifically relieving suffering, as considered in more detail in the following chapter.

Cassell (1991: 33) goes on to argue that understanding of the role of the person in human illness requires one to disregard mind/body dualism. He asserts that as long as the mind-body dichotomy is prevalent in biomedical discourse, suffering will continue
to be either subjective (and not considered as residing within the boundaries of biomedicine), or it will be associated as solely physical. This has several negative effects: it depersonalises the patient and ironically, is a source of suffering itself (Cassell 1991: 34). The mind/body dichotomy thus needs to be discarded before personal suffering can be understood in the domain of biomedicine.

Significantly, the whanau health workers believe that the medical professionals involved understand the degree of suffering (both physical and emotional) that comes with this disease. Although the scientists and other biomedical professionals involved in the project care about the patients, it seems that the whanau health workers are the ones who deal with them beyond the physical side. As Cassell argues, suffering goes beyond the physical side of illness, occurring when there is a sense of imminent destruction of the person, and which continues until this threat passes, or until the person is restored to a sense of wholeness.

He concedes that there are two other ways in which integrity to the person is restored: through assigning meaning to the condition, which reduces the suffering associated with it, and transcendence, which places the person in a larger psychological landscape (Cassell 1991: 45). Assigning meaning to the condition in order to restore the integrity of the person is, however, difficult in the discourse of biomedicine, which, as noted by Taussig (1992: 85), does not cater to answering the ‘why’ of disease. It could be argued, though, that the naming of disease is a way of assigning meaning to it.

Generally, however, the mind/body dichotomy, and subsequently, biomedicine’s focus on the body and the ‘how’ of disease exacerbates the suffering of individuals. In order to overcome this, the mind/body divide must be rethought so that the body is less fetishised in biomedicine, thereby making room for considerations of dimensions of the disease/illness experience that are not only, or more than, physical. Grosz’s (1994) previously mentioned model of the Möbius strip is one way to counter this

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66 Cassell (1991: 40) states that:

People can suffer from what they have lost of themselves in relation to the world of objects, events, and relationships. Such suffering occurs because our integrity as persons, our coherence and integrity, come not only from intactness of the body but from the wholeness of the web of relationships with self and others.

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fetishism, and more concretely, the efforts of the whanau health workers to attend to the emotional needs of those suffering is another way in which fetishism in biomedicine is negated.

The Medical Encounter and Medical Practice

Another negative aspect of biomedicine is the fetishised nature of the medical encounter. In relation to medical altruism, Taussig argues that in modern clinical practice and medical culture the function of medical altruism is camouflaged, stating that ‘This issue of control and manipulation is concealed by the aura of benevolence’ (Taussig 1992: 87). For instance, he notes that the function of the relationship between the doctor and the patient, which is to restore and restructure the understandings of the patient and return them to society (firmly placing them within the ‘epistemological and ontological groundwork from which the society’s basic ideological premises arise’) is disguised or obscured as the social nature of the medical encounter is not immediately or blatantly obvious (ibid.: 86). Taussig argues that this is because in our society, consultation and healing occurs in settings that are both privatised and individualistic, and both the moral and metaphysical elements of disease and healing are obscured and concealed by the employment of the natural science model (ibid.: 87), a point made by the whanau health workers in the opening quotations. Moreover, the interviews which I carved out with these people indicate a strong interest to avoid such concealment in the practicing of science and medicine. For instance, they have a more forthright and overt way of communicating, as well as a more holistic and personal approach to consultation than is generally found in the biomedical context, and this will be discussed later in chapter five.

Concerning the constructed nature of disease, Taussig asserts that these manifestations are like symbols which the diagnostician sees, and interprets in a way that has been conditioned by perception, which is socially determined (Taussig 1992: 88). However, this view is not considered in biomedicine, which believes its products and creations to be ‘out-there’ as they are considered as objective things-in-themselves, removed from the contexts in which they emerged.
Taussig argues that medical practice produces mystifications to which we are all vulnerable in a socially constructed world that we see not as social, human or as historical, but as 'a world of *a priori* objects beholden only to their own force and laws, dutifully illuminated for us by professional experts such as doctors' (Taussig 1992: 89). The implications of this for patients are the many (subconscious, unspoken) messages propounded by these dynamics which imply that patients should not trust their senses, nor their feelings of ambiguity that occur as the socially conditioned senses attempt to comprehend the various meanings placed upon otherwise mute things (ibid.). These things are portrayed as the facts of life rather than the socially constructed entities they really are.

Interestingly, however, the whanau do not adhere to this, as they *do* trust their intuition and are, in many instances, guided by their senses. When interviewed, one health worker mentioned that she 'didn’t feel right about' a certain doctor taking the project on. She also talked about needing to get spiritual guidance from a respected whanau member in order to go ahead with the project (field notes 7/10/03). Moreover, they challenge the *a priori* categories presented to them by questioning the way medical professionals communicate these categories to them and their patients, and by advocating a more forthright and simplistic way of expressing what, to most people, is medical jargon. In addition, the relationship dynamics within the partnership, and between those in the partnership and the members of the whanau are very important in ensuring the continual success of the partnership, and the wellbeing of the patients.

In conjunction, Taussig (1992: 89) argues that the patient in the context of the modern clinic moves between alienated passivity and alienated self-assertion. However, this does not seem to be the case with the whanau as they have a plethora of support networks in place that cover everything from genetic counselling to pre- and post-operative care. Moreover, Taussig argues that the rationalization embedded in biomedicine is an attempt to extract control from the patient, define the status of the person as a patient and as a ‘thing’, rather than treating the patient as ‘mutually interacting partner in an exchange’ (ibid.).
This highlights how, in biomedicine, the social relations that exist in this discourse are fetishised in order to show that disease is natural and objective, rather than constructed; and because patients think and feel, is not only physical (i.e. a thing-in-itself) but also an interactive human relationship (Taussig 1992: 90). However, the conventional biomedical mode of fetishism is rendered problematic by the whanau health workers and the labour undertaken in the partnership with the scientists from the University of Otago. By asserting a large degree of control over the project, specifically the direction of the research, and having more power than the scientists to say what is acceptable and what is not, while advocating that all involved in the partnership are on equal footing, the whanau health workers have mitigated the degree and effect of fetishism apparent in modern medical science and biomedicine.

In accordance, the emphasis placed on the patients’ wellbeing by the whanau health workers as they act on their behalf helps move the patient into a mutually interacting partnership in exchange. This also highlights the complexities involved in medical intervention, and these points are considered further in the discussion below which draws upon Frank’s (1995) post-colonial theory of illness.

**Illness Narratives**

Kleinman et al (1978 cited in Taussig 1992: 105) have distinguished between the notions of disease and illness, noting that while the former can be scientifically and medically measured, the latter is influenced by culture and ‘is what that dysfunction means to the person suffering it’. Thus, from the practitioner’s point of view, disease is the problem and is considered within the narrow biological confines of the biomedical body, meaning that ‘disease is reconfigured only as an alteration in biological structure or functioning’ (Kleinman 1988: 5-6). Although this distinction is useful for exploring the emotional, social aspects of suffering, it does reinforce the aforementioned dichotomy of Cartesian dualism as the personal, emotional aspect of suffering is considered distinctive from physical, material suffering, thereby thwarting an embodied approach, as previously noted by Scheper-Hughes and Lock (1998: 211).

The notion of disease as more than physical is important to consider as it raises questions about the meaning of disease, or illness. While I considered disease as
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textual and semiotic in the previous chapter, I now examine the notion of disease as illness through the concept of illness narratives which have been explored most notably by sociologist Arthur Frank (1995). Frank’s analysis rests on the premise that ‘The body whether still diseased or recovered, is simultaneously cause, topic, and instrument of whatever new stories are told’ (Frank 1995: 2).

According to Frank, these stories, which he emphasises as embodied, have two important dimensions: they are both personal and social (ibid.). The personal side of telling these stories about illness is to allow the body a voice, in order for the transformed body to become familiar in these stories. However, as the language of the story tries to make the body familiar, Frank (1995: 2) argues that ‘the body eludes language’. He notes that while the body is not mute, it is inarticulate, signalling that we must speak for the body; this can be frustrating, however, in that speech purports itself as being about the body, rather than of it. Thus, the mind and body are connected as the mind is diffused throughout the body (ibid.). The social dimension of telling these stories of illness is ‘that they are told to someone’ (ibid.: 3).

Illness narratives are important to consider in that they highlight those elements of fetishism which I have previously discussed in which science can ‘explain the “how” but not the “why” of disease’ (Taussig 1992: 85). Frank’s (1995: 18) assertion that ‘Telling stories of illness is the attempt, instigated by the body’s disease, to give a voice to an experience that medicine cannot describe’ is a particularly important service in view of biomedicine’s focus on and objectification of the body. In addition, because considering narrative is a key means (like discourse analysis) of detecting the values of particular institutions, I will consider the different kinds of narrative that appeared in the popular culture accounts of the identification of the gene for hereditary stomach cancer further in this section.

In terms of specific narrative styles, Frank argues that there are three particular styles, or phases: chaos, quest and restitution. I consider all three, but with particular

67 In addition, Hunsaker Hawkins’ (1999) work on ‘Pathographies’ is another example of the study of such writings. She defines the notion of pathography as: ‘a form of autobiography or biography that describes personal experiences of illness, treatment, and sometimes death’ (Hunsaker Hawkins 1999: 1).

68 This line of inquiry reiterates the work of the early anthropologist Marcel Mauss in his seminal work Sociology and Psychology: Essays (1979 [1950]) whereby he contended that ‘The body is the first and most natural tool of man [sic]’.

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emphasis on the restitution narrative, primarily because it dominates, as asserted by Frank (1995: 77), the stories of most people, including most health workers. It is also a prominent narrative visible in media coverage of science, medicine, and health generally, and I consider this with special reference to my own discourse analysis below. Concerning the restitution narrative, Frank notes that contemporary culture regards health as the normal state that people are expected to have restored. He states that the restitution narrative is comprised of the basic storyline: ‘Yesterday I was healthy, today I’m sick, but tomorrow I’ll be healthy again’ (Frank 1995: 77). This particular narrative thus reflects a ‘natural’ desire to become well, and maintain a state of ‘normal’ health (ibid.: 78).

As previously noted, what is particularly interesting about the restitution narrative is that it is the preferred narrative of institutional medicine, and this culture of illness is shaped from beyond the hospital (Frank 1995: 79). The institutional preference for the restitution narrative is apparent in many of the accounts I studied. For example, one article stated: ‘A family cursed? That was the Maori belief for many years, that a maketu had been put on the whanau. But this “curse”, they would be told in 1997, had a scientific reason. All these victims shared an inherited mutated gene’ (Coddington 2001: 77). Restitution is thus focused on cure, as the body requires ‘fixing’, which, in turn, requires a mechanistic perspective of the body whereby it is seen as a kind of machine. According to Frank (1995: 88), this view normalizes the illness and, I would add, hinders the potential for an embodied experience of illness as the mind and body are separated. The underlying point here is that biomedicine and medical science reject an embodied approach to illness by focusing on the body as an entity separate from the mind as previously discussed in relation to Cartesian dualism. Significantly, however, the whanau health workers adhere to the restitution narrative as they talked about wanting to see an end to the story (in other words, to find a cure). It is perhaps the hope of an eventual cure, along with the way they help to improve the outcome of patients that keeps these workers undertaking the labour they do.

