

# **Visual and Narrative Texts of Chronic Illness**

**An exploration of the relationship between  
disease, the body, and the ontological  
assumptions inherent in medical treatment for  
hepatitis C**

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## **Abstract**

This thesis explores the argument that inherent in medical treatment interventions for chronic hepatitis C, there are certain implicit ontological assumptions about the relationship between the body, disease, and society. Focusing primarily on biomedical practices, it is argued that these assumptions might have a profound effect on the world-views of patients undergoing them. This in turn, might have far-reaching sociological implications. Using a methodology specifically developed for the purpose of explicating the ontological assumptions inherent in medical treatment, the visual and narrative texts produced by thirteen hepatitis C positive participants are examined.

A deconstructive analytical approach is then applied to these texts as they relate to the treatment interventions pursued by participants. An exploration of the way participants engage with, negotiate, and/or resist the discourses and assumptions inherent in biomedicine, traditional Chinese medicine, and to some extent naturopathy, is conducted. Two broad ways in which the participants visualise the relationship between disease and their bodies, relating to treatment undertaken, are identified. The possible social implications of these are then suggested. The first, and predominant view, is aligned with biomedicine. The relationship between disease and the body is antagonistic in this view. It is suggested that this way of seeing might naturalise xenophobic attitudes and perpetuate social conflict. The marginal view is related to non-biomedical treatments for hepatitis C. The relationship in this case is the result of a negotiated accommodation with the disease. It is suggested that such a view might allow for non-resistant social tolerance of that which is perceived of as new and different.

This qualitative study contributes to the body of knowledge in the field of the sociology of health and illness in two ways: Firstly, it proposes a methodology that may be taken up or adapted for future sociological research, and secondly, it suggests something of the social and political nature of treatment decisions made by people living with chronic hepatitis C.

**Disease is a relationship.**

**(Haraway 2000:75)**

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## CHAPTER ONE

### Introduction

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This thesis explores the idea that, inherent in medical treatment interventions, there are implicit discourses and ontological assumptions that may challenge or reinforce the way those undergoing them experience their bodies and their relationship with the social world. Using a methodology that combines the analysis of drawings produced by participants with their illness narratives, I focus on explicating the discourses and ontological assumptions of Western biomedicine,<sup>1</sup> traditional Chinese medicine, and to some extent other treatment modalities as they relate to the treatment of chronic hepatitis C. Drawing upon literature in the sociology of health and illness, the dominant ways of visualising the body and disease are evaluated in terms of their possible social implications.

There is nothing particularly new about the idea that medical treatment is imbued with social values that can profoundly influence those undergoing it. Jean Comaroff for example stated over twenty years ago that:

In the face of the doubt and anxiety which often accompany illness, healing processes powerfully reinforce the cogency of inherent meanings and the implicit images of self and its context drawn from the wider cultural system. Healing reaches down to deep-seated paradoxes of the human condition which illness lays bare, harnessing the physical symbols through which these are expressed with values reflecting specific interests. Healing the person thus reaffirms the integrity of an implicit construction of reality and its enveloping symbolic order  
(1982:52).

Writers such as Illich (1995:237), Comaroff (1982), and Foucault (1973) have in various ways argued that medicine can play a huge part in constructing the world-view of its subjects. From the 1970s onwards, a critical stance towards the workings

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<sup>1</sup> Henceforth the term 'Western biomedicine' is used interchangeably with simply 'biomedicine' to refer to the dominant form of orthodox medicine practiced in the industrialised West as well as many other parts of the globe (Kleinman 1995:25).



of conventional Western biomedicine has become known broadly as the medicalisation critique (Nettleton 1995:18-21; Lupton 1997:97). From within this body of work, some writers such as Ivan Illich (1995:237) have framed biomedicine in wholly negative terms, claiming that it is an oppressive institution that often does more harm than good. The medicalisation critique has, in turn, been critiqued by those who have pointed out that biomedicine is by no means a homogeneous institution of unified actors that works on the 'docile' bodies of their powerless patients (Lupton 1997:104; Williams 2001:138). In this study, I conduct an analysis of biomedicine and traditional Chinese medicine as it applies to a particular group of people classified as having a particular disease. This analysis does not, and indeed cannot, take in the full scope of these systems of medical practice as they are applied universally.

I have chosen hepatitis C because of my own connection with the epidemic, and because of its unique location as a recently discovered and particularly stigmatised disease that has confounded virologists and clinicians, as well as the people living with it. Because there is no definitive cure for hepatitis C, no particular system of medicine has the monopoly as far as treatment is concerned. This raises the question of why and how people make decisions about treatment. In order to address this question I will examine the inherent discourses and ontological assumptions of different medical systems as they apply to the disease. Biomedicine for example, emphasises that hepatitis C is caused by a specific pathogen that the immune system recognises as hostile and then attempts to destroy. Traditional Chinese medicine on the other hand, is more inclined to view the disease as a sign of disharmony in a microcosm of the universe. Understandably, the different perspectives of these respective treatment modalities is reflected in practice, and this in turn can influence the way people come to see themselves and their relationship with the social world. Seen in this way, treatment decisions have far reaching social and political implications and are thus worthy of sociological research. I will argue that there are some unfortunate social consequences associated with an uncritical adoption of the ontological assumptions and discourses involved with biomedical treatment,

particularly for those suffering from chronic hepatitis C. Using the material presented by participants, I will present an alternative way of visualising the body and disease that is more closely related to the ontological assumptions of traditional Chinese medicine.

### **Hepatitis C: back grounding the ‘silent epidemic’**

In the following section, I provide a brief background to the nature of the hepatitis C epidemic. I do this to give the reader a sense of the scale of the phenomenon, and to impart some basic information necessary to set the scene for the rest of the thesis. I then explain my own personal connection to hepatitis C as a way of posing the research question that initiated my research in this area.

The hepatitis C virus (HCV) was not isolated and classified as such by Western biomedicine until 1989. Prior to this it shared the ignominious title of Hepatitis non-A, non-B with a number of other unidentified viral seropresences (Turkington 1998:6; Dolan 1997:36). However, once tests to identify carriers of HCV were developed, the enormity of the epidemic became apparent. It is now thought by epidemiologists that Hepatitis C poses a greater public health problem in the industrialised West than HIV (Kuchment 2002:40; Wherry 2001:133; Kemp 1996:51). The United States Centre for Disease Control, for example, estimates that by 2010, the death toll associated with the disease will surpass that of HIV/AIDS (Wherry 2001:133). Nonetheless, hepatitis C has received little publicity, and it is often referred to as the silent or neglected epidemic (Askari 1999; Turkington 1998).

Although an estimated fifteen to twenty percent of people exposed to hepatitis C spontaneously clear the virus after initial infection, it is thought that all those that do not will be infectious carriers for life (Sievert 2001:153). Half of these people will go on to develop cirrhosis of the liver and other complications that impair liver function (Turkington 1998:9). It is estimated that between 25,000 and 35,000 people

in New Zealand are currently infected with the virus and, according to the Ministry of Health, "...this number is predicted to increase by 50% in the next 10 years" (2002:2.1).

The current hepatitis C epidemic is a result of the 20<sup>th</sup> century technological advances of Western biomedicine. Before the introduction of the hypodermic syringe, blood banks, and the widespread practice of blood transfusions, such an epidemic would not have been possible (Hankins 2002). Hepatitis C transmission requires direct blood to blood contact. Unlike hepatitis B and HIV/AIDS, the hepatitis C virus (HCV) is rarely contracted through sex (Ministry of Health 2002:2.3.2.2; Crofts 2001:226). Due to the technological vectors required to transmit the virus to large numbers of people, the hepatitis C epidemic is a hybrid of nature and technoscience. However, as I will argue, the disease can also be seen, in ontological terms, as a conflict between humans and alien viral invaders. The personal and social impact of this perception is examined throughout the thesis. In developed Western countries the blood supplies for transfusions are now screened, and eighty percent of newly acquired cases of hepatitis C in these countries are attributed to intravenous drug use (Ministry of Health 2002:2.1; MacDonald et al 2001:209-10). As a result there is considerable stigma attached to being HCV positive, regardless of the manner in which the disease was acquired.

The discovery of hepatitis C occurred in the wake of global fears about the HIV/AIDS epidemic, and many of the highly effective policy responses to HIV/AIDS have also been applied to hepatitis C (Puplick 2001a:299; Loveday and Wallace 2001:310). These strategies have emphasised an integrated approach that focuses on the reduction of new infections and improved treatment for those living with the virus (Puplick 2001a:303). There are however, some significant differences between the two epidemics that have affected public attitudes as well as public health policies. Perhaps the most important difference is that hepatitis C is overwhelmingly transmitted through intravenous drug use. The disease is therefore perceived of as little threat to those outside a particularly marginalised and vilified

community (Puplick 2001:307a). Despite its stigmatised beginnings as ‘Gay Related Immune Deficiency’ (Patton 1990:8), HIV/AIDS is predominantly transmitted through heterosexual sex, and as such, has generated a far higher level of fear in the general population. Compared to the resources and influence of communities affected by HIV/AIDS, people living with hepatitis C have very little political clout and this is reflected in public health funding (Loveday and Wallace 2001:312).

There is currently no vaccine available to prevent HCV infection and no definitive cure for those living with the disease (Ministry of Health 2002:2.1; Sievert 2001:153). However, most HCV positive people die with the disease rather than of it (Jenkins 2000:10; Turkington 1998:58,13). Although the rate of progression varies, many people remain relatively healthy for ten to twenty years after contracting the disease (Kuchment 2002:43; Dore 2001:84; Dolan 1997:13, 18, 20). Because of the indolent nature of this virus and its devastating potential, Hepatitis C is metaphorically known as ‘the sleeping dragon’. As no form of intervention can offer a cure, this raises the question of what determines the treatment decisions made by HCV positive people. Obviously there are many possible factors involved, such as the severity of symptoms, information available, and financial costs. Rather than attempting to definitively answer the question of why people with hepatitis C choose certain treatment interventions over others, the question itself will be used in a heuristic sense to guide my exploration of the subject matter. The question of how best to treat Hepatitis C, does however, open an epistemological debate that will be pursued throughout the thesis.

### **Intellectual autobiography**

In the early 1980s I began using drugs intravenously as a recreational pastime. New equipment for this purpose was illegal and generally unavailable and, as a consequence, needles and syringes were often shared and reused. At this time HIV/AIDS had not crept over the horizon and hepatitis C had not even been discovered. In fact hepatitis B appeared to be the only viral disease that posed a

threat to intravenous drug users.<sup>2</sup> Upon receiving the results of a HIV test in the early 1990s, I was casually informed by my doctor that although I was *not* HIV positive, I *had* contracted hepatitis C. At the time I was not ill, and the news had little impact on my lifestyle or the way I saw myself in relation to society. My initial response to being diagnosed with hepatitis C was dismissive in accordance with the doctor's pronouncement that it was not a serious condition. This attitude was common among doctors at the time (Dolan 1997:36). Nonetheless, some of the hepatitis C positive people I knew began to suffer from symptoms of the disease by the time they reached their early thirties. Their GPs referred them to liver specialists who recommended interferon therapy, which is the only treatment offered by conventional Western biomedicine. To my knowledge, no alternatives were ever mentioned. Three of my friends put their names on the waiting list for interferon therapy after being convinced of the efficacy of this treatment by specialists.

In my mid thirties I decided to explore the possibilities of a drug-free life and, with neophyte fervour, I embraced health foods, meditation, and exercise. Within several months of instigating these changes no detectable trace of the hepatitis C virus could be found in my blood. Unfortunately, my friends did not fare so well with interferon treatment. After they had undergone a six-month course of gruelling anti-viral therapy, the disease returned with a vengeance in each case. In spite of this, and despite the fact that no one we knew had been 'cured' by interferon, all three of my friends said they would undertake another course if it were available to them in a subsidised form. One of them even considered paying for the expensive treatment. At the same time, all of them were sceptical of alternative treatments and dismissed many of them as 'mumbo jumbo'. I could not understand why these intelligent people were so unwilling to pursue non-orthodox therapies that might have ameliorated their suffering, particularly as biomedicine had failed to help them. Neither could I understand why their GPs and liver specialists had not encouraged them to seek out so-called alternatives. These initial questions so intrigued me that I

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<sup>2</sup> Hepatitis B is generally an acute but temporary disease that leaves those infected with immunity to further infection from the virus. In the drug using culture that I was part of, hepatitis B was commonly viewed as a rite of passage.

devoted an honours project to addressing them. In turn the project became a pilot study for my masters' thesis research.

### **Honours project/Masters pilot**

Donna Haraway (1997:64) suggests that our understanding of health and illness is constituted by the images, metaphors, and narratives that saturate the fabric of our social worlds. Given this, an account of these images, metaphors and narratives will be necessary to understand both the experience of health and illness, and the treatment interventions undertaken by people seeking wellness. Following this epistemological premise of Haraway's, I proposed in my pilot study that drawings of the way the participants of my pilot study visualised the relationship between their bodies and disease would reveal more about their treatment choices than simply a standard interview. The three major questions driving the pilot study were:

- 1) How do people with hepatitis C visualise the disease?
- 2) Is there an apparent relationship between the way people with hepatitis C visualise the disease and the treatment interventions they have pursued?
- 3) Is the analysis of participant's drawings of these visualisations a useful method for uncovering the ontological assumptions inherent in such interventions?

The findings of this pilot indicated that the answer to the last two of these questions was affirmative. Asking participants to produce drawings (visual texts) thus became a central feature of my thesis research.

As previously mentioned, the idea that ontological assumptions are tacitly inherent in different forms of medical treatment, particularly captured my attention with regard to hepatitis C. I considered that an examination of these assumptions and the discourses arising from them would help me to address the question that had instigated my research in the first place. That is:

How do people come to be unwilling to pursue non-orthodox therapies that might ameliorate their suffering, particularly when biomedicine has failed to help them?

### **Push/pull debate revisited**

Without explicitly attempting to do so, both my pilot study and thesis research have engaged with an old debate; sometimes referred to as the push/pull debate. Put simply, this question debated is: are people *pushed* into pursuing alternative medical treatment due to negative experiences of conventional medicine, or are they *pulled* into non-conventional approaches to health by alternative philosophical convictions? Bonnie O'Connor (2002:55) explains that the implication behind much of the study in this area assumes that conventional medicine is sufficient and that the pursuit of alternatives is somehow deviant. However, studies involving the point of view of users of alternative and complementary medicine have found that, for the most part

...people typically seek complementary modalities for practical, *problem-solving* reasons: they have health needs that go beyond what conventional medicine does or can provide, they wish to multiply their preventative and therapeutic options, they have reason to believe these therapies may be useful, and/or they have philosophical and experiential reasons to find them attractive and reasonable choices...they can not accurately be characterized as “desperate,” and they do not demonstrate higher control needs or greater dissatisfaction with conventional medicine than the general public.

(O'Connor 2002:55. My emphasis in italics)

The above summation is consistent with the findings of Ursula Sharma (1992:203), who suggests that although the participants of her study generally sought alternative health care out of dissatisfaction with conventional treatment, their concerns were pragmatic rather than ideological. If, as Sharma and O'Connor have argued, treatment decisions are essentially problem-solving exercises, what ‘toolkits’ do people bring to these exercises? Or, to put it another way, what ontological, discursive, and cultural resources are they drawing upon to inform the decisions they make to optimise their health?

Throughout the thesis I will explore these questions relating to the push/pull debate by examining the drawings (visual texts) produced by participants to see if there is

an apparent relationship between the way these participants visualise hepatitis C and the treatment interventions they pursue, or have pursued. In doing so, I will attempt to explicate for the reader the discourses and ontological assumptions inherent in different forms of treatment available for the disease. This is a different take on the old debate that has led me to view health, illness, and medicine from a deeper and far more political perspective. In the course of this thesis I hope to make this perspective available to the reader.

### **Thesis overview**

This thesis explores the contention that there are tacit ontological assumptions inherent in different forms of medical treatment, and that these assumptions may have a profound effect in terms of challenging or reaffirming the way people undergoing such treatments understand the relationship between the body and disease, self and society. By analysing drawings (visual texts) produced by participants, along with the stories of their lives with the disease, I aim to show the reader how hepatitis C is visualised, and how these visualisations relate to the treatment interventions that the participants of this study have undergone, or currently pursue. In the light of this analysis, I will re-evaluate the dominant cultural metaphors, images, and narratives used to describe disease, with respect to how they might work to naturalise stereotypes that perpetuate xenophobic hostility.

Broadly speaking, this thesis is concerned with two related research questions. Firstly, I am addressing the social factors that influence the treatment decisions made by people with chronic hepatitis C. As these decisions are arguably problem solving exercises (O'Connor 2002:55; Sharma 1992:203), that have far reaching social implications, I am interested in the culturally circulating narratives, images, and metaphors drawn upon by the participants of this study as they negotiate the various treatment options available for their condition. Secondly, this thesis trials a methodology that combines the analysis of drawings produced by participants along with narrative methods. As such, this study provides an opportunity to evaluate this methodology for its usefulness in sociological inquiry.



In *chapter two* I position the body of the person living with hepatitis C as a site of competing medical discourses and practices. I then introduce biomedicine, traditional Chinese medicine, and naturopathy as treatment modalities based on radically different ontological assumptions, and demonstrate how ideas associated with these assumptions are manifested in typical clinical encounters. In this way I hope to disrupt any notions the reader may have about the ‘real’ nature of hepatitis C, and thus the most appropriate form of treatment to be pursued. Instead I will show how forms of medical knowledge frame both the disease and treatment in culturally specific and historically contingent ways. I then trouble the idea that these different forms of medicine are discrete and unified systems. For the purposes of my study however, they will for the most part be treated as such. This is because of the unique location of hepatitis C in relation to the treatments these different modalities have to offer. It is also because, at an ontological and epistemological level, they are in fact radically different (Unschuld 1992:45, 58-59).

*Chapter three* charts the development of a methodology capable of apprehending the complex and often subtle shifts in participants’ world-view as they negotiate and undergo different forms of treatment. Here I tell the story of my search through the available literature and epistemological debates concerning the use of visual material in social research. Because I have been unable to locate any work that adequately addresses my research questions, I have had to develop a specific methodology for my purposes. Nonetheless, I have been informed along the way by work in feminist geography, visual sociology, semiotics, and narrativity. In *chapter four* I discuss how the above methodology has worked in practice. In part this is a description of what I did and how I went about it, and in part an evaluation of the methodology. It stands as both a guide and a caution to others interested in using visual methods in their research.

In chapters five, six and seven I analyse the data collected according to themes that emerged during the research and analysis. I begin in *chapter five* with the uncertainty common to all of the participants of my study as an introduction to the

phenomenological experience of hepatitis C with regard to medical treatment. Here I suggest that a desire for a sense of control (certainty) is congruent with the scientific emphasis on control that underlies biomedicine. In my examples, the appeal of interferon therapy leads to, or reaffirms in patients, a certain view of disease that reifies the mind/body dualism characteristic of Western culture. I show how this pervasive ontological assumption tends to exclude the pursuit of alternative treatment such as traditional Chinese medicine, even when biomedicine proves to be ineffective. Here my initial question about treatment decisions is addressed. I then tell a story of the development of the drug, interferon, as an example of how 'value neutral' scientific enquiry and corporate interests are interwoven. Throughout this chapter I argue that, as a system driven by commercial and political interests, biomedicine has the capacity to colonise the lifeworld and bodies of people with hepatitis C.

In *chapter six* my focus shifts to the political nature of epidemics as they apply to the collective social body or body politic. Once again, the dualistic assumptions of Western culture are examined as they appear in public health and immune system discourses. I then narrow the lens to show how these assumptions and discourses are experienced and internalised by those living with hepatitis C. Here the themes of self/non-self, pollution/purity, stigma, discrimination, and late capitalist modes of production are discussed as they arise in the narratives and visual texts of the participants.

*Chapter seven* revisits the idea that the implicit ontological assumptions inherent in treatment interventions can challenge or reinforce the world-view of those undergoing them. Using examples from my study, I draw upon Simon Williams' (1996) concept of the chronic illness trajectory as an analytic framework for charting these possible transformations. The way HCV positive people reconstruct the story of their lives to accommodate the uncertainty, treatment options, and stigma of the disease is then discussed with reference to the narratives, images, and metaphors made available to them through treatment. Finally, using the material presented by

participants, I will propose an alternative way of visualising the body and disease that avoids many of the possible negative social consequences associated with the dualistic assumptions of Western biomedicine. This reframing is more closely related to the ontological assumptions of traditional Chinese medicine.

The initial question motivating my research concerns the decision made by several people known to me, who chose to pursue biomedical treatment for hepatitis C. While attempting to definitively answer this question is abandoned, I do use it to navigate an exploration that examines the possible relationship between the ontological assumptions inherent in medical treatment for hepatitis C, and the way patients visualise the disease in their bodies. The development of a methodology aimed at apprehending these visualisations, and the way this methodology was applied in practice, appear in chapters three and four. In chapters five, six, and seven, the visual and narrative texts produced by participants in this study are analysed with reference to literature in the sociology of health and illness, and in science and technology studies.

## CHAPTER TWO

### Ontological assumptions and medical treatment

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The people living with hepatitis C that I have interviewed in the course of this study have used a variety of different interventions aimed at improving their health. For some this has taken the form of a desperate attempt to rid themselves of the virus at great physical and emotional cost. For others, the treatment that they have pursued has had far reaching benefits in other areas of their lives. I have also spoken to people who have taken no direct action with regard to the disease. The three main forms of treatment used by these participants are interferon (Western biomedicine), traditional Chinese medicine, and naturopathic herbal remedies. Because no treatment for hepatitis C can *actually* be said to have the monopoly in terms of efficacy,<sup>3</sup> the disease can be seen as a location that particularly highlights competing medical discourses as they vie for epistemological hegemony. Nonetheless, biomedicine currently appears to hold the privileged position with regard to medical treatment in New Zealand and within contemporary industrial societies generally (Nettleton 1995:22; Kleinman 1995:38). I will therefore attend primarily to the biomedical view in this thesis.