In conjunction, Frank (1995: 92) asserts that restitution stories are powerful because often they are true – many people do get well, returning to their previous state of ‘normal’ health. He states that ‘The cultural power of these stories is that their telling
reflects one of the best impulses in modernity: the heroism of applied science as self-overcoming' (ibid.). This is briefly explored here on two levels: in relation to the culture of biomedicine generally, and more specifically, the role of the ‘hero’ – for example, scientists, doctors, and other experts. Concerning the latter example, Frank (1995: 93) states that:

The respective heroism of physicians and patients are complementary but asymmetrical. Each heroism is required by the other, but physicians practice an active heroism, while patients accept a passive heroism.

This highlights the power dynamics embedded in the process of the restitution narrative and parallels some of my own findings in relation to media representations of the identification of the gene for inherited stomach cancer and the issues that arose from my discourse analysis of these. However, particular portrayals of this case study disagree with Frank’s portrayal of patients accepting a ‘passive heroism’. For example, in the popular culture accounts of this case, several comments were made that asserted the active stance of those who were, and continue to be, involved in the project. They continue to have an impressive degree of control over the way medical scientific research is carried out in relation to them. For example, in the television documentary *Gene Hunters* (video recording 1998), one of the whanau research coordinators states that: ‘We didn’t want to be a guinea pig-type programme, and we wanted to...have some control over the process’. Moreover, the whanau health workers talked about the manner in which they and the scientists involved in the partnership referred to themselves as the ‘A Team’, highlighting the relatively egalitarian power relations and the sense of team work involved in the partnership.

Concerning the chaos narrative, Frank (1995: 97) states that: ‘Chaos is the opposite of restitution: its plot imagines life never getting better’, and he observes that chaos flourishes when there is a sense that no one is in control (ibid.: 100). In the same vein, Gwyn (2002: 156) notes that ‘chaotic stories reflect the chaotic trajectory of the illness, lacking causality or sense’. The chaos narrative can be related to the notion of the curse as experienced by some members of the whanau. It could be tempting to argue that their own narratives move from chaos to quest to restitution as the idea of the curse is ‘disproved’ by medical science, which restores a sense of organization, and allows the possibility for reflection and expression, both of which, according to
Frank, are unavailable to the sufferer in the chaos narrative. However, only some members of the whanau believed in the curse, and despite the identification of the gene for hereditary stomach cancer, some members continue to believe in this notion, which serves to explain the ‘why’ of the disease, just as medical science strives to explain the ‘how’, thereby satisfying their need for a socio-cultural and spiritual explanation.

In accordance with this idea of a chaos narrative, Younger (1995) argues that chaos can be another way of describing suffering. This is what she terms the stage of ‘mute’ suffering, which is ‘the experience of being struck dumb by the sheer force or unexpectedness of suffering and thus lacking a language that will express the experience’ (Younger 1995: 56). Another comment made by a whanau member in a popular culture account illustrates this phase of the chaos narrative:

Not only was the personal loss heavy to bear, so too was the fear that the family constantly carried. “We were continually thinking the worst,” says Hira. “We would think – who is next? Will it be my brother, my sister, or me? Every pain you get, you think – that’s it. And you become too frightened to go to the doctor” (O’Brien 2001: 2).

The construction of a narrative, according to Younger, is tantamount to having an authentic voice, which signifies healing. The process of regaining voice, which is part of the healing process, can be observed in phases: mute suffering, expressive suffering, and finally, finding a voice that is both autonomous and authentic (Younger 1995: 56). In relation to what Frank terms the quest narrative, Younger conceptualises the notion of expressive suffering, which often comes in the form of a story or narrative. This is important in that the narration plays a central role in transforming the suffering (ibid.: 57). Frank (1995: 115) states that: ‘...the quest is defined by the ill person’s belief that something is to be gained through the experience’. This partially illustrates how the quest narrative can be thought of as a bridge between the chaos and restitution narratives, and how it can be conceptualised as a stepping stone to the restitution narrative, as the sufferer believes that the quest will be beneficial in some way. This is the case with the whanau (as presented in the popular culture accounts of the identification of the gene), who move from chaos (they do not talk
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about the illness, they do not know what the cause is, and some members think it is a
curse), to quest (they are proactive, take initiative, and move into the realm of
biomedicine undertaking a journey with the hope they will find a scientific
explanation of their illness), to restitution (with the help of scientists, the cause of
illness and death is ‘discovered’, and there is hope for management and eventually a
cure). While, as previously noted, the restitution narrative is the preferred narrative of
biomedicine, the quest narrative is emphasised in the institution of the media’s
accounts of the whanau’s situation.

The example below of narrative from a newspaper article follows a similar pattern of
the previous examples in that it begins with the chaos narrative, moves to the quest
narrative, and finally, due to scientific and medical intervention, there is the
appearance of the restitution narrative:

Before the breakthrough many families were resigned to dying at an early age
from stomach cancer, which took a terrible toll on the whanau...“Many of
them have lived with this terrible threat all their lives, convinced they are
going to get it and will not live to normal old age,” said Professor Reeve.
“Now, thanks to this blood test, we can tell certain families that they will
definitely not get stomach cancer and treat the ones at risk before they do.”...
[whanau member] “We are future-looking people who do not dwell on the
past. We faced the problem and didn’t just sit down and wait for someone else
to take the initiative” (New Zealand Herald 26 March 1998: A3).

In the popular culture accounts of the identification of the gene for hereditary stomach
cancer which I analysed in the previous chapter, one theme I considered was the ways
in which the moral qualities of science and biomedicine are constructed. Related to
this is one prominent narrative to emerge from much of that material, which was a
restitution story of ‘poor natives saved by white medicine’. This narrative was
perceived and briefly mentioned by one of the scientists and one of the whanau health
workers I interviewed. The scientist talked about its negative effects and the fact that
it was a warped version of the reality of the partnership, stating that the media
portrayed it as “Bright Pakeha Scientists/Dumb Maori come Together to a Great
Solution”, and how the Maori should be very grateful that these bright, brainy white
boys came along. And that’s not really how it was’ (field notes 2/9/04). Similarly, one whanau health worker noted that the media coverage was partial because ‘they [the media] look at the scientists because they discovered the gene, or they look at the poor little Maoris on the hill because they started it all’ (field notes 7/10/03). This is discussed at more length in the following chapter.

The discussion below on colonial narratives serve as examples of what these people are saying, and I found many more examples of this kind of narrative in the media coverage of the identification of the gene. For example, one article stated that: ‘The lives of thousands of people will be saved because of the co-operation of Hira’s whanau and Parry Guilford’s amazing discovery’ (Cancer Gene n.d. online); and ‘Lives are being saved around the world, thanks to a team of New Zealand doctors who discovered a mutant gene causing stomach cancer in one Maori family’ (New Zealand Herald 31 Dec. 1998: A13).

Public Health and Surveillance

Another interesting point of divergence between conventionally ‘critical’ social science accounts of medicine (especially in the public health arena) and the whanau is their emphasis on surveillance in medicine as a positive outcome of their experiences. Generally, social science has been critical of the notion of surveillance, and this adds to the conundrum in that this criticism, when considered in light of the example of the whanau, does not hold true. This notion of surveillance has been explored in relation to public health by Petersen and Lupton (1996) who base their arguments on the work of Foucault (1980 cited in Petersen and Lupton 1996: xii), thereby contending that in modern societies, power operates more through the ‘creation of expert knowledges about human beings and societies, which serve to channel or constrain thinking and action’ (ibid.), rather than through direct coercion and control. They note that, since the 1940s, emphasis has been placed upon the prevention of non-infectious diseases, such as cancer, and this has become the main focus of public health activities in the past decade (Petersen and Lupton 1996: 2). However, their main argument is that the new public health is the most recent manifestation of a regime of power and knowledge that is directed at the regulation and surveillance of individual bodies, and collectively, the social body (ibid.: 3).

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Public health thus depends upon surveillance as a way of countering the fear and disorder brought about by disease as it seeks ‘to establish and maintain order in the face of the disorder of ill bodies’ (Petersen and Lupton 1996: 6). Genetic testing and surveillance, through such means as endoscopy, can be related to this. The reasons for such surveillance are promoted as being in the best interests of the individual or group: improving life expectancy and population well-being. Petersen and Lupton (1996: 3), however, are concerned that this ‘idealistic and progressionist view of public health...serves to obscure its profound moral, political, and social implications’.

The moral and political implications are obscured by a modernist discourse which places special importance upon the role of rationality (especially science) in social progress (Petersen and Lupton 1996: 175). Furthermore, the logic of the new public health draws upon expert knowledges and technologies in order to increase the good of members of the public through improving their health status. The ideology of the new public health tends to make sense because of its emphasis on the notion of personal responsibility – specifically, on individuals participating in activities in order to improve their own health, and this is the main reason why this ideology remains largely unquestioned (ibid.: 175-176). However, the general impression I received after speaking to the whanau health workers and the scientists was that most people were happy with the surveillance programme, seeing it as a small price to pay to ensure that cancer is detected early, thereby increasing the chances of maintaining good health, or more extremely, living longer. Those who do not agree with it are not forced to participate as the individual has the right to choose.

Colonial and Post-Colonial Narratives

Frank (1995) also puts forward a post-colonial theory of illness, noting that many members of what he terms the ‘remission society’ feel they need to claim their status actively. He terms these people ‘post-colonial’, arguing that modernist medicine has claimed the bodies of patients as its territories during, and often beyond, treatment (Frank 1995: 10). Generally, post-colonialism in relation to biomedicine is the desire
to speak, rather than being spoken for – it is the demand to represent oneself, rather than being spoken for by an expert (ibid.: 13).

In consulting two scientific studies of the whanau’s disease, Frank’s post-colonial theory of illness becomes especially relevant. The earlier study by Doctor Edward Jones (1964) outlines his thesis (based on evidence and intuition) that the whanau were suffering from hereditary stomach cancer, although, at that time, the technology was not available to prove it. Comments peppered throughout his study indicate the colonial nature of biomedicine (and to some extent, himself) at that time, highlighting the lack of cultural sensitivity apparent in both biomedicine, and himself:

> It is still difficult to understand why so many young folk have been affected. The Maoris explain it simply. The family is afflicted with makutu. This is because they sold a hill made tapu by the presence of the graves of their ancestors, for quarrying when Mount Maunganui harbour development began in the early 1950’s (Jones 1964: 292-293).

He goes on to write that:

> The Rotorua family of Bridgeman is similarly cursed for naming a meeting house after a woman. Obviously, the persons who laid these curses had a sound insight into genetic tendencies (ibid.: 293).