This thesis explores the idea that the ontological assumptions underlying different forms of medical treatment are tacitly inscribed in the technologies and practices of treatment interventions. In this way certain discourses implying different world-

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<sup>3</sup> At the United States National Institutes of Health Consensus Development Conference in 1997, a standard definition of treatment efficacy for hepatitis C was agreed upon. This is called a *sustained viral response*, which is constituted by no detectable level of HCV in the blood as determined by a polymerase chain reaction (PCR) test, six months following the cessation of treatment. Although by no means a cure, a sustained viral response is widely considered to be the best indication of a beneficial treatment outcome (Sievert 2001: 143, 153). However, this is a biomedical definition of treatment efficacy, arrived at by scientific trials using double blind methods. Many treatments, such as traditional Chinese medicine, are difficult if not impossible to assess using scientific methods. It is therefore not possible to compare the results of clinical interferon trials with traditional Chinese medicine in terms of successful treatment outcomes. For a fuller explanation see Arachne (2001:155-171).

views might be conveyed to patients in the course of their treatment. In some cases these world-views might reaffirm the patient's ideas about their bodies, themselves, and their place in society, and in some cases it might challenge them. Simon Williams (1996:29) argues that an encounter with the practices of biomedicine may in fact serve to "reinforce and perpetuate" a perception that there is a profound split between a patient's mind and his/her body. I will investigate the narrative accounts and visual texts of a number of individuals who have undergone biomedical intervention for hepatitis C for evidence supporting Williams' contention.

The following section introduces the biomedical practices employed for the treatment of hepatitis C. I begin with a typical scenario of the biomedical encounter and briefly explain how the ontological assumptions behind conventional Western medicine are manifested in clinical practice. The possible implications of these inherent assumptions in terms of reinforcing or challenging the patient's view of self and society are then examined. In the light of this enquiry the practices of traditional Chinese medicine and naturopathy are discussed.

### **Biomedical technologies and practices for hepatitis C**

Prior to diagnosis, someone with hepatitis C might visit his or her GP presenting with symptoms such as nausea, lethargy, and headaches. The GP will typically perform a variety of blood tests and thereby discover the presence of HCV antibodies. Alternatively, the antibodies may be identified as part of routine testing for some other ailment, as many people with hepatitis C do not suffer from any noticeable symptoms.

Epidemiology and biomedical practice are both generally characterised by the theory of 'specific disease aetiology'. According to this theory, disease is caused by specific biological agents (Berliner and Salmon 1980:138). Put simply, biomedical practice is concerned with identifying the specific disease agent responsible for illness and eradicating it.<sup>4</sup> Since microbes were made visible in scientific

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<sup>4</sup> The specific biological agent responsible for hepatitis C is usually identified by the presence of HCV anti-bodies in the blood. However, the regular blood test analysis is not sophisticated enough to

laboratories during the 19<sup>th</sup> century, viruses have, for the most part, been understood as the enemies of human health (Harding et al 1990:53). If undeterred, viruses might be said to threaten the notion of individual autonomy that is central to the Western notion of personhood by colonising the vehicle of this autonomy (the human body) (Waldby 1996:1; Tauber 1994:186-87).

According to the biomedical view, viruses reproduce by appropriating the reproductive mechanisms of living cells. Once inside a host cell, viruses begin to replicate until the cell bursts, whereupon new viruses seek out other cells (Petro Roybal 1999:7). Similarly, Jenkins (2000:11) describes host cells as virus factories. Using militaristic metaphors, Fred K. Askari (1999:141) describes HCV as “foreign viral proteins” that invade the host’s body. The host’s body then mounts a counter attack by firing missiles in the form of antibodies at these invaders. Like immune system discourse generally, there is a clear self/other binary evident in such accounts. The relationship between actors is entirely antipathic. If someone with hepatitis C were to view the relationship between disease and the body in this light, would it follow that he or she would then allow the body to be a battleground where the war between biomedical technologies and viral invaders is fought out?

Once hepatitis C has been identified as the cause of illness, the patient is usually referred to a gastroenterologist or infectious disease specialist. In New Zealand, the patient will then be put on a waiting list for approximately twelve months before getting an appointment with one of these specialists. As few GPs have any specialised knowledge of hepatitis C, the patient is generally left to their own devices while waiting. The patient is seldom (if ever) encouraged to seek alternative health care or referred to a Hepatitis C Resource Centre. The process of waiting without attention or information for so long may leave many people feeling as if

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determine whether the virus is still present and active in the body. From here, a PCR blood test is necessary to gauge the amount of the virus present in the blood (viral load). But even if the results of a PCR test are negative, this does not mean that hepatitis C has been cleared, as the virus may still be present in the body at undetectable levels (Dolan 1997:57-59). It is therefore not possible to know if one has attained an absolute clearance of hepatitis C using biomedical technologies as a definitive gauge.

they, and their condition, are of little importance. Here the practice of medicine within the health system, can be seen to have a de-personalising effect.

Upon seeing a specialist, the patient will have another round of blood tests to recheck his/her liver functions. One of these tests will determine the particular subtype of hepatitis C (genotype) that the patient has contracted. A liver biopsy and follow-up appointment will then be arranged. The liver biopsy is required to determine the condition of a patient's liver and their eligibility for interferon therapy (Dolan 1997:61).<sup>5</sup> Individuals I spoke to in the course of this research described this is an extremely painful and invasive procedure. Liver biopsies have actually proved to be fatal in some cases (Dolan 1997:61). A biomedical clinician will "almost invariably" suggest interferon therapy for someone who meets the criteria related to their liver condition (Arachne 2001:168). The primary aim of interferon is eradication of the pathogen. It is a specific, yet relatively standard, course of treatment for a specific disease entity. A distinct *self* and *hostile other* dichotomy is apparent in this biomedical view. Elimination of *the other* equals a restoration of health.

As an advocate of alternative treatments for hepatitis C, Matthew Dolan (1997:100-01), describes interferon treatment as focusing almost entirely on the status of the virus, while ignoring the overall health of the patient. In other words, the patient's body becomes an incidental backdrop to the showdown between biomedical technologies and the virus. Practitioners of interferon therapy seldom consider symptoms often associated with chronic HCV infection, such as vitamin deficiency and poor digestion (Dolan 1997:100-01). The liver and virus specific nature of interferon treatment excludes other aspects of the patient's health, as well as his/her subjective experience of living with hepatitis C. This focus can be seen as objectifying the patient's body.

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<sup>5</sup> Other factors such as alcohol consumption and intravenous drug use also determine eligibility for interferon treatment.

Simon Williams (1996:23, 31) and Anne Scott (1998:1-2) argue that the pervasive Cartesian dualism of Western culture has led to an implicit (albeit general) worldview in which there is a radical split between the mind and the body. According to this dualism, the mind is privileged to such an extent that the body is generally taken for granted or viewed as a subservient vehicle for the mind. As embedded in, and arising from, Western culture, mainstream biomedical practice tends to reinforce the mind/body dualism by objectifying the body in such a way that it becomes isolated from the patient's social context and lived experience (Scott 1998:2; Kleinman 1995:32). The typical scenario presented above illustrates this process with reference to biomedical treatment of people with hepatitis C. If these practices then successfully restore the patient's health, this mind/body dualism can be further reaffirmed. The integrity of this culturally specific world-view and its "enveloping symbolic order" can thus remain intact (Comaroff 1982:52).

Many critics have noted the tacit dualistic assumptions inherent in the theory and practice of Western science and biomedicine. Treatments such as interferon can be seen to be implicitly organised around hierarchical binary dualisms that privilege culture above nature, self over non-self, mind over body, and science (as culture) above other ways of knowing (Scott 2001:1; Kleinman 1995:30; Plumwood 1993:42-43; Haraway 1988:592; Birke 1986:110). There is a logic of domination implicit in these dualisms that grants one half of the binary with primary value in relation to the 'other' half, which is conceived of as inferior (Seidman 1998:223; Plumwood 1993:47).

Western biomedical practice is reliant on scientific epistemology and methods.<sup>6</sup> Proponents of science claim that these methods are transparent, value neutral, and therefore objective (Joffe 1997:133; Patton 1990:5). However, as critics have pointed out, the ontological assumptions inherent in science and biomedicine, such as mind/body dualism, are culturally specific and far from value neutral (Weasel 2001:30; Barr and Birke 1998:2; Leslie and Young 1992:3). In Western societies

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<sup>6</sup> The diversity and heterogeneity *within* biomedical practice is discussed on page 23.



such ‘objectivity’ is often thought of as synonymous with ‘truth’ or ‘reality’ (Haraway 1997:182). Such credibility naturally has implications with regard to which treatments are taken up by medical authorities and funded by governments, as well as the decisions made by sufferers of diseases such as hepatitis C (Sharma 1992:28). Williams (1996:29) and Scott (1998:2) argue that if a treatment intervention is successful the implicit ontological assumptions inherent in such treatment are often reified, thus contributing to their continuing reproduction over time. In other words, if someone with hepatitis C was ‘cured’ through undergoing interferon therapy, which is inscribed with the ontological premise of mind/body duality, they would have less reason to question this dominant discourse of Western culture.

Donna Haraway (1997) has shown that the dualisms that Western biomedicine is based on, make increasingly less sense in a world populated by entities that traverse and implode binary categories. OncoMouse™ for example, is at once an animal, a commodity, and a scientific instrument (Haraway 1997:79). As the world’s first patented animal whose natural habitat is the laboratory, OncoMouse™ implodes the master binary of nature/culture, from which all other variants of this dualism stem in Western culture (Birke 1986:110; Haraway 1989:13). In the light of Haraway’s argument, these dualisms can be understood to be illusory. Nevertheless, as Haraway (1989:12) points out, the dualistic ontological assumptions of Western culture, and the logic of domination that has been crafted from them, have been particularly advantageous to some members of society and particularly problematic for others. She argues that it is “crucial” to investigate how binary dualisms “...may be deconstructed and maybe redeployed” (Haraway 1989:12). A large part of my thesis is involved with the deconstruction and possible redeployment of binary dualisms as they relate to medical treatment interventions for hepatitis C.

### **Traditional Chinese medicine and ontology**

The first consultation with a traditional Chinese medical practitioner may take up to an hour while the ‘four examinations’ are carried out to diagnose the patient’s state of health (Woodham and Peters 1998:142). This assessment involves:

- 1) Observation of physical appearance; particularly the tongue.
- 2) Listening to the patient's voice and noting any distinct body odour.
- 3) Questioning the patient about personal habits, bodily functions, and symptoms of illness.
- 4) Taking the patient's pulse.

From the information gleaned through the four examinations, the practitioner of traditional Chinese medicine builds up a picture of the patient's overall condition or "unique pattern of disharmony" (Woodham and Peters 1998:142). Someone suffering from hepatitis C will be prescribed a course of treatment specific to their individual condition or pattern of symptoms rather than one that targets the virus (Arachne 2001:168). Such a course may include Chinese herbs, acupuncture, moxibustion, and even Qi gong.

There is a significant difference between the traditional Chinese and Western biomedical understanding of the nature of causality, or disease aetiology. This difference is reflected in the medical practice of these respective systems. According to Ted Kaptchuk (1983:13-14), the laws of causality proposed by Aristotle in *Physics* have had a profound influence on Western philosophy. Aristotle emphasised the importance of discovering the "primary cause" behind a phenomena in order to understand it. This concern with causes in order to unveil the 'true' nature of things that lie beneath the surface has characterised modern science and biomedicine (Kleinman 1995:29, 30; Jordanova 1989:92). In traditional Chinese philosophy and medicine there is no original causative factor or prime mover. Kaptchuk explains:

The Chinese assume that the universe is continually changing. Its movement is the result not of a first cause or creator, but of an inner dynamic of cyclical patterns...The cosmos itself is an integral whole, a web of interrelated things and events. Within this web of relationships and change, any entity can be defined only by its function, and has significance only as part of the whole pattern  
(1983:15).

Historian of Chinese medicine, Paul Unschuld (1992:57) and medical anthropologist, Arthur Kleinman (1995:27) relate the biomedical preoccupation with

specific disease aetiology and singular truths to the Western monotheistic religious tradition in which there can only be one true god. Chinese religious thought on the other hand, tends to be polytheistic or atheistic in character, and this is reflected in traditional Chinese medical practice where plural and even competing paradigms are tolerated. Kleinman also points out that Chinese medical traditions seem to be “...less troubled with the uncertainty of human experience” that plagues biomedicine and Western culture generally (1995:27).<sup>7</sup>

Traditional Chinese medicine is based on ancient Taoist philosophy that divides the universe according to the binary of *yin* and *yang* (Kaptchuck 1983:8). While this may suggest a binary dualism similar to that of Western culture, the Taoist world view is very different (Kaptchuk 1983:139). Yin and yang are the two fundamental energy principles in the universe and they are manifested in Qi. Qi is largely ineffable, but it is often described as ‘life force’ (English and Foster 1997:104; Arachne 2001:155) or ‘vital energy’ (Sagli 2001:215). In simple terms, Qi is what animates matter (Dolan 1997:117). According to Chinese thought, Qi flows along energy channels (meridians) in the human body. Infections associated with hepatitis C can disrupt or block the even flow of Qi, resulting in symptoms of disease.

As one aspect of the binary, Yin is associated with cold, interior, and passive, while yang is heat, exterior, active, and so on (Hicks 1996:3). Yin and yang are interdependent and in constant and dynamic relationship to each other. A cold yin substance becomes yang in relation to an even colder substance and an external yang organ becomes yin in relation to an organ that is even more external. The major difference between Taoist and Western binaries is that Taoist classifications are not dualistic. Instead they are complementary. According to traditional Chinese medicine, a hierarchical relationship where either yin or yang dominated the other would lead to disharmony and disease (Pritchard 1999:13). In this system it is disharmony between yin and yang, rather than a virus, that causes the symptoms of

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<sup>7</sup> The theme of uncertainty as it relates to medical practice and treatment decisions is picked up on in chapter four.

hepatitis C (Dolan 1997:125; English and Foster 1997:104). In fact some traditional Chinese medical practitioners may not even recognise the hepatitis C virus as causing such symptoms (English and Foster 1997:107). Instead the practice of traditional Chinese medicine aims to redress disharmony between various elements and organs by clearing blocks and allowing Qi to flow evenly throughout the body's meridian system.

The major ontological understanding reflected in the practice of traditional Chinese medicine is that no part makes sense except in relation to the whole. Likewise, each person is considered to be a microcosm of the universe (Kaptchuk 1983:18; McNamara and Xuan Ke 1995:26). The universe is understood as “circular and self-contained”, and within it there is a constant dynamic flux unfolding as yin and yang (Kaptchuk 1983:256). This is the ontological assumption upon which traditional Chinese medicine is based. As a consequence, traditional Chinese medicine is referred to as a *holistic* system of medicine (Kaptchuk 1983:7). During diagnosis a practitioner of traditional Chinese medicine attempts to address the patient's overall physical, emotional, and spiritual condition, in order to diagnose illness and prescribe treatment aimed at restoring a balance of yin and yang that will then flow evenly through the body in the form of Qi.

### **Naturopathy and herbal treatment**

Faced with the discouraging success rates and adverse side effects of interferon therapy, many people with hepatitis C decide to pursue naturopathic remedies to improve their health (Dolan 1997:174). As with traditional Chinese medicine, the first consultation with a naturopath usually takes up to an hour, and here the patient's particular as well as overall condition is addressed. One HCV positive person I interviewed described naturopathy in relation to biomedicine by saying that people undergoing interferon therapy only get interferon, whereas through naturopathy the whole person is treated.

The philosophy behind naturopathic treatment has more in common with the ontological assumptions of traditional Chinese medicine, than those inherent in biomedicine. In naturopathy it is postulated that the body has an extraordinary capacity to heal itself through ‘vital force’, which is similar to Qi. Naturopathy is also similar to traditional Chinese medicine in that a state of balance or ‘homeostasis’ is emphasised as important for good health. This ‘natural’ balance is threatened by poor diet, stress, pollution, and lack of exercise (Woodham and Peters 1997:118). In the practice of naturopathy, surgery and synthetic drugs are avoided in favour of a range of ‘natural’ remedies such as herbs, fasting, mud packs, and colonic irrigation. These are used to stimulate the body’s innate healing power (Dolan 1997:175; Stalker and Glymour 1985:381-82). Implicit in naturopathy is a distinction between ‘natural’ and ‘un-natural’. Nature and natural remedies are privileged in naturopathy above what is considered to be un-natural or synthetic. Here a reversal of the culture/nature dualism can be seen in which nature is valorised above culture. However, as writers such as Haraway (1991, cited in Bryld and Lykke 2000:30) have pointed out, nature is by no means a natural, pure, or innocent category. Like other categories, what passes for nature is mediated by social and technical interventions (*ibid*). The hepatitis C epidemic, for example, blurs the boundaries of a binary distinction between nature and culture, by being a hybrid of nature and technoscience.

## **Medicalisation and medical systems as heterogeneous networks**

### **The medicalisation critique**

Biomedicine is not just any bureaucracy and profession, it is a leading institution of industrialised society’s management of social reality...This process of *medicalization* is responsible for certain of biomedicine’s most controversial attributes. Biomedicine’s sector of influence continues to grow as more and more of life’s problems are brought under its aegis...No other therapeutic system can exercise this degree of power, because no other has become so powerful a part of the state’s mechanisms for social control (Kleinman 1995:38. Emphasis in original).

For well over thirty years a large body of work has emerged in the social sciences that critically examines the political and social interests served by modern medicine. From the 1970s onwards, this critical stance towards the workings of conventional Western biomedicine has become known broadly as the ‘medicalisation critique’ (Nettleton 1995:18-21; Lupton 1997:97). In her summary of the medicalisation critique, Deborah Lupton (1997) distinguishes the orthodox critique of Western medicine, which arose from Marxist and liberal humanist perspectives, from that of writers informed by the work of Michel Foucault. The orthodox medicalisation critique emphasises the repressive aspects of medicine and its alignment with the dominant interests of capitalism and patriarchy (Nettleton 1995:18; Armstrong 1995:46). Ivan Illich (1995:237), for example frames biomedicine in wholly negative terms, claiming that it is an oppressive institution that does more harm than good. The underlying assumption of the orthodox medicalisation critique is that society should be de-medicalised to the extent that patients can reclaim power and autonomy from the overbearing influence of modern medicine.

The orthodox medicalisation critique has in turn been critiqued by those writing from Foucaudian perspectives, who argue that the workings of power are far too complex for such patient liberation to occur. From a Foucaudian perspective, power is relational; it is not exclusively possessed by dominant groups such as the medical profession (Lupton 1997:99; Lacombe 1996:339). Instead, power is disseminated or translated throughout society chiefly through discourse and discursive practices.<sup>8</sup> Gail Bederman (1995:24) describes discourse as “...a set of ideas and practices which, taken together, organize both the way a society defines certain truths about itself and the way it deploys social power”. The discourses associated with medical treatment for hepatitis C allow certain understandings of the body, disease, and society to be transmitted to patients, and at the same time constrain others. Conventional immune system discourse for example, relies on a distinction between *self* and *non-self* (Weasel 2001:29). Here the immune system protects the body (self)

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<sup>8</sup> For an extended explanation of Foucault’s notion of discourse, see Fillingham (1993) and McHoul and Grace (1998).

by recognising foreign bacteria and viruses (non-self) that threaten health. An immune response is then mounted to attack what has been distinguished as not part of the body (Birke 1999:142). Without a distinction between self and non-self, conventional immunology would be rendered unintelligible.<sup>9</sup>

Some interpreters of Foucault concentrate on the repressive nature of discourse and suggest that there is no biological reality or lived experience outside of discourse; that the human body is little more than a passive or docile entity created and dominated by the clinical gaze (Williams 2001:148; Lupton 1997:102). However, Foucault's later work emphasises that power and resistance are two sides of the same coin. Here power always encounters resistance, which generates creative possibilities for change (Lupton 1997:102-03; Lacombe 1996:339,342). Danny Lacombe argues that in Foucault's notion of power there is room for individual agency and practices of emancipation as well as social control (1996:332).

### **Heterogeneity of treatment modalities**

Other sociologists of health and illness have pointed out that biomedicine is by no means a homogeneous institution of unified actors that works on the 'docile' bodies of their powerless patients (Lupton 1997:104; Williams 2001:138). Simon Williams for example, asserts that Western biomedicine is in fact made up of varying "disciplines and sub-disciplines" that are "...not 'all of one mind', and do not 'hunt as a pack'" (2001:138). Williams also cautions against medicalisation critiques that caricature biomedicine as unreflectively embracing the medical model in a reductionist manner (2001:140-41). Kelly and Field explain that disease

...taxonomies, aetiologies and therapeutics are used in medical practice as ideal types, *constantly subject to revision*... [And that] *medicine tends to be much more holistic than medical sociology traditionally gives it credit for* (1994:35, cited in Williams 2001:141).

Mei Zhan (2001:461) argues similarly that

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<sup>9</sup> The pervasiveness of this particular discourse and its possible social implications, are discussed in chapter six.

...traditional Chinese medicine cannot be reduced to a self-contained, coherent system which is then presumed to be emblematic of an ancient Chinese culture... [But rather] that what we know today under the umbrella of “traditional Chinese medicine” is a set of heterogeneous practices shaped by their intricate relations with science and biomedicine.

Using Chinese doctors who combine biomedicine with traditional practice such as Li Fengyi as examples, Zhan demonstrates that the epistemological divide between traditional Chinese medicine and biomedicine is straddled effectively in day to day practice in China. Dr Li’s patients, like the participants of my study, are more concerned with what works for them, than with an adherence to cultural norms regarding medical treatment (2001:472). Zhan challenges medical anthropologists to move beyond the “great divide” between biomedicine and traditional Chinese medicine, just as many of those involved with these practices have done. He recommends envisioning science and other ways of knowing as “...translocal, open ended processes and networks for knowledge, identity, and community formation” (2001:475). In such a view, medical systems and ways of knowing are understood to be shaped and maintained in relation to each other by networks of heterogeneous actors. Patients and clinicians, as well medical technologies, all participate as actors in this process (Law 1992:380). By focusing on the day to day practices of actors, this understanding of medical systems avoids the establishment of a dualism involving Western biomedicine and traditional Chinese medicine. Whether or not this perspective is consistent with how the hepatitis C positive people of my study negotiate treatment options will be addressed later in the thesis.

On the face of it, my study may appear to lump the heterogeneous systems of medicine used by people with hepatitis C together as if they were homogeneous institutions whose constituent members all shared the same world-view. However, this is not my position. My critique of biomedicine, traditional Chinese medicine, and other treatment modalities is confined to medical treatment practices as they relate directly to hepatitis C. In the case of biomedical treatment for this disease, there is only one offering: that is, interferon therapy and the biomedical diagnostic



technologies associated with it. This treatment, as it applies to the participants of my study, *is* consistent and invariable enough to be discussed as such.