The sarcastic tone of this comment signals a disregard of the social meaning of the illness as, as noted earlier in the discussion by Taussig, the doctor focuses solely on the disease at the cost of ignoring the ways in which the afflicted make sense of it and what it means to them. Although he considers the context in which the meaning of the illness emerged, he disregards it as nonsense. The following comment highlights another ideological facet of biomedicine. Jones (1964: 293) writes that:

> It is also interesting that all these families do in fact consider themselves related to the proband family. Unfortunately, even the memories of even their oldest members do not stretch far enough for one to be certain of the exact degree of relationship. Maori-wise, they are just “cousins”.

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69 This term refers to 'the first patient to be investigated in a family study, to whom all relationships are referred' (Khan, A. 3 March, Pers. Comm. 2004).

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This illustrates how familial relationships in biomedicine are considered to be based solely on hereditary. This has been explored by Finkler (2000: 3) who argues that, presently, we are experiencing genetic hegemony which is leading to the medicalization of kinship. This refers to the way in which family and kin relationships are being drawn into the domain of biomedicine through current notions that diseases are genetically transmitted from generation to generation. Moreover, Finkler notes that while Durkheim proposed that modern society is fixed in traditions, monuments and habits, she argues that instead of traditions, contemporary society is leaning towards an ideology of genetic inheritance to remember its ancestors. Within this ideology, people's heredity is reduced to nucleic acid and molecules, and notions of honour, social classifications, moral imperatives and the ability to mythologize the past are absent (Finkler 2000: 10). Following the logic of the new genetics then, an individuals' kin relations are prescribed on the basis of birth and not choice. According to Finkler (ibid.: 185), 'the medicalization of kinship thus subverts the ideology of choice regarding the people one selects as one's kin'.

Jones's (1964: 295) concluding comments are particularly telling of the sense of colonialism apparent not only in biomedicine, but also in himself. He states that:

The influence must ultimately be considered a genetic one... Any member who develops symptoms referable to the gastro-intestinal tract should be intensively investigated. Many difficulties arise here, not the least of which lies in persuading the apathetic Maori to co-operate. Previous studies seem to have met a similar lack of response on the part of the kindred. In that of Maiman and Zinninger two of those who later developed carcinoma refused early investigation and subsequently all surviving members have done likewise.

This comment demonstrates several things. It highlights that this doctor thinks of this particular group as a homogeneous entity, insinuating that they were all uncooperative and adverse to 'help'. It also suggests that he did not have a close or meaningful relationship with any of the members as he has little respect for their beliefs or opinions. Third, he does not seem to have any substantial knowledge of their beliefs or the complexities of these in the first place. In addition, this comment also shows how the apparent unwillingness of the Maori to co-operate with the biomedical
professionals is taken to mean that they are ‘apathetic’, rather than resisting the colonizing forces of this practice. A different interpretation therefore suggests that those afflicted and their whanau were resisting entering a domain that has no consideration for their beliefs. In this way, they were resisting being fetishised by biomedicine.

Jones (1964: 295) ends by stating:

> Then, too, the present survey seems to have done little more than imbue the family with a deep sense of *makutu*. In the event of other members becoming affected they may be more inclined towards their gods than their doctors...Because so few of the surviving kindred have yet reached the cancer age they must remain at grave risk but the practicality of intensive follow up among Maoris is questioned.

Again, this is another example of a patronising comment that establishes a sharp contrast between rational biomedicine and the irrational Maori. His generalizing comments imply that *all* of the whanau believed in the notion of the curse which, as previously discussed, is not the case. Furthermore, he portrays their questioning of the biomedical processes negatively, implying that they are putting themselves at grave risk by not following the ‘doctor’s orders’. Generally, his comments indicate a lack of any significant human relationship with the people.

Although much has changed some thirty years later, there is still evidence of medical colonialism in the most recent, groundbreaking study of the whanau’s affliction which appeared in the prestigious international science journal, *Nature*. The paper outlines how the gene for hereditary stomach cancer was identified. Several features of the article resonate with issues raised by Frank in terms of textual colonialism. While the members of the whanau research team are noted as contributing authors, the whanau is not referred to in the body of the text as anything other than subjects and patients, codes and numbers: ‘In one family, a frameshift mutation was identified in exon 15, and in a second family, a premature stop codon interrupted exon 13’ (Guilford et al 1998: 402). This resonates with Frank’s (1994: 12) example whereby an unusual orthodontic occurrence in one man is published in a medical journal. Frank notes that
the man’s name is not mentioned, and goes on to state that he is ‘ignored as anyone...other than a body’.70

To place this in a wider context, Frank cites the work of post-colonial theorist Gayatri Spivak (1990 cited in Frank 1995: 12), stating that ‘the master text of the medical journal article needs the suffering person, but the individuality of that suffering cannot be acknowledged’. This reflects the ideology of contemporary Western biomedical discourse which constructs people as objects rather than individuals. Frank argues that there is a degree of resistance to such reductive portrayals, (for example, the whanau research team contributing to the Nature publication). He argues that the post-colonial members of the remission society are refusing to be reduced to ‘clinical material’ in the construction of medical discourse by reclaiming their voice and demanding that medicine recognize its need for them (Frank 1995: 12).

I was reminded of the notion that such members are resisting being reduced to ‘clinical material’ generally as one whanau member took offence at my suggestion that they ‘played an important role in the research’. She responded by saying that: ‘We are the research!’ reminding me of the human dimension of scientific research, which is often disembodied and ignored as anything other than ‘research’. Paradoxically, however, the whanau have taken up biomedicine relatively uncritically, and in terms of genetic testing, they are willingly being reduced to clinical material as their blood is sent away for testing.

Yet, in small but significant ways, the Nature study is post-colonial in that those who comprise the whanau research team are named, alongside the scientists, as authors of the publication. This is compounded by the use of the pronouns ‘we’ and ‘our’ throughout the study, signalling that the work of the whanau research team was recognised as important in scientific discourse. Furthermore, where New Zealand is mentioned, Aotearoa, the Maori term for the country, is placed beside it in brackets.

70 This man had cancer of the mouth which required extensive reconstructive surgery to his jaw and face. This treatment was so extraordinary that his surgeon was able to publish the case in a medical journal. The article also included pictures illustrating the varying stages of the reconstructive process. When the man offered to show the article to Frank, he assumed it would be about the man’s suffering throughout his ordeal. However, when he saw the article, he was surprised the man’s name was not mentioned, even though there were pictures of him. This led Frank to conclude that rather than being the man’s article, it was his surgeon’s.

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Negotiating and Negating Fetishism

In relation to the fetishism of disease, the manner of the whanau health workers is telling. Their holistic and straightforward approach lessens the degree of fetishism as it emphasises the social aspect of the medical encounter. Their different perspective on genetics highlights that the body can be conceptualised in various ways. It can thus be argued that their weariness and mistrust of some health professionals previously stems from the tendency in biomedicine to fetishise the patient through objectifying the disease in a very particular and disembodied way at the cost of obscuring the very important social relations and meanings of that disease. Their resistance to being fetishised is highlighted by their desire to have a large degree of input into the labour involved with managing both physical and socio-cultural aspects of the disease.

The whanau health workers are not naïve in their approach – far from it. They are working within a socio-cultural framework that acknowledges the dual complexity of the body – that is, they acknowledge the physical aspect of the disease while paying attention to the embodied notion of the body which takes into account the experience of embodied suffering and the idea that bodies are also social and culturally inscribed. In terms of the material body, they see genetic testing, endoscopy and gastrectomy as opportunities for improving their health, and more radically, saving lives. However, unlike contemporary biomedical practice, they pay attention to not only the ‘how’ of disease, but also the ‘why’.

Thus, in the following chapter I consider the perspectives of the whanau health workers and the scientists involved in the identification of the gene for hereditary stomach cancer. This highlights the cultural labour of the gene as one has to learn (labour) in order to see and understand this construct. However, the physicality of the body is only one aspect of disease. It has to be reiterated that, indeed, people suffer and consequently, search for meaning – meaning that is often ignored by biomedicine.
which fails to acknowledge the embodied aspect of suffering as well as the social significance of disease.
Chapter Five

Personal Accounts

'...we all move in and out of the bustling city of knowledge production' (Martin 1996: 102).

As I move at this point in the thesis to consider the personal accounts of the labour undertaken in the partnership which identified the gene for hereditary stomach cancer, it is not to uncover any truths in relation to this. Rather, the point is to consider a range of opinions, taking into account the thoughts, feelings, and motives of those I interviewed. Throughout the previous chapters, I have discussed varying themes and discourses in relation to this particular case study. In undertaking interviews with the principal researchers (three scientists and two whanau health workers) involved in this case study, I asked them about what they thought of some of the most prominent discourses to emerge from my research. Therefore, in this chapter, I consider how these people move through the busy centre of knowledge production around medical genetic research in New Zealand. I do this by comparing and contrasting the participants' views on the orthodox notion of science, technoscience, the construction of the gene, embodied suffering, and the portrayal of science and biomedicine in the realm of popular culture.

As previously mentioned in chapter two, Martin (1996: 101) has argued that the citadel of science is not a walled-off area separate from the rest of society. Rather, its walls are open as people constantly move in and out of it. This analogy is useful for

71 The scientists are Tom, Peter and John, while the whanau health workers are Allison and Janet.
72 As previously noted, Martin (1996: 102) states of the city of knowledge production that: The walls of the citadel are porous and leaky; inside is not pure knowledge, outside is not pure ignorance...Scientific knowledge is being made by all of us; we all move in and out of the bustling city of knowledge production (Martin 1996: 102).
illustrating the complexities of the social reality of technoscience, as portrayed by those who live it. This view makes all sorts of beliefs about science equally useful to hold, and negates the notion that a ‘pure’ science exists that is separate from society (as reflected in my rejection the ‘orthodox’ view of science which was critiqued in chapter two).

The Social Reality of (Techno)Science

The first point to consider in discussing the views of science held by various participants in the stomach cancer gene research, concerns the different boundaries of science employed by the scientists and the whanau health workers. Through these personal accounts, I will also elucidate how they understand science and the culture of science.

Generally speaking, it seems that the scientists adhere more to the orthodox notion of science, while the whanau health workers move more freely in the realm of technoscience, acting as translators between the scientists and non-scientists as they shift from one language to another, and explore all corners of Martin’s ‘citadel’ of knowledge production. In doing so, they acknowledge the varied labour that occurs in these various worlds.

As discussed in chapter two, the foundations of modern (orthodox) science sit upon premises of objectivity and rationality and the scientists adhere to this notion of a value-free, neutral and somewhat Eurocentric model of science. This was indicated by several factors in my interviews with them, including a limited view of who was involved in the project, in which the scientists had a more limited view compared to the whanau health workers, who acknowledged a wider range of the varied labour involved, and who were also more self-reflexive about their labour. The scientists, who distanced themselves from the webs of interactions that constitute the labour of science, prefer to see themselves as just ‘doing’ science. Throughout their interviews, however, the scientists were open about the importance of the whanau’s role to the partnership, and their role in initiating it.
The scientists' responses to a question about who was part of the team that helped them along signal, however, that their worlds are more 'split' than those of the whanau health workers. For instance, only one scientist mentioned the role of the whanau in initiating the research; two scientists mentioned that there were others in the lab who helped out, while all three named only those who were principally and directly involved in the ‘science’ side of things as ‘fellow scientists’. The boundaries that demarcate the work undertaken by the scientists and the work undertaken by the whanau health workers are more clearly defined and boldly accentuated by the scientists. Therefore, they do not move around the ‘city of knowledge production’ as freely as the whanau health workers.