Furthermore, at the abstract level of ontology that is central to my thesis, the aforementioned systems of treatment are radically different, particularly those of biomedicine and traditional Chinese medicine. Medical historian Paul Unschuld (1992:45,58-59) argues that while biomedicine and traditional Chinese medicine have more in common than is usually understood, there is a profound discrepancy between these two systems at an epistemological level. In Western culture, science and biomedicine, truth is generally thought to exist, and this truth is progressively sought. There is consequently a dependence on an either-or logic to discover this truth. The discovery of a new truth displaces what was previously considered to be true. In Chinese thought however, new knowledge joins old knowledge and forms what Unschuld calls ‘patterned knowledge’. He writes:

Patterned knowledge is based on a concept of truth that reveals itself through usefulness. A knowledge is true when its application leads to a desired end. Different truths may coexist if their application results in a successful manipulation of a perceived reality  
(1992:58)

Put simply, within traditional Chinese medicine there is the possibility for plural truths and their coexistence is determined by efficacy of treatment in practice. This is an anathema to Western scientific logic and biomedical practice, where definite answers are required. Because of this fundamental epistemological discrepancy arising from radically different ontologies, I will make a clear distinction between biomedicine and traditional Chinese medicine in my discussion of these treatment modalities for hepatitis C.

In summary, Western biomedicine, traditional Chinese medicine, and naturopathy are not discrete systems of medicine. Nor are these systems entirely incompatible with regard to treatment for hepatitis C. The boundaries or ‘great divide’ between what is considered to be medical treatment based on science, and alternative methods, is a distinction that has arguably been strategically constructed and

maintained by all three of these forms of medicine to further their interests (Zhan 2001; Broom 2000). Zhan claims that it is also a distinction imposed by medical anthropologists for academic purposes (2001:472). Some practitioners of traditional Chinese medicine recognise hepatitis C as a viral entity, and use biomedical diagnostic tools to determine the success of treatment. At the same time many practitioners of Western biomedicine have incorporated the use of acupuncture. But how do those living with hepatitis C make use of various different treatments for hepatitis C? While the ontological assumptions upon which these treatments are based are radically different, and in most cases incompatible, it is how these assumptions appear in the accounts I examine, and the sociological implications of this, that I am concerned with in this thesis.

The aim of this chapter has been to alert the reader to the presence of certain implicit world-views, or ontological assumptions, inherent in different forms of medical treatment for hepatitis C. Using typical clinical encounters as examples, I have argued that the ontological assumptions underlying biomedical treatment, are implicitly dualistic and congruent with Western capitalist world-views. The ontological assumptions of traditional Chinese medicine, on the other hand, are based on Taoist philosophy. In the Taoist world-view, balance and harmony are considered essential for good health. Here, dualism would lead to disease. I have argued that the dualistic assumptions inherent in both biomedicine and Western culture are imbued with a logic of domination that serves some members of society at the expense of others. I have therefore proposed that a deconstruction and redeployment of these dualisms present in biomedical treatment for hepatitis C is in order. However, before beginning this deconstructive analysis, I lead the reader through the theory, epistemology, and development of the methodology I used in my research. In this discussion there is a particular emphasis on the use of visual methods in social science. Following this, I describe the application of my methodology in some detail so that the process can be followed by others interested in using similar visual research methods.

## CHAPTER THREE

### Visual methodology: theory, epistemology, and development

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Images allow us to make statements which cannot be made by words, and as the world we see is saturated with sociological meaning. Thus it does not seem peculiar to suggest that images enlarge our consciousness and the possibilities for our sociology (Harper 1998:38).

Setha M. Low (1994) points out that the methods traditionally used by social scientists have largely failed to grasp the lived experience of illness and embodiment. She argues that this is partly due to the unseen nature of the biological “sensing body” (1994:139). Initially, the idea of asking participants to draw the way they visualise hepatitis C in their bodies seemed to me to be an intuitively commonsense method of gaining extra insight into how the disease is understood and experienced by people living with it. Having been inspired by the drawings of the immune system produced by people in the work of Emily Martin (1994), I was under the impression that there would be established conventions for the analysis of such material; if not in sociology, then at least in some neighbouring discipline. I have found, however, that this is not the case, particularly with regard to drawings of the relationship between the body and disease. This alarming dearth of sociological work using drawings suggested to me that such a method might be somehow untenable, and at this point I almost abandoned the idea.<sup>10</sup>

My search for material to support the use of drawings produced by participants as a research strategy has taken me on a journey from ‘new age’ visualisation practices to the sub-field of ‘visual sociology’, and then from art therapy to semiotics. In this chapter I review the literature that I have uncovered, and chart the process of formulating a methodology for my work. In chapter four I explicate the methods I

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<sup>10</sup> If it were not for the enthusiasm and support of my supervisors and colleagues, I might have indeed abandoned this strategy.

used to gather information and analyse it so that the process can be followed by others interested in using similar visual research methods for their own work.

### **New Age visualisation**

I discovered early on in my research that the term ‘visualisation’ that I originally coined, following Donna Haraway (1992:319), has some associations with what is known broadly as ‘New Age’ thought. Scholar of the world’s religious traditions, Ken Wilber, argues that every philosophical approach makes disease meaningful in a particular way. Wilber explains that according to New Age thought, disease is an opportunity for the sufferer to learn; an aid to spiritual growth (1994:40, 46). In the popular New Age text *Creative Visualization* (1982), Shakti Gawain describes visualisation as a technique whereby the power of imagination is used to create what is wanted in one’s life. The concept behind this technique is that we consciously and unconsciously create our own reality according to our beliefs and thought patterns (Gawain 1982:2-3). This would suggest that hepatitis C, or at least illness related to hepatitis C, is a manifestation of beliefs and thought patterns rather than viral (or other) infection.<sup>11</sup>

Positive visualisation is a key component of many New Age practices aimed at self fulfilment and healing. Rosalind Coward (1989:114-15) explains that underlying these practices is the assumption that there is a ‘real’ self that can be found, and that this self will have goals unencumbered by negativity. By implication, these goals will be healthy. Positive visualisation

...involves the formation of ‘positive’ imagery - either of something we would like to be or something we would like to happen. These images are most effective, we are told, in a state of deep relaxation when they can insert themselves in our subconscious and become part of our being, chasing away the shadows of negative and limiting self-definitions.

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<sup>11</sup> If illness is created exclusively by thought patterns and beliefs, it could be argued that disease and suffering are a choice. “Victim-blaming” or “New Age fascism” can follow from such logic (Scott 1996:151; Wilber 1994:42).

(Coward 1989:114)

In the case of New Age visualisation, the conscious mind is used to shape both the 'subconscious' and material reality. These visualisation practices have been applied to everything from weight loss to cancer treatment with varying results (Coward 1989:114-15). Asking the participants of my study to draw the way they visualise hepatitis C in their bodies had no intentional therapeutic value. Nor was I aiming to access the 'subconscious' or 'real selves' of these people. Rather I hoped to capture a glimpse of the culturally circulating images, narratives, and metaphors that constitute the socially constructed aspects of living with hepatitis C for this particular group.

To illustrate this distinction I refer to my experience with one participant who misunderstood my definition of the term 'visualisation'. I was taken aback in this particular interview when the participant (Juan), rang Tibetan toning bells and prayed for the highest spiritual good to come out of the occasion. Juan began his picture by drawing with his left hand to contact his 'inner child' so that he could ask permission for the interview to go ahead. Fortunately the answer was affirmative. He drew in silence for a long time with his eyes closed and what he produced would have been difficult to decipher without his assistance.<sup>12</sup> Juan became offended towards the end of the interview when I asked if he could think of any books, television programmes, and suchlike that might have influenced his visualisation. He told me that he had gone to a great deal of trouble to perform rites and invoke his inner child in order to expunge the very influences that I was aiming to apprehend with my visual methodology. For Juan, visualisation is a way to access an inner reality that is more 'real'. However, for the purposes of this study, this form of New Age Visualisation proved to be somewhat problematic.

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<sup>12</sup> See appendix A for Juan's visual text.

### **Visualisations of the body: In search of a method**

The idea behind this thesis began to take shape during the course of an Honours' paper that I undertook in 2001.<sup>13</sup> In fact, the project I produced for this paper became the pilot study for my Masters' research. One of the major questions driving this study was: is there a relationship between the way people visualise disease in their body, and the way they understand their body to work? The findings of the pilot study indicated that the answer is affirmative. Following from this is the question:

*Is there a relationship between the way someone visualises/understands their body to work and the treatment they seek to ameliorate disease?*

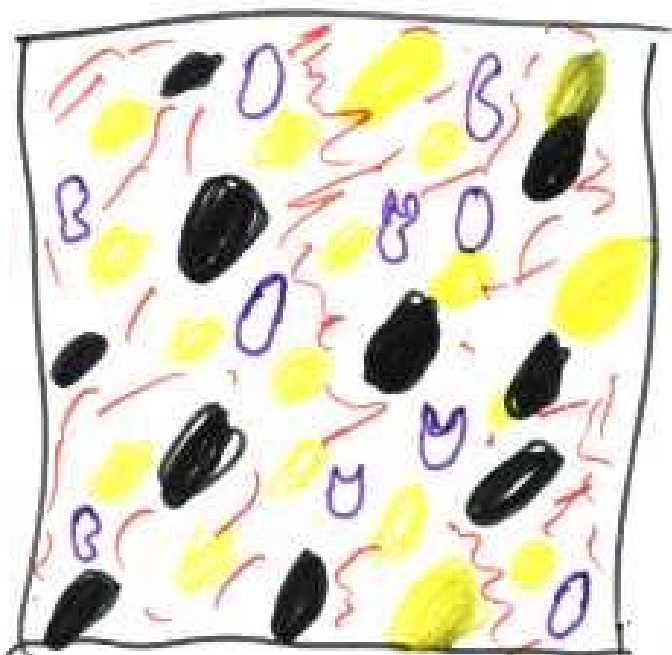
If, for example, someone with hepatitis C visualises their body as a machine, are they more likely to pursue a course of treatment based on the ontological premise that the body *is* a machine? On the other hand, would someone who visualised their body as a dynamic relationship of elements, be more inclined to seek treatment such as acupuncture, homeopathy, or herbal therapy? To address these questions more fully I first had to develop my methodology for uncovering how it is that people visualise or understand their bodies.

### **Vision and visualisation**

The inner workings of our bodies are not routinely *visible* to us, but they can be *visualised*. Barbara Duden (1993:568) argues that the visible content of what is viewed through biomedical technology makes little sense unless the viewer takes it on faith that they are seeing what they are told to see. Duden compares illustrations in *Life* magazine of early foetal development and argues that, since the 1960s, there has been a move away from representing what is visually comprehensible, to that which requires an authoritative explanation (1993:569). A case in point is Fran, whose naturopath took a sample of her blood and projected an image of it on a television monitor. Below is a drawing of how this appeared to her:

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<sup>13</sup> SOCI 430 (Science, Technology & the Politics of Knowledge) University of Canterbury (2001).



Fran tells me that the first time this was done:

...there was big blobs of yellow and big blobs of black, and these kidney-shaped things that he said were white blood cells...but they're not meant to be that shape...After six months on the herbs there was no fat in the blood anymore and the cells were starting to look better. The yellow is fat, and the black is toxins...Now the cells are looking really, really good.