The Scientists' Views

Tom, for example, acknowledged only the principal scientists involved in the research. He does not mention the whanau workers and, while he does mention that there were others in the lab who were not directly associated with the project, it seems as though he assumes that they were also scientists. In other words, he does not consider those who cleaned the laboratory, worked in administration or who acted as support networks, such as friends and family. Thus, the worlds of the scientists are dramatically divided. Although they are moving within the city of knowledge production, they work behind closed doors.

Tom: I've said there was Peter, there was another Post-doc researcher Fernanda da Silva Tatley; there was a Ph. D. student, Anita Dunbier, and there were other people who worked in the lab as well, who weren't directly concerned with the project. But otherwise, there was Tony Reeves as well, who was involved with the project as well. Um, that's about it.

Tom came into the research later than Peter, who was involved from the beginning. However, he also failed to acknowledge the role of the whanau.

Peter: At the time, it was just Tony, who wrote the original grant, and then that was for right of my salary, and the salary for the Junior Research Fellow, and that was a guy called Justin Hopkins, who was a guy with a BSc who came to work with us in the lab at the time.
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This scientist however, had a slightly broader idea of who was involved, including the whanau and a technical assistant:

**John:** The researchers from the family instigated the project, collected samples and recorded all the genealogical relationships. AER was the first point of contact for the family and by winning their trust enabled the lab research to begin. PG was the director of this project and main provider of technical expertise. PG, along with AER were successful in obtaining funding for the project, including my salary. J Haraway joined the team at the same time as me, and worked in parallel on an area which so far has turned out to be unimportant etiologically, although he provided much intellectually to discussions. Other members of the CGL [Cancer Genetics Laboratory], although not part of the stomach cancer team, provided technical assistance, notably Les McNoe, an ‘old hand’ of the lab.

**The Whanau Health Workers’ Views**

In contrast, the whanau health workers have a broader view of who is involved, and a wider conception of what their own roles entail. Throughout the interview, and subsequent conversations, they mentioned the roles of individuals, including those who work as doctors and scientists, as well as a gastroenterologist, as all being ‘part of the team’.

**Janet:** I suppose you could call us anything now... I mean, we do our natural ways. We’re the genetic counsellors, we’re the gastroenterologists. We know so much about it now; we’re part and parcel of the whole thing with the people. We go in with them when they have their ’scopes, we go in with them just before they have their ops. Yeah, we’re everything now.

One of the whanau health workers also spoke of their role as advocates, and this, she asserted, involves a variety of roles, but most commonly involves negotiating on behalf of patients and their families, as well as dealing with government organizations, including Work and Income New Zealand (WINZ), the local District Health Board, and the Ministry of Health. The whanau health workers also made a point of recognizing the labour of others. They spoke fondly of the other principal
players involved in the research, offering a more holistic view of who was involved, highlighting some of the points of interaction that the scientists did not consider.

**Janet:** He [Dr Shaw] should be a professor, but because of his work here, he hasn’t got time for the university, because, you have to get that to do a professorship.

**Allison:** And whatever he’s done for us, he’s hasn’t gone wrong...He gets less recognised than us, and we don’t care about ourselves, and we want some recognition for him, and Professor Martin, nobody knows him.

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**The Scientists and Science As Culture**

The thoughts of the scientists in relation to the notion of science as culture are interesting to consider in that they highlight the ways in which they define the boundaries of science and adhere to the orthodox view of science. The scientists either explicitly stated or implied that they consider ‘science’ to be separate from the notion of culture, and considered it to be distinct from Maori culture, thereby believing it to be a part of Pakeha culture, which they understand to be a neutral, rational, universal practice, free of any notions of ‘culture’. As considered in chapter two, technoscience renders science as a practice and a culture. Comments made by the scientists are therefore implicated in this as they do not acknowledge this notion.

However, before giving consideration to how it might be that science resides in Pakeha culture, or no culture at all, it is important to acknowledge that:

Maori do not conform to a typical presentation either physically or psychologically. Even though there are discernible shared attributes, and a common DNA pattern, there is no single set of mental or emotional constructs which can be said to make up a typical Maori identity (Durie 2001: 4).

Acknowledging this ensures that one does not essentialize Maori beliefs or reality, and following Durie’s assertion, there is no longer ‘a simple definition that will encompass the range of Maori experience’ (2001: 5). Perhaps the same should be understood for the groupings of Pakeha and ‘scientists’ as well.
Tom, a scientist who identifies himself as ethnically Maori, states that he was brought up as a Pakeha, and considers the scientific world as distinct from Maori culture. While initially ambivalent about whether or not requests made by the whanau had changed the way he viewed the body or genetics, he believed that the scientific world was removed from Maori culture, thereby residing more in the domain of Pakeha culture:

I'm of two minds there because I am Maori, but I was raised as a Pakeha, right? through the education system...Because of that, I believe in both Maori beliefs, and also non-Maori beliefs – being in the scientific world, and genetics and so on and so forth...Not really, not really, but it's made me, sort of, you could call it – like there is Maori superstition right? In some ways, I am sort of superstitious of that.

T.C.: Superstitious of the superstition, or?

**Tom:** Aware of the superstition. For example, when you go to urupa or a cemetery, you always wash your hands after that...Now, that's a Maori belief, and I always do that, so does that mean I believe in that or I do that because that's how I was raised? So I just learnt that from my parents when I was a wee young kid. Same thing for when you're at a funeral and there's an open casket and it's in a house or a marae or something like that. When you leave the room that the body's in, you wash your hands. Now, I do that because I was taught that, but with respects to that specific case, I believe in that superstition as well. But that does not affect the way that I do my work in the scientific lab – so a yes and a no.

This highlights how he is in two worlds as he views Maori culture as distinct from the science he practices, signalling that science is perhaps 'culture-less', or a part of Pakeha culture. Adding to the complexity of this, this scientist believes in aspects of Maori culture that he terms 'superstitious', and specifically mentioned the curse. This makes for an interesting dynamic whereby culture and science cross-over, but then he goes on to claim that this does not affect the way he goes about his work in the laboratory. This shows how this particular scientist believes science to reside outside
of culture – his different perspective signals that he is working not only with the doors closed, but with the blinds pulled down as well.

The Scientists’ Accommodation of the Whanau’s Views
Related to the previous point are the following comments made by the scientists which highlight that although they acknowledge that science is a cultural practice, they do not articulate it. Particular elements of the whanau’s involvement in the partnership, which are acknowledged by the scientists, highlight the fluid and dynamic nature of science. For instance, the fact that the whanau wanted to have as much control as possible over the entire project highlights how science is a heterogeneous enterprise that can accommodate varying cultural elements. Tom, a scientist, asserts that the main difference between this case, and the same (hypothetical) case involving Pakeha is the whanau’s beliefs, and the degree of control they wanted:

The main differences are their beliefs, and I think, I can’t specifically say about the non-Maori family or anyone like that, but I think they wanted to have a lot more control of what was going on. And that’s good – and that’s just their personal preference, and maybe their cultural beliefs as well. Or maybe from the point of view that they’ve been shat on for so many years prior to, and post the Treaty of Waitangi – they wanted to keep things close to their own area, or grasp, so they have their own control, and I don’t know how that could be taken over to non-Maori as well, I think it just depends on each individual case.

Another interesting element of this statement is the scientist’s mention of the Treaty of Waitangi, which resonates with the notion of technoscience by citing possible political reasons for the degree of control desired by the whanau. This highlights that science (as technoscience) has an undeniable political element, and that Tom is aware of the social, cultural and political influences in the realm of technoscience. However, this does not infiltrate the clearly defined boundaries he has created around what he considers ‘science’. In other words, he does not see that the walls of the citadel of science are open to the city of knowledge production, and are constantly permeated by citizens of this city.

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In addition, there was a sense of resistance on the whanau’s part to conform to the traditions and conventions of science. This is noted by Peter, who stated that:

I think another thing which was very, very striking was the desire for self-determination amongst them. Perhaps that’s not such a cultural thing, that’s a pride issue, and an honour issue, but that’s very strongly felt. And that was probably the biggest lesson to learn was that these people did not want to be told what to do – there’s no room to say ‘this is how it is’. The approach we took, it was all over so fast. They had a lot to contribute at that level, and how things were organized at the local level, and really that was how it had to be. And nine times out of ten, their approach was appropriate.

The whanau health workers expressed this sense of resistance. For example, Allison is defiant about science having to accommodate them, and not the other way around:

Don’t come our way [if you’re not going to change], ‘cos we’re not going to change. And we never change, for anyone. This is the way we are, and that’s it.

And the sense of control is echoed by Janet, who states that:

So, everything that happens to us, happens to us with our say so...we’re in charge, we’re in control of this whole thing.

This degree of control over the project highlights that science is a malleable practice and culture. This is also exemplified by other factors, and while the scientists do not consciously acknowledge or understand science as a practice and culture, two other outcomes of the interviews indicate that it is. The significance of DNA and the whanau disregard for the medical community show how the boundaries of science are fluid as the whanau attempts to make these visible. In relation to the significance of DNA, one scientist has changed his views of this as he has come to realise its cultural significance and become aware that DNA is fetishised in Western society. He describes being struck by the Maori notion of DNA – he used to think it was ‘a bit of a line introduced by Maori’, therefore failing to realise how deeply held this belief was. He has since learnt of the ‘value’ of DNA, stating:

I’m more acutely aware of, um, the value of DNA. Yeah, I don’t send anyone’s DNA to another researcher without careful thought that that DNA’s...
going to be looked after, and that it's only going to be used for what that researcher suggested in the first place. So, yeah, it increased my awareness of that value.

Thus, the fact that its significance as it stands in Maori culture can be appreciated and accepted in science highlights that scientific knowledge is both a located and heterogeneous practice (Haraway 1997: 137). However, there is a contradiction as Peter (at the same time) understands molecular biology to be free from culture, free from any sort of socio-cultural contexts.

**Peter:** ...well I think that's the thing about molecular biology - it strips away - you work at a level which doesn't really consider race or gender or personality - it goes below that stuff.

This highlights the unusual complexity of his thinking. Like Tom, he moves through two separate worlds, but depending upon the subject matter, there is a connection between these worlds that he does not acknowledge; doing so would render elements of these two worlds problematic.

Furthermore, in another sense, this scientist denies that science is a multicultural (or cultural, for that matter) enterprise. However, that the Maori worldview can be accommodated by science highlights that science is a multicultural practice. Peter describes what struck him about Maori culture:

I think the question of their ownership of the DNA, and how their DNA is the embodiment of their whakapapa. I used to kind of think it was a bit of line introduced by Maori, I didn’t realise how deeply held that feeling was. So that struck me, the consistency of that. Maori, they have different occupations, and social standing within the Maori community, and they all had the same kind of line, so it’s not just promoted more by outspoken Maori. So that ownership thing was very, very important...

In addition, Peter explains that what he learnt from the whanau was a cultural rather than scientific education. This is because:

My scientific methodology is very firm, very established, I wouldn’t say, it’s not inflexible, but there are certain principles which are a common theme
throughout, and that for example, is, you pay little attention to anecdotal information...I don’t think I learnt from them too much about the scientific side, but from the cultural side, an extraordinary amount. It’s really opened my eyes up to their culture, and the strength of the culture.

This highlights how this scientist has clearly marked boundaries of science, while at the same time, he recognises the broader context in which he practises – this is the boundary defining of science.

Related to this is the fact that the whanau health workers believe that they taught the scientists and others involved about cultural values:

Janet: ...[We had to] teach them all about cultural values and cultural sensitivity.

They talked particularly about a genetic counsellor from South Africa and how they had to teach her ‘a few lessons’ about cultural sensitivity. They also noted that she was interested in taking the project on (before they got in contact with the University of Otago), but because of her lack of cultural sensitivity, they did not feel that she was the right person to do so.

In addition, while it was necessary for the scientists to become (to some extent) familiar (if they were not so already) with the many cultural aspects of the whanau that differed from their own conventions, the whanau health workers did not need to become versed in the complexities of ‘scientific’ labour, such as learning to operate a micro-array machine. Thus, in the same way that the scientists can skirt around dealing with WINZ, the whanau health workers do not have to be at the laboratory. The labour undertaken by the two groups is divided and therefore involves different roles that influence how they come to see and define themselves around and through the city of knowledge production.

For instance, Peter noted that there was a distinct disregard and lack of respect by the whanau for the (bio)medical community. He emphasised that with the whanau, there was not the same degree of respect for the medical community as there is with many Pakeha. He also stated that they wanted more control and involvement with the project, signalling that the whanau does not accept the conventional Pakeha way of doing science and medicine. This highlights the fluid boundaries of technoscience.
which can accommodate a variety of cultural practices. Peter also noted that this case was also different from a case involving Pakeha primarily because of their desire to do things their own way, on their own terms.

...we had to have another look at all their systems of genetic counselling. Because Pakeha would say “you go down to the hospital and get counselling there, and then go back in two weeks time”. There would be no question, you would do that. It would be cap in hand to the traditions that it’s done. So that was all gone. There wasn’t the same respect for the medical community that you see with Pakeha. There was this desire for independence. There was a tendency to be less compliant with medical professionals.

T.C.: So they wouldn’t just take your word for everything?

Peter: No, they wouldn’t, that’s right, yeah. And this need to be very closely related with all the aspects of the project. Pakeha tend to be more hands-off and say ‘well, you go do it, doc, come back when it’s done’.

T.C.: They put more trust in you.

Peter: Yeah. That trust had to be developed because it wasn’t there. It’s probably the same thing, you know, Pakeha probably already had the trust there when they grow up trusting the medical profession. The Maori people didn’t really have that trust from day one, so that had to be built up, and now things do happen a bit easier because they do trust me, they know I’m not going to go off and do anything strange.

A point to make in relation to these comments is that in the same way that it is considered a Pakeha ‘tradition’ that many Pakeha would go to the hospital and receive counselling and not question the work and knowledge of the doctor, the fact that many whanau members were not trusting of the biomedical community can be considered a tradition in itself, perhaps stemming from the years of colonization that instilled this distrust (for instance, the medical article on the whanau which appeared in the 1960s as discussed in the previous chapter). Moreover, when I talked informally to the...
elderly mother of one of the whanau health workers I interviewed, she told me that she had never been to the doctor, and when she or one of her eleven children became sick, she would cure many ailments with grass (field notes 6/10/3).

The Whanau Health Workers Criticise Biomedicine

Unsurprisingly then, the whanau health workers were critical of biomedical practice, especially in terms of the hierarchies and the way in which doctors communicate with patients. The way in which they have gone about working thus resonates with the practice and culture of technoscience. Allison states that she has witnessed the impersonal and nonsensical way doctors communicate with their patients:

I’ve seen it, because I was a nurse. I’ve seen them talking to Pakeha old people. This and that, rattling on. And I say ‘C’mon c’mon’. When I was working in Nelson, there was this Taiwanese, he came in off the ships because there’s a port there. And he had a pneumothorax and the doctors would go ‘we want to put a needle in you and we want to draw it all out’ and he had no idea, couldn’t get hold of the interpreter. So I said, ‘let’s draw it’. He’s not even listening to you’. So he said ‘can you?’, and I did – ‘this is what we’re going to do’. …It’s across the board. It’s common sense. He had no idea, this poor guy, what the doctor was talking about. And I said ‘move aside’, I told the doctor to move aside, I’ll explain it to him, and I drew the whole thing. And he was quite happy.

This highlights that Allison is something of a translator, translating between cultures and the divides of expert/layperson, scientist/non-scientist. Her need to translate between different worlds signals the specific doctor’s inability to work outside the confines of biomedicine and to consider the person as more than a physical, material entity.

The whanau health workers also mentioned their dislike of hierarchies in the medical community, as Janet stated:

I suppose one of the things that has come out of what we do [is] that you don’t have to have a doctor’s degree or a physics degree or whatever, it’s just to be on equal footing with both people.

She went on to state that they are a team of equal players in the project:
Chapter Five

Personal Accounts

Yeah, that’s how we become with our [people] – we’re called the ‘A Team’, they’re called the ‘A Team’. Yeah, these are all the principals involved in our work.

In addition, Allison stated that the scientists did not educate the whanau members about the condition. Rather, the whanau health workers did it ‘in a simple form’:

There’s no education about it, we just told them where they had a gene.

This point is also considered in relation to the notion of suffering, biomedicine, and science in popular culture further on in this discussion.

The Construction of the Gene

A central area of inquiry throughout this thesis has been the domain of technoscience, of which biotechnology is an important component, and I now want to consider the aspect of biotechnology in relation to my research, especially in terms of the construction of the gene. This industry is a major player in business pursuits and therefore signals a site of genetic fetishism in the sense of being ‘a non-critical relationship to genetic technologies’ (Haraway 2000: 91).

As the scientists operate in the realm of biotechnology, the whanau do not want to be involved. Two of the scientists I interviewed have gone on to continue gastric cancer research (and other cancer research) at Pacific Edge Biotechnology in Dunedin. The purpose of this in terms of cancer is coming up with unmet medical needs, such as new drugs, earlier detection, and more effective management (Guilford 2004: 2). The aims of the company are ‘to apply a diverse set of skills working in concert to develop improved diagnostic and disease management tools for cancer and other diseases with a genetic component’ (Pacific Edge Biotechnology 2002: 8). The company is also entangled with the University of Otago, and is often described as the commercial arm of the Cancer Genetics Laboratory at this University.73

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73 From a national perspective, the Government has estimated that current export earnings for the biotechnology sector in New Zealand are approximately $250 million per annum. Currently, New Zealand is experiencing rapid growth of this industry as nearly half of the forty two biotechnology companies in New Zealand were created within the last three years. Biotechnology has therefore become a significant industry in this country (New Zealand Trade and Enterprise 2003: para. 4).
Chapter Five

One Scientist’s Views on DNA

The following comments illustrate how DNA is fetishised (disembodied and commodified) within this realm. Peter seems to understand the dynamic of genetic fetishism, but does not articulate it. This indicates that he is aware of the potentially negative consequences of the whanau’s DNA being entangled in commercial enterprise. Peter explains why the whanau have been excluded from Pacific Edge Biotechnology:

They’ve been specifically excluded from that. All the intellectual property from the Cancer Genetics Lab came over here with an exception, a clear exception of all that stuff...so that has been excluded, and I, or we, approached a lot of new areas, so we patented over the test and with the family and all that kind of stuff, and I just didn’t want to bring the new area of commercial development to that project. There wasn’t any need for it anyway, so no, it’s been clearly excluded. I was also concerned that if the company was ever sold, and it got into overseas hands, there might be a control issue there as well. So, no it’s been very, very, clearly kept out of the company.

Peter is also aware of the tension in biotechnology between commercial enterprise for profit and for helping people. He criticises the way some people are suspicious of the motives of those working in this area:

And this is where I think I get frustrated in the company where some people will look at us, you know, the commercial side, and go 'oh yeah, just making some money'. But it’s not that way at all, we’re trying to finish off research, we’re trying to actually improve outcomes, it’s the only way that we’re going to, as a company, ever do well, is if we actually improve outcomes. It’s to improve the outcome of the patient.

As previously noted, the whanau team helped to negotiate a shared patent for the genetic test (Rankine and McCreanor in press: 10). And although they did not talk to me about this, Rankine (1999: 37) notes that ‘The patent decision was a difficult one for the whanau’. In this article, one whanau member states that:

“The project is to help people, not to make money...The whanau wanted the two things kept separate, so non-involved members have formed a trust to
manage it. If any money does come out of it, it could go towards training whanau members to do counselling” (Rankine 1999: 37).

This highlights how the whanau are weary of being involved in the realm of biotechnology and are sensible about their decisions in relation to patents so as to minimise the fetishisation and potential exploitation of their DNA.

Another interesting point to emerge from the scientists’ explanations of how they understand their work is that their vision is trained to look for certain things and ‘see’ in a particular way, thereby signalling that the ways in which the gene is represented are constructed as one has to labour to see it. This is important to consider in relation to how the gene as a construct is viewed differently by the scientists and the whanau health workers. The following quote illustrates how scientists fetishise the gene, as it comes to be understood as a thing-in-itself, an object which is free from socio-cultural contexts, connections and relationships.

The Scientists and the Gene
In the following interview extract, Tom is describing how they find genes which are active in tumour cells.

**Tom:** So, once you’ve done all those, you’ve hybridised everything, all those 30,000 spots with the majority of them will be either lighting up red, green, or yellow. Red means it’s over-exposed in tumour [tissue sample], and green means its being more expressed in normal [tissue sample]. From there we can quantify that, quantify the red, the green and the yellow. And from there we can determine what genes are being expressed in tumour [tissue sample], identify what the protein is, or the product of the RNA, and then, you could carry on and do further studies.

The subsequent example also illustrates how the gene has become separate from the labour involved to understand it. Here Peter describes to me how they come to understand the change in the sequence which becomes the mutation, and what it looks like:

**Peter:** Well, the gene itself is about 2,800 nucleotides long, so it’s a long run of As, Cs, Gs and Ts – this is the name we give the chemicals. And within the 2,800 nucleotides would be one change. So a G is changed to a T – that’s all it
is, one change. So, there's three billion nucleotides based in the whole genome, and one change, a G to a T, has caused the whole problem... So, it's a single base change in one gene, called the E-cadherin gene. And, it looks like the presence of an extra blob. Reading the DNA sequence, reading the two copies of the gene, so your mother's and your father's copies and they're basically the same, in most cases they're the same, and where they differ you just see a base split out a little bit, instead of one spot, there are two spots. So, to look at, you just see the separate rungs gel like a ladder, and then you get the mutation and there's a double band... So, it's a very clear thing to determine, when you see it, it's moved out a bit. I'll show you, you can see it with your own eyes, I haven't described it very well, I'll show you what it looks like.