With the explanation of her naturopath, this visual technology provides Fran with a clear picture of how her health has progressively improved since she has been taking the prescribed herbs. Nonetheless, the multi-coloured swirls and blobs viewed through this technology require the interpretation of an expert. Fran takes it on faith that what she is seeing is what she is told to see. Her drawing suggests that Fran could just as easily be viewing the balloons and streamers of a child's birthday party as the status of her health.

While it is not possible to *see* the relationship between disease and the body with eyes unmediated by technology, it is possible to *view* a mental image in the mind that represents such a relationship. I call this a *visualisation*. A visualisation in this

sense is a representation; a pictorial metaphor in lieu of what can be seen with the naked eye. Visualisations do not arise in a vacuum. They are inevitably influenced by the images and concepts made available to us through popular culture, public health education, and biomedical technologies such as x-rays and electron micrographs. I contend that how people come to understand the inner workings of their bodies, and the treatment interventions that they pursue, will to some extent be informed by visualisations constituted by the above elements.

It seemed appropriate to use a visual method to convey a predominantly visual process. It also seemed reasonable that the actual process of visualising and then creating such pictures might also allow participants to access understandings not available to them by other means.<sup>14</sup> However, I was plagued with questions such as: What strategies should I use to collect these pictures? How should I interpret and analyse them? What kind of validity can I claim for these methods? Perhaps the most daunting question facing me was: If asking participants to draw their understandings of their bodies, health and disease is an effective technique for eliciting information, why has this method not become part of the standard repertoire for qualitative researchers in the sociology of health and illness?

Many, if not most, forms of qualitative research offer researchers' methodological frameworks to follow, refer to, and build upon when designing their research (Prosser and Schwartz 1998:117). Despite a lengthy search, I have been able to find very little sociological work that uses drawings produced by participants. Although Martin (1994:64-81) does include pictures of the immune system drawn by some of the people she interviewed, there is little analysis or discussion of them. In the appendices of *Flexible Bodies*, Martin provides a list of the questions asked in the neighbourhood interviews she conducted (1994:263-265). There is however, no

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<sup>14</sup> Research in psychology since the 1960s has shown that the left and right hemispheres of the brain process information differently. Rational, linguistic and analytic thought is associated predominantly with the left side, while the right side is generally associated with intuitive, visual, and creative processes. See Gregory (1987:740-746), Anderson (1995:26,142), Ward and Daley (1993:10,41), Woodham and Peters (1998: 175). As visualisation and drawing use the right side of the brain where memories are stored and recall occurs, it seems likely that different information would be accessed in this process.



indication that each participant was invited to draw the way they visualised the immune system. This suggests that, unlike in my own research, the drawings featured in her book were not an integral part of her methodology. Nonetheless, I did find her list of questions to be a useful guide when compiling my own interview sheet. One major difference in our respective projects is sheer size and scope. Martin interviewed more than 200 people over a period of 3 years, whereas I have conducted interviews with 18 people (including my pilot study) in less than a year (1994:9). Martin's aims were also different in that she was interested in the public conception of the immune system. I, on the other hand, have sought to gain an understanding of how people with a specific health problem come to understand/visualise the relationship between the disease and their bodies.

### **Scientific epistemology**

Since Enlightenment agendas of liberating humankind through the application of reason displaced religion as the predominant way of apprehending 'reality' or 'truth', the 'metanarrative' of science has arguably pervaded Western culture (Johnson 2000:104-05; Seidman 1998:226). As a consequence, appeals to science, rather than God, hold the most sway in arbitrating truth claims. Blaikie (2000:185) suggests that there is a hierarchy of what counts as the most objective and accurate data in research. At the top of this hierarchy there are numbers. Numerical data is then followed by text. Below these lie what are considered to be less reliable forms of data, such as drawings. Visual research methods are seldom used by social scientists, and when images do appear, they are usually in the form of graphs or photographs that illustrate findings discovered by other means (Prosser 1998:100; Collier 1967:x cited in Harper 1994:404).

The hierarchy of epistemological validity can be linked to the 'modern' scientific emphasis on objectivity, precision and control (Birke1999:86, 177n.3). Lynette Hunter (1999:5,67-8) explains that because language does not accurately represent the experimentation central to the scientific method, written text is replaced by

mathematical figures, which appear to be more precise. However, once data from an experiment has been generated in numbers, it has to be translated into written language to produce scientific theory, that is comprehensible to anyone outside the particular experiment. The conventions of language then allow social values and ideology to permeate scientific theory despite the scientist's best intentions of value neutrality (Hunter 1999:67; Keller 1992:127). Using examples of scientific writing about sexual reproduction in evolutionary theory, Evelyn Fox Keller shows how text is at once value laden and protected from critical investigation (1992:142-43). To illustrate this mechanism, she gives the example of a description of a particular scientific experiment in which the technical and supposedly neutral term "competition", takes on its colloquial meaning to give the experiment an ideological bias (1992:121). However, the slippage of meaning is such that the ideology of competition can remain implicit and its existence can be denied if challenged (1992:122).

Harding (1991:142, 45) argues that all knowledge is socially situated, and that even though extreme forms of objectivism claim that a 'true' account of the world is possible through an application of the scientific method, such accounts are themselves socially situated. One reason for this is that all scientific projects are constituted by and through social, political, and commercial interests with their particular historical context. The massive pharmaceutical company funding of interferon research is an example of the way commercial interests are interwoven with scientific research (Richards 1991:214-15).<sup>15</sup> The above critiques of scientific methods demonstrate that, as a way of knowing, scientific methodologies are not necessarily any more objective or value neutral than those based on qualitative visual data.

Given the evident gender, sex, and racial biases inherent in the practices of science, Feminist scholars have been challenged to develop alternative epistemologies that might represent a 'truer' or less biased account of the world (Weasel 2001:28).

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<sup>15</sup> For the development of interferon technology see chapter five.

Some, such as Sandra Harding (1991:144), claim that although social values and interests are inherent in all research, some values are better than others in terms of epistemology. She argues that projects driven by “maximally liberatory” interests for example, tend to be better able to identify assumptions that distort research than those that are not. This is because antilibertary “...interests and values silence and destroy the most likely sources of evidence against their own claims” (1991:148-49). Harding proposes that the standpoint of marginalised groups such as women provides a better perspective from which to explicate the unreflective assumptions inherent in accounts of the world made by members of dominant social groups (1991:150).<sup>16</sup> Later in this chapter I discuss how, as a member of a ‘dominant’ social group (white male), I have attempted to negotiate this epistemological conundrum.

### **Visual epistemology**

While it is quite common to see images of participants, particularly in anthropology, it is unusual indeed to find studies that use visual images produced by the participants themselves (Bolton et al 2001:501). Perhaps the earliest, or most well known of these studies is *Through Navajo Eyes: An Exploration in Film Communication and Anthropology* (Worth and Adair 1972). In this ethnographic project, the participants were given film equipment, taught how to use it, and then encouraged to record something of their way of life. Although this ethnographic work was mediated by a technology unfamiliar to the Navajo Indians, Worth and Adair attempted to instruct them in a way unbiased by filmic conventions; the idea being that an emic or insider account would be produced rather than another example of *us* (the white ethnographers) doing it to *them* (the indigenous people) (Prosser and Schwartz 1998:120; Harper 1994:411).

In my research, I have attempted to include something more of an insider account than is usually present, by asking participants to produce visual images themselves. Although their subject matter was constrained by my own research interests, and the medium of expression provided (felt-tip pens and paper), the participants were

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<sup>16</sup> For a comprehensive discussion of this epistemological debate, see Hunter (1999).

encouraged to freely draw a personal depiction of the relationship between hepatitis C and their bodies.<sup>17</sup> I think the wide range of images produced is a testament to this.

According to Ruth Holliday (2000:504), the “endemic” mistrust of the use of visual images within sociology is countered by what she calls “...an undue faith in text.” Holliday argues that the use of images has long been associated with art and that, within the social sciences, art is considered subjective, whereas text is aligned with science and objectivity. Similarly, Jon Prosser (1998:97), one of the key figures in ‘visual sociology’, explains that image-based research has been indirectly marginalised in an attempt by the social sciences to gain credibility by adopting a scientific or objective stance. Prosser explains that images, and particularly photographs “...are unacceptable as a way of ‘knowing’ because they distort that which they claim to illuminate; and images being socially created and mediated are skewed by the socio-context of ‘making’, ‘taking’ and ‘reading’”. He goes on to say that there “...remains a strong belief that to include images would serve to undermine social research as a science” (Prosser 1998:102). Similarly, Howard Becker suggests that the use of ‘the visual’ in sociology has been frowned upon as “...pandering to the low tastes of the public or trying to persuade readers to accept shaky conclusions by using illegitimate, ‘rhetorical’ means. In short, using visual materials seems ‘unscientific’, probably because ‘science’ in sociology came to be defined as being as objective and neutral....” (1998:87). It stands to reason then, that any sociologist wanting to be taken seriously within a discipline that privileges text so highly would attempt to distance themselves from the visual research methods.

Steven Seidman (1998:11) argues that the romance with science within the discipline of sociology can be traced back to Comte and Marx, who used the rhetoric of science to gain public favour for their utopian social theories. However, as the

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<sup>17</sup> I made it clear to participants before the interview that they were free to use materials other than felt pens if they preferred. However, apart from one person who produced four paintings prior to the interview, all but one of the eighteen participants chose to use the standard materials I provided.

nascent discipline of sociology became institutionalised in the late nineteenth century, these utopian visions gave way to the “empirically controlled social explanations” of Durkheim and Weber (1998:11). Seidman argues that, although knowledge of the social world became framed in the scientific language of objectivity and value neutrality, it was, and still is, nonetheless coloured by the social scientist’s own particular moral and ideological perspective as well as the interests of those funding the research (1998:346-348).

When charting the history of sociology, Seidman explains that although there has been much dispute within the discipline about the role of theory and the relative merits of different research methods, an appeal to science for credibility has been common to all the dominant competing arguments (1998:345). As previously mentioned, it is text that is considered the most neutral and objective (that is, scientific) means of conveying knowledge. The visual and other forms of data, such as oral narrative, are treated with suspicion and generally dismissed as subjective (that is, unscientific). Scientific or positivistic sociology is built on the premise that the universe is ordered and “...made up of discrete and observable events” (Blaikie 2000:102). Scientific findings should be derived from unambiguous observable data that can be quantified and reproduced (Kvale 1996:62-63). When discussing the use of visual methods, Becker (1998) explains that an exponent of scientific sociology would be likely to criticise the use of images in research because they

...would not be sure, and have warrant for their uneasiness, that the images have the meaning I am imputing. They would not, however, take the next step, which would be to see that every form of social science data has exactly these problems, and that none of the commonly accepted and widely used sociological methods solves them very well either.  
(1998:91)

In other words, the speech of participants transcribed into text, can be *equally as ambiguous and open to interpretation* as the pictures drawn by them. The research methods I have used do not fit easily within a positivistic paradigm, and the drawings produced by the participants in my study are certainly not unambiguous.

However, the information I am seeking cannot be found within the limits of a positivistic approach. It is my contention that by triangulating a number of different methods to elicit and substantiate information, I can claim substantial veracity for my methodology with regard to my research findings.

### **Visual sociology**

There is growing interest in a sub-discipline known as ‘visual sociology’. This movement within sociology has at least one journal dedicated to image-based research (Harper 1998:38), and as of September 2002, the *International Visual Sociology Association (IVSA)* boasted 307 members worldwide.<sup>18</sup> An internet list-serv group also provides a forum for discussion and ideas sharing about the use of visual methods.<sup>19</sup> By becoming a member of this group I have been able to track down some work that makes use of drawings by participants and that to some extent explicates a visual methodology. For example, Patrick Krueger and Leslie Irvine (2001) elicited over 600 drawings and over 100 written descriptions from undergraduate students of a “sociologist at work”. With a view to assessing stereotypes regarding the gender and activities of sociologists, Krueger and Irvine then used both quantitative and qualitative methods to analyse this data (2001:65). When making comparisons “within and between” the written and visual media, they found that “...drawings revealed stereotypes held by the students that did not appear in the written accounts” (*ibid*). Krueger and Irvine’s findings indicated to me that the use of participants’ drawings may help to uncover some of the ontological assumptions that guide people’s decisions about medical treatment interventions; especially as such assumptions may be difficult for participants to put into words.

Visual sociology as an "empirical tradition" can be traced back to the 1960s and 1970s, and is seen in the work of Sol Worth, Howard Becker, John Collier Jr., and

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<sup>18</sup> The recent proliferation of work in the social sciences that uses visual methodology is no doubt partly due to the advances in technology that make such methods possible. The widespread use of computer scanning technology and desktop publishing has allowed researchers to copy collected data and make quality reproductions with ease and at low cost to themselves and publishers.

<sup>19</sup> [listserv@pdomain.uwindsor.ca](mailto:listserv@pdomain.uwindsor.ca)

Jay Ruby (Prosser and Schwartz 1998:116, Prosser 1998:100). When describing the history of visual sociology, Douglas Harper (1994:405) explains that the early visual sociologists took much of their inspiration from the temper of the times and were influenced by documentary photography, which is based in the tradition of liberal humanism. Consequently, their work focused on photographic studies of drug culture, racism, new social movements, and poverty. In these studies there is a sense that the photograph captures ‘reality’, and that social problems could thus be exposed to the public, and that this exposure would in turn lead to social change. Harper points out that “...in the documentary movement there was very little, if any, discussion of issues of representation, ideology, or how the relationships with subjects influenced these largely photographic studies” (1994:405).<sup>20</sup> Since the early work in visual sociology, the notion that photography unproblematically represents reality has been soundly criticised along with the idea that empirical methods alone are enough to understand the social world (Harper 1994:406).

From the visual sociology literature I have reviewed, there is a general consensus that visual research should be carried out in conjunction with other methods of gathering information such as interviews, written descriptions and participant checks. A triangulation of complementary methods can then be used to enhance, support or verify the visual data (Wetton and McWhirter 1998:274; Warburton 1998:260; Bolton et al 2001; Krueger and Irvine 2001:78; Wakefield and Underwager 1998:187). My research has combined in-depth semi-structured interviews, drawings produced by participants, photo elicitation, and a final round of data collection in the form of discussing provisionally analysed material with the participants.

Karen Nairn (2002, 1999, 1997, 1996) has made extensive use of participants’ drawings as a source of information regarding the social construction and

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<sup>20</sup> The documentary photography movement was paralleled by an intellectual phenomenon in Britain around the same period called the ‘History Workshop’ or ‘People’s History’. Both are examples of micro-sociology that aimed to ‘return to the source’ by focusing on the subject without a reliance on quantitative methods (Floud 1984:116-117). In both these movements there was a noticeable under-theorisation of empirical material.

reproduction of gendered identities through student fieldtrips. Nairn asked participants to draw pictures of what they thought geography students do on fieldtrips (1997:236). These drawings were then subjected to a poststructural analysis in which implicit and explicit binaries such as masculine/feminine, indoors/outdoors, and student/staff were examined (Nairn 2002:155). Also within the field of geography, Jaleh McCormack (2002) has analysed children's drawings "...to establish what elements, images and meanings children used to generate their constructions of rurality (2002:194). Both Nairn and McCormack conducted standard interviews with participants in conjunction with the drawings in order to triangulate or verify their findings. Both researchers found this method to be a fruitful way of gathering information (McCormack 2002:195; Nairn 1997:237, 2002:158). Although none of this work is directly concerned with the relationship between disease and the body, it does offer some general insight in terms of analysing pictures drawn by research participants.

Apart from the above research, and some work dealing with visual methods for investigating child abuse (Wakefield and Underwager 1998), much of the literature I have sourced from the field of visual sociology is concerned with photography, *by* sociologists and anthropologists, *of* the people they are studying. While some of this work is useful in a general sense, it deals mostly with methodology and issues of veracity particular to photography. The question of how people living with hepatitis C imagine or visualise their condition led me beyond these concerns to how I could best collate, interpret, and analyse the visual representations they produced. For guidance I looked to Art Therapy literature.

Occupational and other therapists often encourage patients to engage in various art forms. As many patients find it difficult to acknowledge and express themselves verbally, art can be a useful part of the therapeutic process (Crisp 1980: 111; Case and Dalley 1990; Read Johnson 1999:126). Nairn points out that most literature dealing with the analysis of drawings is from an art therapy approach, which is based on psychoanalysis (1997:236). Such approaches are concerned with



interpreting the inner workings of the ‘unconscious’ psyche through artwork.<sup>21</sup> Like Nairn, I feel that analysing participant’s drawings with a view to probing their ‘unconscious’ drives would be invasive (1997:236). In any case, neither I, nor most other sociologists, are skilled enough in the field of psychoanalysis to carry out such an analysis.

Viennese child psychoanalyst, Gertraud Diem-Wille (2001) uses an interesting combination of psychoanalysis, narrative interview, and participant drawing in her study of how the “psychic inner reality” of career people may influence their level of ambition. Diem-Wille asked participants to draw their family of origin at a stage of the interview when they were describing them in words. Informed by psychoanalytic theory, she used this method to access “...an idea of what goes on behind the censored image of verbal description” (2001:129). Diem-Wille then drew conclusions “...about the unconscious motives and dispositions for a successful career” (2001:130). Diem-Wille’s work demonstrates that drawings produced by participants can make additional information about complex concepts visible. Although used differently, her combination and analysis of both drawings and narrative interview is similar to my combination of these methods. Nonetheless, I have chosen to focus on the visual texts produced by participants as illustrative of their conscious experience of living with hepatitis C. I have therefore avoided psychoanalytic theory in my development of an analytical framework.

### **Semiotics**

Instead I approached these texts from an angle informed by semiotics. For me, these drawings present a potentially rich source of collective and shared social meanings in the form of icons and indexes (signs). From these signs, information about the participants’ sense of embodiment and their understanding of the relationship

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<sup>21</sup> For examples, see Case, C. and T. Dalley, Eds. (1990). *Working with Children in Art Therapy*. London and New York, Tavistock/Routledge, and Diem-Wille, G. (2001) ‘A Therapeutic Perspective: the Use of Drawings in Child Psychoanalysis and Social Science’, in Van Leeuwen, T. and Jewitt, C. *Handbook of Visual Analysis*. London, SAGE Publications.

between hepatitis C, themselves, and society can be drawn. Semiotics was originally intended to be a science of signs that became closely associated with structural linguistics and literary criticism. However, as a method of textual analysis, semiotics has more recently been incorporated within the paradigm of post-structuralism (Denzin and Lincoln 1994:358,359).

According to Lister and Wells (2001:73), there have been repeated attempts to apply “elaborate and systematic” semiotic methodologies based on linguistics to the analysis of images. This has occurred through changing intellectual trends such as structuralism, post-structuralism, and deconstructionist approaches. Nonetheless, it has become evident that rigid adherence to such models is counterproductive. Lister and Wells explain that there is “...always a tendency in such attempts to miss the specificity of the medium, and the practices built around it in social use, where signification takes place” (2001:73). Similarly, Kress and Van Leeuwen (1996:264-65) argue that the “richness of the actual semiotic world” is lost when a cold, clinical semiotic analysis is applied. To put it another way, semiotic analyses tend to abstract the text from the subjective experience and intention of those involved in the study (Manning and Cullum-Swan 1994:474). The mere fact that the participants of my study drew their pictures in the context of a semi-structured interview with a social researcher will have impacted on the texts they produced in ways that a purely semiotic analysis could not take into account. I have therefore approached the analysis of the participant’s drawings *informed* by semiotics rather than rigorously applying any particular semiotic model.

### **In summary**

My search for material to aid the development of a visual methodology and support the use of drawings produced by participants as a research strategy has traversed a number of different fields such as Medical Anthropology, Art Therapy, Geography, Visual Sociology, and Cultural Studies. Although the idea of collecting drawings and using photo elicitation initially came from the medical anthropology of Emily Martin (1994), it was the field of visual sociology that furnished me with the wealth

of articles and studies necessary to support my own methodology. Closer to home, Karen Nairn's work in Geography has provided me with perhaps the most compelling and reflexive example of the use of participants' drawings in research. However, because none of the material I have uncovered deals with the way people visualise the relationship between a specific disease and their bodies, I have had to fashion a visual methodology that can address my primary research question, which is: Does the way people visualise disease in their bodies relate to the forms of treatment they undertake to ameliorate disease?

I have taken what I consider to be useful from the literature I have reviewed, and have discarded that which is superfluous or incongruent with my epistemological positioning. As a result, I have developed a methodology that is at once specific to my research questions, and yet available as a guide to others wishing to use visual methods and particularly drawings produced by participants. As previously mentioned, my study combines the collection and analysis of both the visual texts produced by participants and their illness narratives. In the following section I introduce the notion that narrative constitutes a foundational aspect of social life and that by attending to the illness narratives of people living with hepatitis C, important information about the way medical intervention may challenge and/or reinforce the world-view and identity of those living with the disease may be sought.

### **Illness narratives**

...personal narratives are a means by which the links between body, self and society are articulated. As such they are an attractive subject for sociological analysis, especially in the context of chronic illness (Bury 2001:281).

### **Ontological narrativity**

Margaret Somers (1994:606) contends that, "...social life is itself *storied* and that narrative is an *ontological condition of social life*" (1994:613-14. Emphasis in original). This argument has been similarly stated by Frank (2002:7, 8, 9); Bury (2001:264); Arras (1997:71-73, 82); Frank (1997:43, 44); Plummer (1995); and

Kiefer (1974:232-233, cited in Chalfen 1998:229-230). In other words, a number of social theorists are now working with the assumption that stories, lived experience, and identity are all inseparably linked elements of what it is to be human. According to Somers, who we are, how we act, our expectations and aspirations, and even our memories are largely determined by a multiplicity of available “cultural narratives” (1994:614). Although there is a proliferation of such narratives or stories circulating throughout society, they are nonetheless limited, and are seldom of our own making (Somers 1994:606). The way we position ourselves, or are positioned, in stories is also generally an unreflective process according to Somers (1994:606). Reflective and unreflective narrative positioning is therefore a major factor in the constitution of our identities as well as our understanding and experience of illness. Nonetheless, the social sciences have generally eschewed a serious engagement with narrative theory because stories have been traditionally considered as representational and unscientific (Somers 1994:606). The same prejudices that blight visual methods in the social sciences are also applied to the use of narrative methods. Neither of these strategies for researching social life fit easily within a positivistic sociological framework, where the generation of ‘evidence-based’ knowledge corresponding to an ‘objective’ reality is privileged.