**T.C.:** So, you're absolutely certain about it?

**Peter:** Absolutely certain, yes.

These examples resonate with Haraway's assertion that the scientist (as fetishist) comes to see 'the gene itself in all the gels, blots, and printouts in the lab and "forgets" the natural-technical processes that produce the gene and genome as consensus objects in the real world' (1997: 146). They also illustrate how scientific objects in general are considered by fetishists (or, more appropriately, scientists) as being 'simply and purely technical and representational, rooted in processes of potentially bias-free discovery and nontropic, even if conventional, naming' (Haraway 1997: 136-137).

The following event, whereby Peter showed me a small blob on a piece of paper, illustrates how scientists are trained to see in particular ways. While I could not make sense of it, to him it was a very important piece of genetic information - the variation in the DNA sequence. This illustrates that science is learnt and shows how knowledge shapes ways of understanding and seeing. The subsequent examples thus resonate with Haraway's assertion that the scientist does not acknowledge the natural and technical processes that construct the gene as an object (1997: 146).
Peter: These are tests of individual people. This is the DNA sequence, and you read in this direction here. There's a normal sequence through here. See, this person has an extra band here, see this person has it as well. These people are all normal. These two people have that extra block, so this lane is the 'G' lane, and it's changed to a 'T', so you still have one normal copy from one parent, and you also have a fault, or a mutation from another parent. So, that's all you look for, so a very clear test. There's no doubt that they have a mutation.

T.C.: It could be quite easy to miss.

Peter: Yeah, but we know where to look, we know to look at this little patch here, so we know exactly which place to stare at, and we don't do everything twice, so we don't make mistakes.

Again, the whanau health workers have a contrasting view. They do not conceptualise the condition as genetic, but as hereditary. This perception is more holistic in that it considers the gene in relation to the body as opposed to the gene as an isolated entity represented by spots, as previously discussed.

Allison: This is how I see it. I see it as hereditary, not genetic, whatever the word is. It's hereditary. If you think of anything that's hereditary, you've inherited things, just like me. So, that's how it is. I don't see it as a genetic problem, I see it as a hereditary problem.

The Notion of Embodied Suffering

As discussed in the previous chapter, Taussig (1992) argued that emotional and social suffering is disguised in biomedicine and that science can 'explain the “how” but not the “why” of disease' (1992: 85), and although identifying the 'how' of disease can be profoundly positive, biomedicine fails to explain the social significance of disease and acknowledge the embodied aspect of suffering. Kleinman (1995: 31), for example, notes how the experience of suffering is given little consideration in biomedicine:
biomedicine presses the practitioner to construct disease, disordered biological processes, as the object of study and treatment. There is hardly any place in this narrowly focused therapeutic vision for the patient’s experience of suffering.

Similarly, as previously mentioned, Cassell notes that persons, rather than bodies, suffer (1991: vii). In chapter four I considered the notion of suffering and the importance of considering this in terms of embodiment. While the scientists made the point that because of the nature of the project they had become emotionally involved, the whanau health workers were reluctant to talk about this aspect of the illness. And why should they? After all, this is a very private and personal area and they should not have to expose this part of the lived, embodied experience to a relative stranger.

However, the embodied experience of suffering is more profound for these people as they have to deal with the very real, day-to-day aspects of suffering more than the scientists. This is not to underestimate the vested interests of the scientists in alleviating suffering. A sense of emotional involvement and altruism comes through in comments made by the scientists, especially Peter, who wholeheartedly believes that genetic testing for this predisposition is a positive step, one that has contributed to saving lives and relieving the social suffering of the whanau:

Well, I think there’s no doubt, you know. The alternative is to just go back to the way this family was where you’d wake up with a tummy pain, and you’d think ‘oh god, is it me now – I’ve got it now’. And that destroyed that community, that fear, and people didn’t, you know, I mean stable relationships were under pressure, career options were under pressure, because ‘I’m going to be dead when I’m thirty – if I live to thirty I’ll die at forty’. Any kind of pain that you or I, presumably mutation-negative, have, we just put down to a big night or whatever, and you get on with it. If you have that family history, you’ll be thinking ‘ohhh no, this is it’, and that’s a terrible thing to have over you.

He also judges his own work in relation to how much he can relieve the suffering of the whanau, indicating that he considers the wider implications of medical
intervention as he understands that what goes on in the citadel of science affects the citizens of the city of knowledge production:

I judge myself on how well these people do – I’ll be just so happy if these people do well, and how well these people do. And if you get someone whose cancer is picked up early, I’ll go ‘yahoo’. That’s what I’m doing.

Significantly, the whanau health workers affirmed that the scientists were aware of the suffering (physical and emotional) involved. This awareness is one likely reason for the continual success of the partnership.

The Whanau Health Workers and the Naming of the Disease

The following conversation highlights how the identification and naming of the physical condition has played a key role in alleviating physical and emotional suffering, not only for the afflicted, but those who are also intimately involved, such as the whanau health workers. As previously mentioned, these workers also made a point of emphasising that they always knew it was hereditary:

**Allison:** Well, we knew it was hereditary, or we wouldn’t have got those geneticists in.

**Janet:** There was a misconception about the whole thing, for years people believed. And they [were] believing it to the point where “I’m going to get it, I’m going to get it, I’m going to die”.

**Allison:** So, our thing was to prove that it was hereditary. We knew it was.

**Janet:** Prove to our family.

**Allison:** ’Cos we did some research prior to Tony and them, and the research was that there were certain families having it. So, we knew it was hereditary. All we had to do was try and prove it to the people. Because they thought they had a curse on them, well anyone would. Pakehas think that, they even told me.

**T.C.:** And after the discovery?
Allison: They were glad. Elated.

Janet: The fact that ‘this is what’s happening now – we feared for this thing, and now we can do something about it.’

The Scientists and Embodiment
Another interesting consideration in relation to the notion of suffering is the representation of the whanau as both symbols and people. Significantly, all three scientists felt working with the whanau had been an enriching experience in that there was human face-to-face contact, rather than them just knowing individuals as blood samples, or symbols on a piece of paper. This signals that the scientists became aware of the wider implications of what they were doing, and considered the human, embodied element of this:

Tom: Just finding out the way that they think, and actually just having a one-on-one situation with them as opposed to just being in the lab and just dealing with blood or DNA or something like that; and just knowing that there’s someone on the other end of that. And that’s been quite important, I think, and it’s been a great sort-of motivator as well.

This sentiment was also expressed by John, who spoke of moving out of the citadel and interacting with his research subjects socially:

Initially, the relationship was a professional, clinical one. (I knew the members only as symbols on paper and the contents of test-tubes). After meeting several members of the family on multiple occasions and staying twice on the Marae, I considered them to be friends and we were made to feel members of the extended family.

The Whanau Health Workers and Trust
However, the whanau health workers stated that they found it difficult to trust the scientists at the beginning of the partnership. That trust could gradually be built over a period of time indicates that the scientists were working according to the whanau’s
specifications. This trust, and the fact that they covered themselves religiously, indicated that they were doing 'the right thing' in terms of actively alleviating suffering.

**Allison:** Well, I must say, that in the beginning, it was hard to trust, you know. Because there was a bit of hoo-haa in New Zealand at the time, in the early '90s about genetic testing on sheep and all that. So it was hard to trust at first. It was when the gene came that I think the final trust was there, and even then.

**Janet:** We used to have three or four phone calls a day to Peter, checking, making sure, ringing, making sure.

**Allison:** "Are we doing the right thing?...Were we doing the right thing for our people?" Because it was like putting our whole family into a risk situation. We did. And we were taking their blood – are we doing the right thing? Mind you, we had prayed, and we had covered ourselves because we're religious, and we did do that so that we're not doing the wrong thing.

**Janet:** Yeah, our very being here is covered by a spiritual thing.

**Allison:** Yeah, it is.

**The Realm of Popular Culture: Media, Metaphors and the 'Public'**

In chapter three I considered media accounts of the identification of the gene of hereditary stomach cancer, drawing on my own discourse analysis as well as that of Rankine and McCreanor (in press) on the same topic. As previously mentioned, they termed the newspaper articles they analysed 'Colonial Coverage' as most of the stories 'cast the Maori family as a problem that Pakeha scientists had to fix' (in press: 21).

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74 The whanau are followers of the Ratana faith, and one member stated that because of this 'delving into the background of our ancestors is not something we would normally do. It's a bit like opening a grave' (O'Brien 2001: 6). With the help of the marae minister, they sought a spiritual blessing and wrote and signed a kawenata (covenant) between the whanau and God which noted that the research was to be used only for the purposes of the illness (ibid.).
When I asked all of those I interviewed what they thought of the media coverage of the identification of the gene for hereditary stomach cancer, the scientists, more than the whanau health workers, thought it was misleading. This was mostly due to the emphasis on the notion of the curse and the lack of acknowledgment given to the whanau’s role in initiating the research and the subsequent whanau health workers’ involvement in the partnership.

The Scientists and the Media Coverage

Generally, however, the scientists also thought that the accounts were sufficient.

Tom: I think it’s quite misleading in some respects, because, as far as I’m aware, how it came about was that the family approached us – we’d nothing to do with the family prior to that, it was their ‘get-up and go’ that basically got the project started...I sort of agree with it, but not really because the family approached us, and we had the skills that were there already – they’re using us, which is what it should be, as opposed to we’re using them to progress our standard of scientific grounds. So, I think it is somewhat misleading, I think. They get more of the human interest sort of thing as opposed to what’s really going on.

Tom also thought, however, that most of the media accounts of the work he took part in were good enough. He thought that the articles which emphasised the relationship between the family co-ordinators and principal investigators were especially good. However, he was aware that the majority of accounts were not from the whanau’s point of view. He hints at the stigma of the curse, and notes that the freedom of individual choice was not emphasised:

Tom: I thought most of it, this is just going back a few years though as well, I thought most of it was quite good, but I think there were some instances of what I would call a witch-hunt. Most of the accounts were not actually from the family’s point of view, but even within the family there were people who were against it as well, and that’s fair enough. But, I believe, that they have a choice, and it’s up to them whether or not they want to take that choice. And I
don't think that was conveyed in most of the media reports or nine times out of ten there wasn’t information about it.

Like Tom, Peter felt that the media coverage was generally sufficient. However, he notes that the notion of the curse was emphasised to the point of being detrimental to the whanau. Moreover, as noted in the previous chapter, he was aware of the narrative portrayal that was also detrimental to the whanau:

**Peter:** I didn’t like the stuff about the curse – that was really overdone. And it made it the ‘Bright Pakeha Scientists/Dumb Maori come Together to a Great Solution’, and how the Maori should be very grateful that these bright, brainy white boys came along. And that’s not really how it was.

Regarding the curse, he notes that some members of the whanau still believe in it, and that it makes a good story:

**Peter:** And the curse, I mean some people still do believe in that curse. I was struck by one, I was there about a year ago for hui, and one of the elders was speaking on the lawn outside of the marae...And he turned back and pointed to the hill and said how it was starting to heal over now, and that’s why things are going better. So, there’s still that belief by some people. But when Maybelle and Hira and Rangi came to see me, they knew it wasn’t caused by selling the hill, so lovely story, but over-amped I think.

He also thought that their research was represented realistically, except that they did not give the involved whanau members enough credit for the labour undertaken by them.

**Peter:** I think that was one area where they didn’t give the Maori involved enough credit for their awareness of what was going on.

In terms of the marking of ethnicity, Tom was not initially sure why the whanau were always marked as Maori while the scientists were never marked, even though he is Maori himself, and identifies his iwi as Ngati Ruanui (a South Taranaki tribe). He decides that it is because the project leaders are non-Maori. He stated that:

I don’t know, I’m not too sure about that one. I think because the project leaders are non-Maori, and I consider myself not a project leader. So
obviously, I believe that if they were Maori, then I believe that people would actually mention that. Because they’re not, they won’t mention it.

In contrast, Peter believes that the whanau are marked as Maori (in relation to the unmarked scientists) because it makes ‘good press’:

Peter: ...I think it’s a part of, perhaps the desire to make a good news story where the Maori with their simplistic beliefs meet modern science, as in Winston Peters’ line – it makes a nice story. You know, the crossing of the cultural divide and working together for a common cause kind of story. So, that makes good press.

However, personal experience leads him to claim that there is some truth in this representation:

And, there is a degree of truth, you know, I’ve come from a very different world and have come to find myself quite immersed in a Maori environment, so there has been crossing over. And I think that’s perhaps hyped up, because of that, and it makes a good story – it’s only when the venture of the whole project is always reduced to that, the cultural aspects.

The Whanau Health Workers and the Media Coverage

In contrast, the whanau health workers were not overly concerned with the way in which they and their work had been represented in the media. Janet notes that they had a large degree of control over the content in terms of monitoring and overseeing the reports before they were filed. Allison stated that: ‘It had to be for our specification’, and they were not concerned with being marked as Maori, even though the ethnicity of the scientists was not noted. Allison has seen the article written by Rankine and McCreanor (in press) and although initially disgusted with the media coverage,

...it didn’t worry me too much. Because it’s how, if Peter and them think they’re better than us, then there’s a problem there, but they don’t, and so it doesn’t worry me.

Moreover, Janet mentioned that ‘We are equal partners with all our people.’
When I stated that I had never come across the name of one doctor intimately involved in the project before, Janet made a comment that signalled she is aware of the media bias that ensued after the identification of the gene, and that she resists the degrading portrayal:

Yeah, because they look at the scientists because they discovered the gene, or they look at the poor little Maoris on the hill because they started it all. We’re not poor.

In addition, another point of interest is that the whanau health workers mentioned that they are tired of dealing with the media. Allison said ‘it’s a pain’ having to deal with them, but a necessary evil in that they need to keep up publicity in order to ensure funding is continuous. However, they spoke of a reporter and photographer from the New Zealand Herald who were coming down the next day, and sounded excited about the planned ‘photo shoot’, and joked about wearing gumboots to it.

The Scientists and the ‘Battle’ Against Cancer

Having given consideration to what the key researchers thought about the popular culture accounts of the identification of the gene for hereditary stomach cancer, I asked them what they thought about the metaphors of cancer and the body that exist in scientific and medical discourse as well as popular culture. As previously noted in chapter three, Montgomery (1991: 347) asserts that in Western culture, war is the reigning image-system for all diseases, and indeed, my own analysis illustrated that metaphors of the body and cancer were overwhelmingly masculine, militaristic and mechanistic. The following discussion considers what both the scientists and whanau health workers think about the way language in these discourses is used.

Two of the scientists thought that language with mechanistic and militaristic connotations which is characteristic of scientific and biomedical discourse, as well as popular culture accounts of science and medicine, were appropriate. One scientist (Peter), however, began to see how words are fetishised in science, considering the wider implications of word use. He does however, explain cancer in terms of a biological process, adhering to the notion of microbiology as neutral and disembodied as it does not consider the wider socio-cultural and emotional implications of the
disease, although, as previously discussed, he does have some idea of the suffering involved.

**Peter:** I get really frustrated with that when people talk about, (that’s probably a very good point), you know ‘So and so lost their battle against cancer’. That just drives me crazy – it’s not a battle against cancer, it’s not a nice way, a good way to describe the disease – again, it’s implying that, yeah you’re absolutely right, that cancer is a foreign invader and you’ve got to invade it back, and it’s not, it’s part of your own body, a normal, a very normal process of your own body gone wrong. Cancer is abnormal cell proliferation, and abnormal cell migration, and that is a very normal part of us. When we develop as an embryo, cell proliferation, and cell migration is what happens when your cells regenerate… If you’re wounded and get a cut, it heals by cells proliferating and moving. So normal processes, and every single cell in your body has the capacity to do that, and it loses it’s control – so it becomes too strong, wrong direction, wrong time, then you’ve got cancer. But it’s not something that foreign, you know, it’s not a foreign invader.

The Whanau Health Workers on Communicating Science

The whanau health workers, however, had a more extreme response. While they agreed that science and medicine is full of jargon, they believe these discourses generally are not an appropriate way of explaining information, and they talk of teaching another way to communicate science:

**Janet:** Yeah, well we agree that that’s how they describe it, but when they talk to us, or any of our people, they have to put it in lay people’s terms. They have to be down to earth, telling them exactly, none of that medical rubbish. If you’ve got cancer, then that’s what you’ve got. It’s not ‘carcinoma something something’.

**Allison:** Straight up the guts. You know how I told you about David Shaw? Well, he said to me, with that sixteen year old, and there were about 30 of them sitting in the room and he goes ‘what should I say?’ and I said ‘tell the truth’. ‘Be honest, tell them the truth’. And now he knows it works for anyone. You don’t have to be a Maori.
Chapter Five Personal Accounts

Such language helps to cross the expert/lay divide as discussed by Taussig (1992) in chapter four. The statements of the whanau health workers here help to illuminate the ways in which words are fetishised in the aforementioned discourses. Their direct approach takes into account the embodied experience of illness by not falling into the trap of lessening the emotional impact by placing emphasis on the physicality of the disease (as in the term ‘carcinoma’). Such terms, it can be argued, distance the medical professional from the embodied notion of suffering, as they believe that they work solely on a physical level, alleviating physical suffering.

Allison spoke of why the partnership had been so successful, emphasising that it was egalitarian and understanding through speaking the same language:

Allison: And we have been able to make relationships work. That’s why they call it a ‘Blue-print relationship’, because it is. You can have relationships, but not on an even par. And this is an even par relationship, and unless you see it, you’ll never know. When the Cancer Control saw it, they knew. And they couldn’t even describe it to anyone. It was ten minutes before the show, and I said to her, Vanessa, you facilitate this, I’m hungover. And she could, ’cos we’ve all got the same language.

The Lay/Expert Divide?

One interesting meeting point between the intersection of scientific views of genetic testing and the realm of popular culture is the public understanding of science. The scientists and whanau health workers I interviewed had differing perspectives on this topic, which I will now consider. They differ from my own analysis as discussed in chapter two where I revealed the constructions of popular culture and the public understanding of science as complex, heterogeneous and fluid categories. One striking revelation of this was Nowotny et al’s (2001: 2) point that that science and society are inseparable as they rely on the same foundation. Similarly, as previously noted, Irwin and Wynne (1996: 9) warn against perceiving and portraying the public as ‘a homogeneous mass which needs to be rendered more receptive to the insights of science’. This is because of the fact that ‘masses’ do not exist naturally, but are constructed to appear as such in particular ways (ibid.). These points resonate with Haraway’s (1997: 67) argument that understanding science as a culture and a practice.
makes room for non-scientists to influence the forms of scientific knowledge and who this knowledge will be relevant to. They are also important to consider in relation to the thoughts of those I interviewed on the public understanding of science.

All of the scientists interviewed thought that the public (or, more appropriately, non-scientists) generally did not have a good grasp of what the scientists do. Tom expresses that he has difficulty in explaining what he does to lay people, stating that it is more difficult to communicate to people ‘outside’ of what he does than it is to his colleagues. Tom, in explaining the genetic sequence to me, stated that:

So, I think if you don’t really understand that, you don’t really understand what those red and green lines actually mean. I think that’s the hardest part to convey 'cos you try and actually represent things as simply as possible, but people don’t understand or maybe don’t know what they represent, and it makes you work twice as hard. But for us, because we know what they actually mean, what they indicate, what they represent, well, it’s easier to understand that sort of thing.

Thus, this scientist finds it difficult to communicate with some of the other citizens of the city of knowledge production, however, that is not to say that these citizens have a lesser understanding of the complexities of technoscience than these scientists. Rather, it signals that this scientist finds it easier to communicate with those who reside within the laboratories inside the citadel.

In contrast, the whanau health workers believe that scientists generally and doctors especially, need to learn a new way of communicating scientific and medical knowledge to non-scientists. They advocate teaching another way to communicate, and emphasise the importance of equality between medical professional and patient, which requires the professional to communicate with the patient in a way that the patient will understand. This requires ‘unlearning’ what they have learnt to some extent, and also, as advocated below, ‘chucking the Book away’, allowing a degree of ‘plain speaking’ to take place.

The whanau health workers believe that the patient feels more comfortable in this personal setting, and this type of communication ensures a degree of honesty, as the
professional cannot hide behind medical terminology that no one but that expert understands. They also believe that this sense of equality makes for a more humane medical encounter (for both doctor and patient), and believe the foundations of effective communication are built upon honesty and common sense. Therefore, they assert that their work has changed New Zealand society in the sense that it has shown a way to bridge the gap between expert and lay knowledge:

Janet: ... I suppose one of the things that’s come out of what we do [is] that you don’t have to have a doctor’s degree or a physics degree or whatever, it’s just to be on equal footing with both people.

Allison: We have a natural ability. You know, even though I was a nurse, I put all of that aside, because that’s by the Book, you use your common sense. It’s all by the book in nursing. Chuck it aside.

Janet: It’s all about common sense. And honesty, you know. People don’t understand medical terminology and stuff like that. So you can tell them in lay people’s terms and they understand. When you talk about a ‘carcinoma of something something’, they’re not going to bloody understand any of that crap.

Allison goes on to criticize the way in which doctors generally communicate with their patients, but praising the fact that one doctor in particular acknowledges his mistakes.

David, I love David because he always admits his mistakes, and he admits it to the people and that’s what I love about him. He’s learnt to be honest. Doctors – they are so roundabout it’s not funny. And they make them believe they’re going to be alright when they are not. But he knows they’re going to be alright. He always tells the truth, well you know, from that time on. When I say the truth, I mean it’s straight up.

Considering the thoughts and opinions of the scientists and the whanau health workers on the aforementioned themes illustrate the complexities involved in the social reality of technoscience as it is played out in the dynamic city of knowledge production.
Investigating the opinions of these key science workers in the stomach cancer gene research project has provided some empirical support for understanding the complex social reality of science as technoscience while at the same time demonstrating the importance of understanding cultural contexts and the constructions embedded in various discourses. I will now move on to the final chapter of this thesis which discusses the general conclusions I have drawn from my fieldwork and research for this thesis.
Chapter Six

Conclusion

'Nobody wants to leave until there's an end in the story' (Allison, field notes 7/10/03).

The purpose of the following discussion is to briefly summarise key findings which have emerged from this project and consider them in light of the broader picture of the partnership which identified the gene for hereditary stomach cancer as considered throughout this thesis. It has become apparent that, in various ways, the intersection between scientific views of genetic testing and the realm of popular culture is a messy one. The complex knots embedded in the intersection of these realms have been illuminated by the employment of anthropology and, to a lesser extent, cultural studies, which has also been useful for untangling some of these complexities. How genetics is represented in biomedical and scientific discourse as well as popular culture speaks volumes of how we construct these worlds, and subsequently, what we value in these contexts. This project has shown the importance of considering both textual, semiotic portrayals of genetic testing, and the lived reality of living with hereditary stomach cancer in New Zealand society.

Donna Haraway's (1997: 142) notion of gene fetishism has been used throughout this thesis as an organizing thread to highlight the ways in which relations and practices get mistaken for things-in-themselves as they are taken for granted as both natural and objective. In this case, the thing-in-itself is the gene, and focusing on this as a neutral object reinforces the separation of the natural from the cultural. This is also the case in practices that are characteristic of medical science and biomedicine whereby many practitioners of these institutions focus on the physical 'how' of disease, at the cost of considering the emotional and embodied 'why'. The notion of corporealization
revealed the constructed nature of the gene and frames it less as an object and more as a web of action made up of human and nonhuman actors (Haraway 1997: 142).

The use of the notion of technoscience has been useful in highlighting the complexities of science as ‘cultural practice and practical culture’ (Haraway 1997: 66), signalling that rather than transcending culture, science is entangled within it. One interesting thread to emerge from this is the premise that science is multicultural. This argument, as considered in chapter two, was put forward by Harding (2001: 189), who argued that multicultural perspectives are necessary tools in re-thinking science. Her key point is that modern science does, in fact, have non-Western origins. Modern science, then, can be considered multicultural in the sense that is has incorporated components of the knowledge traditions of a myriad of non-European cultures (ibid.: 192). This project has shown that, indeed, science is multicultural. This is demonstrated by the fact that aspects of Maori culture have been incorporated into mainstream scientific practice. For example, as noted in the previous chapter, one scientist is now very careful with tissue samples in order to respect the notion of whakapapa. Thus, that aspects of the Maori worldview can be accommodated by science highlights that science is not only a fluid and dynamic practice, but one that may (if prodded) become more multicultural in its practice as well as in its theoretical borrowings. This is exemplified by the manner in which the whanau, and the whanau health workers especially, have retained a large degree of control over the project and the way in which the processes stemming from the original project have been conducted.

As discussed throughout this thesis, popular culture is a crucial site for accessing representations of scientific views of genetic testing. It is no more or less privileged as a setting of understanding science, as illustrated by the public understanding of science which highlights that, as noted by Latour (1987), Haraway (1997), Nowotny et al (2001) and myself, science and society are inseparable as they rely on the same foundation. This has implications for the public understanding of science as the ‘public’, who, as part of society, engage with ‘science’ actively and critically.
The undertaking of discourse analysis as part of the empirical research carried out for this thesis revealed the portrayals in popular culture of the identification of the gene for hereditary stomach cancer to be both culturally constructed and politicised. The forums to discuss this event generally did not appropriately or realistically represent what the actual situation was. The discourses operating within these media accounts presented indigenous people as victims instead of the initiators of the project and directors of the research. My findings also reveal that it is common to use masculine and militaristic metaphors in technoscientific and biomedical discourse, as well as in popular culture to discuss the relationship between the body, genetics and disease and this was indeed the case for New Zealand accounts of the stomach cancer gene research. This highlights how such accounts are not objective and neutral. Rather, they are culturally constructed to represent material in a certain way. This was certainly the case when I examined some of the most prevalent metaphors of the gene to exist in contemporary popular culture, which revealed that the broader cultural meanings of these metaphors offer a limited and partial understanding of the complex socio-cultural relations embedded in technoscience.

Contrary to the common western portrayal of the gene as an entity is the holistic notion of whakapapa, which takes to task the reductive portrayal of the gene in popular culture. This Maori perspective highlights that the body can be conceptualised in various ways. Maori discourses of genetics as observed in this particular study break open the fetishism apparent in science and genetics by offering an understanding of the gene and DNA that is more than a physical entity, one that is connected to the spiritual and socio-cultural contexts of their worldview, and one that western scientists should take heed of.

In considering the importance of the material body, I examined the complexities of medical intervention in relation to this specific case study and considered how the whanau health workers negotiate the fetishism apparent in biomedicine. A key way in which they do this is by emphasising the importance of communication that makes sense to lay people, thereby negating the jargon, which hides the social relations in which the practice of biomedicine is embedded. The holistic and straightforward
approach of the whanau health workers lessens the degree of fetishism as it prioritises the social aspect of the medical encounter.

Another interesting thread to emerge from this study has been the fact that non-scientists can be so influential in directing scientific research, especially by emphasising the importance of the human component of this research. The whanau driven aspect of the project has also been beneficial in that generally, those on the receiving end of the project are very satisfied, certainly more so than if the whanau had had little say or control in the project. However, it could have been negative: for instance, the whanau could have refused to undergo surveillance because of its invasive and uncomfortable nature, not to mention the schism between the practices of biomedicine and their cultural beliefs.

Thus, the whanau have manipulated biomedicine for what they want, which debunks some writing that has emerged from the social sciences that critiques biomedical practices such as surveillance. Taking into account the fact that the whanau are generally happy with the outcomes of the partnership and the surveillance programme, it is evident that the social science commentaries decrying surveillance and the uneven power relations characteristic of indigenous peoples' experiences of biomedicine and biotechnology need to be questioned. For example, the bleak argument of the new public health, as asserted by Petersen and Lupton (1996) does not apply to this case. As previously mentioned in chapter four, they argue that the new public health is a recent addition to the regimes of power and knowledge which are geared towards the control and surveillance of both individual bodies, and the social body (1996: 3). However, as the whanau example shows, this is not the case as they have a large degree of agency within this, and they have had, and continue to have, a positive experience of surveillance as they see that the beneficial aspects of its technologies outweigh its negative aspects.

The whanau health workers are working within a socio-cultural framework that acknowledges that the body is physical, emotional, and spiritual, taking into account the embodied self which considers suffering that is more than physical. Interventions to improve the physical body, such as genetic testing, endoscopy and gastrectomy are
opportunities for improving their health, and more radically, saving lives. However, unlike contemporary biomedical practice, they pay attention to not only the ‘how’ of disease, but also the ‘why’. In addition, the personal accounts of the whanau health workers indicate a strong interest to avoid such concealment in the practice of science and medicine.

Talking to those primarily involved in the partnership has revealed different perspectives and experiences of the partnership as the stories they relayed varied significantly. These stories also revealed how the categories that we normally put people within are unstable and fluid; for example, a Maori scientist who leaves Maori culture at the door of the laboratory, and a Pakeha scientist who is mindful of the Maori belief in whakapapa.

The holistic and straightforward approach taken by the whanau health workers and their resistance to being fetishised is also reinforced by their desire to have a large degree of input into the labour involved with managing both physical and sociocultural aspects of the disease. These whanau health workers therefore have an embodied understanding of both suffering and the implications of this as they live, more than the scientists, with the day-to-day reality of this affliction (a point which the scientists involved in the research project have readily acknowledged).

In terms of science and medicine and authorising intervention, we do not find grateful people at the Kimihauora Health Centre – rather, they are dynamic with their own understandings and ways of negotiating medical science. This highlights that there is scope within science to change, to recognise cultural worth, and highlight the fact that we have to labour to accept each other. The scientists had to take the whanau health workers on their own terms, but these health workers also allowed that within the project, mistakes would be made, and they allowed for things to go wrong, an approach that is uncannily similar to the philosophical and sociocultural understandings of science as an ongoing falsifiable and culturally relative process.

The notion that scientists are neutral and that they have privileged knowledge is questioned by the personal accounts of the projects which are recorded in this thesis.
Chapter Six

Conclusion

There is also complexity in their world as, while they continued undertaking the same scientific work they had done in the past, their worldviews have become deeply enriched, many of them having learnt a great deal about Maori culture, and one scientist in particular incorporating aspects of this knowledge into his scientific practice. Thus, this has influenced how they go about their work in the laboratory, although, they did not acknowledge this, signalling the complexities of living in two 'split' worlds. Moreover, the whanau health workers have become cultural translators, acting as a buffer between potentially deeply divergent understandings of cultural activities. However, there is room for improvement as the procedures used to detect and treat stomach cancer, such as genetic testing, endoscopy and gastrectomy, are all, to varying extents, uncomfortable and invasive procedures.

In terms of the broader picture, what can be said about the partnership is that it continues to be a success. However, it is not a modernist success story – rather, it is complex and tangled and is therefore more a postmodern story than a fairytale. Since the partnership’s inception, there have been both negative and positive consequences, and to use a scientific term, it has been not dissimilar to the process of ‘trial and error’. This process has been necessary, however, to allow for improved relations and more effective delivery of procedures. The knowledge that has emerged from it has given help and hope to many, not just those within the whanau, but other sufferers of hereditary stomach cancer as well. More specifically, it has produced essential financial aid and the development of appropriate facilities to help both the whanau and other families in New Zealand who carry the disease.

Overall, the experience seems to have been positive and it is evident that this case study is a landmark of skilful indigenous appropriation of technoscience. The ‘standard’ social science commentary about issues raised in the partnership – such as surveillance, unequal power relations and bioprospecting – do not hold true here for this particular project as the whanau have an unusual degree of control over how the surveillance procedures are carried out, and how relations within the partnership and between the whanau and other biomedical professionals are carried out. They have contracts and protocols in place to ensure that any sort of bioprospecting or exploitation of their DNA does not take place. Because of this, the scientists seem to
be more aware of the (cross-cultural) 'value' of DNA, and consequently, such bioprospecting would appear abhorrent to them.

The labour undertaken in the partnership continues to be an ongoing process. While the majority of the whanau now have confirmation of the cause of the disease, in a sense, none of their problems have vanished. Arguably, it could be said that there has not been a medical breakthrough as there is not yet a cure. However, the scientists have learnt something in the process, and beyond the enrichment of Maori culture, one scientist in particular is wearier of science, especially in relation to the notions of DNA and the commoditization of knowledge. This is thus a hopeful story with complex pathways, but through these pathways many of those involved in the stomach cancer gene project have come out with better solutions.
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