Nonetheless, Mike Bury (2001:265-268) explains that the use of narrative methodology, particularly illness narratives, has recently gained prominence in the social sciences. He claims that this is in part due to a “...relative decline in the importance of the infections on which the biomedical model was founded, and the growing impact of degenerative and chronic illness” (2001:267). As a consequence of biomedicine’s increasing impotence in the face of an aging population’s growing concern with chronicity and symptom management, the grip of biomedical authority has loosened, and room has become available for the patients’ own stories to assert themselves. This trend has also been fuelled by information technologies that make accessible what was once privileged professional knowledge (Bury 2001:268).

Medical anthropologist, Byron J. Good, states that illness narratives are

...a primary means for giving shape to experience and making past experience available to sufferers themselves. Significant experience is stored in the stockhouse of memory as stories, and remembering and recounting those stories provide access to the attendant experiences.  
(1994:164)

Good goes on to explain that the stories people tell about illness provide a particularly “fine mesh” for catching ideas that may otherwise “defy rational description” (Good 1994:165). I contend that collecting these fine meshes will provide me with a useful tool with which to explore treatment choices made by people with hepatitis C, as well as the ontologies implicit in these treatments. Illness narratives, along with other culturally available resources, such as metaphors and imagery, are drawn upon by people with hepatitis C as they attempt to make meaningful their condition.

In telling me the stories of their lives with hepatitis C, the participants in this study have told me a version, or reconstruction, of events in response to my invitation. In a sense then, these narratives are co-constructed, particularly as I have reiterated them to include ideas and theories that the participants themselves were not aware of at the time. These illness narratives are ‘snapshots’ taken at a certain time, and while the long-term nature of hepatitis C would perhaps be captured more effectively in a longitudinal study, the constraints of this thesis preclude such a study. Nevertheless, most of the participants have expressed interest in further involvement, and I may follow this up in the future.

The methodology I have developed and used in the research for this thesis includes both visual and narrative methods. I consider that both of these methods will help me to focus on the discursive ‘toolkits’ that people with hepatitis C bring with them when making decisions about treatment interventions. These methods should also allow me to apprehend traces of the implicit ontological assumptions inherent in medical practice. Although both of these strategies for gathering information about

social life have a history of marginalisation within the social sciences, I contend that by combining them with standard qualitative interviews and follow-up participant checks, I can effectively triangulate the data to address my topic of enquiry. That is:

1. *How do the hepatitis C positive participants of my study visualise the disease in their bodies?*
2. *How do these visualisations relate to medical treatment decisions?*
3. *What are the possible social and political implications of such decisions?*

### **My located and embodied epistemological assumptions**

With the burgeoning popularity of poststructural theory within both the social sciences and literary criticism, an emphasis on the discursive nature of social life has resulted in a turn away from the embodied or biological aspects of having a body (Ussher 1997:4, 7). In its most extreme form, poststructuralism leads to a relativistic world-view in which nothing is ‘real’, and in which all claims are equally valid (Ussher 1997:5-6). Such a view might not resonate particularly well with the illness narratives of the participants in my study. For many of these people, the *embodied* suffering involved in having hepatitis C, is no doubt *very* real. I have then, been challenged to reach an epistemological position with regard to my deconstructive analysis, that takes the biological/physical nature of bodies into account. In so doing, I have attempted to avoid an epistemological stance that might slip into the extreme objectivism of some scientific accounts of the body, or extreme relativism, in which the material body is reduced to a ‘text’, or collection of symbols and signs (Ussher 1997:2-5).

Haraway (1991:191) argues that extreme relativism is only the inverse of extreme objectivism, a view which also denies embodiment by "being nowhere while claiming to be everywhere equally". In order to avoid producing knowledge from either of these positions, Haraway advocates that social researchers recognise the importance of their *location*. By critically locating oneself in a particular situation, it is then possible to produce ‘situated knowledge’, which will always be a partial interpretation of the social world, that nonetheless avoids the tyranny of a totalising

perspective that appears to transcend the embodied and partial view of its author (Haraway 1988:583).

With Haraway's epistemological proposal in mind, I think it is important for me, the researcher, to locate myself in relation to my research, so that the knowledge I produce is seen as situated and partial, rather than 'objective'. As a male sociologist from a white middle-class background, there are many aspects of living with hepatitis C that will elude me. It could be argued that as an able-bodied white male, I will be less able to identify or critically examine the assumptions upon which my privileged social position rests (Harding 1991:144; Haraway 1989: 6-7). Although I have a history that includes intravenous drug use, and antibodies that suggest hepatitis C infection, my position is very different from many of the people I have interviewed in the course of my research.

To begin with, I have never suffered any noticeable symptoms of the disease, and the results of PCR tests I have had since 1995 indicate that there is no detectable level of the virus in my blood. It seems I am one of the fortunate ten to fifteen percent of people who spontaneously clear the virus without medical intervention. My embodied experience of hepatitis C is thus different from that of the participants in my study. Put simply, I do not know what it is like to have my health and quality of life compromised by a disease that I am told will become progressively worse. Perhaps because of my fortunate HCV status, and general good health, it is easier for me to be critical of biomedical practices such as interferon therapy. Meanwhile, I am comforted by the knowledge that biomedicine can be a very effective form of treatment if I need it. However, in light of the research I have conducted for this thesis, I think I would pursue alternative methods, such as traditional Chinese medicine and naturopathy, before resorting to interferon therapy to treat chronic Hepatitis C. Fortunately, however, I will probably never be challenged with the treatment choices that face most people living with this disease. I do not share the lived experience of illness and uncertainty common to the participants of my study, and this will be reflected in my analysis.

Although this thesis is not an explicitly feminist project, my ontological and epistemological assumptions have been deeply informed by feminist scholarship, particularly that of Donna Haraway. The work I refer to has critically examined and sought to deconstruct the dualistic ontological assumptions underlying Western culture and metaphysics.<sup>22</sup> The identification and deconstruction of the dualistic assumptions inherent in biomedical treatment for hepatitis C is a major part of my analytic project. While I have not conducted a close reading of Foucault's work, my deconstructive analysis is nonetheless indebted to a Foucauldian poststructural approach. Seidman (1998:236) states that Foucault was not concerned about whether scientific knowledges were 'true' or not, but rather, the social effects of these knowledges. Similarly, I am not interested in discovering the 'true' nature of hepatitis C, or what might be the most effective medical treatment for it, but rather how biomedical, and other discourses, might shape patients' ideas about the relationship between the body, disease and treatment. My theoretical and analytical approach in this thesis is thus informed by poststructural and social constructionist work in the sociology of health and illness. Feminist work in the field of science and technology studies has also greatly influenced my thinking. Because this thesis encompasses a wide range of theoretical and conceptual issues, I do not review all the literature in one section. Instead, I attend to these theories and ideas as they arise throughout the body of my work.

The form of knowledge produced in this thesis is intimately related to my ontological and epistemological assumptions. It is also intimately related to my embodied social location, which necessarily means that my view can only be a partial one. Using a methodology developed specifically for the purpose, I attempt to capture something of the way the participants in this study visualise hepatitis C in their bodies. How these 'ways of seeing' might relate to medical treatment

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<sup>22</sup> In this thesis, I refer mostly to the work of: Birke (1986,1999); Haraway (1988,1989,1991,1992,1997,2000); Jordanova (1989); Plumwood (1993); Scott (1996,1998,2001); and Shildrick (1997).



undertaken, and the possible social implications of this, are discussed in chapters five, six, and seven. In the next chapter, I describe how the methodology developed for this thesis was applied in practice. Here the various methods used are to some extent evaluated, and possible improvements are suggested.

## CHAPTER FOUR

### Methodology: methods and practice

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The purpose of this chapter is to describe the strategies and methods I used for my research in some detail. In doing so I hope to provide a 'roadmap' of what I did, and how I went about doing it, for others interested in pursuing a similar form of research. As I describe the progressive stages of my research, I reflect on some of the difficulties experienced and suggest how these might be avoided in the future.

#### Recruitment

As eighty percent of hepatitis C positive people in New Zealand are estimated to have used drugs intravenously, there is a certain amount of stigma associated with having the disease (Ministry of Health 2002:2.21). Many of the people I have interviewed have experienced some form of discrimination as a result of being hepatitis C positive, and all of them indicated some awareness of possible negative social sanctions. Because of the illicit nature of intravenous drug use and the stigma attached to having hepatitis C, I decided to employ a snowball sampling method to access a sample population.

I employed three main strategies to recruit participants for my study. These were:

- 1) Asking hepatitis C positive people from my social network if they would be prepared to be interviewed.
- 2) Joining a hepatitis C support group from which to make contacts for snowball sampling.
- 3) Placing an information sheet about my research and the need for participants in both the Hepatitis C Resource Centre's newsletter, and the Christchurch needle exchange magazine *Mainline*.

By using these methods I was able to access more than enough people willing to participate in the research. Other methods, such as approaching medical practitioners or gaining permission to use Public Health records, might be necessary for studies on a larger scale.

### **Selection of participants**

Mathew Dolan (1997:97) suggests that interferon and traditional Chinese medicine are two of the most popular forms of treatment for hepatitis C. My initial intention was to conduct interviews with an evenly matched number of participants who had undertaken either Western biomedical treatment (interferon) or traditional Chinese medicine. I also planned to recruit a smaller number of people who had not had any treatment. I hoped that this would give me three distinct groups to compare in terms of the way they visualised/understood their bodies, disease, and the treatments that they had undertaken.<sup>23</sup> Because traditional Chinese medicine and Western biomedicine are based on radically different ontological and epistemological assumptions (Unschuld 1992:57-59), such a neat division promised to provide the data necessary to clearly evaluate my research methodology in terms of uncovering traces of ontological discourse.

In actuality, I was unable to recruit such clearly delineated groups for my sample. Although several people who had used traditional Chinese medicine were recruited, it seems likely that this form of treatment was more popular in Britain, when Dolan wrote his book, than it was at the time of my research in Christchurch, New Zealand. My initial assumption that people would have undergone *either* interferon *or* traditional Chinese medicine also turned out to be less accurate than I had hoped. In the course of my research I discovered that few people with Hepatitis C rely solely

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<sup>23</sup> At the outset, I planned to recruit twelve participants from each of the above categories and six participants who had not undergone any treatment. However, I soon realised that the transcription, analysis, and follow-up meetings of thirty qualitative interviews would constitute an unrealistic amount of work for a one year masters thesis. I finally settled on qualitative interviews with fourteen participants.

on one form of treatment.<sup>24</sup> I therefore had to broaden the definition of my participant categories to those who had *predominantly* used either conventional Western biomedical treatment (interferon therapy), or traditional Chinese medicine.<sup>25</sup> As my research unfolded I also included naturopathic herbal remedies as a form of treatment, because this also proved to be popular with participants. Nonetheless, the forms of treatment represented in the study have enabled me to make some qualified statements regarding the ontologies inherent in the practices of Western biomedical technologies, traditional Chinese medicine, and various other forms of treatment for hepatitis C.

The participants chosen for the study were also selected by age, as I chiefly wanted to talk to people who had been living with the virus for some time, so as to get a sense of their illness trajectory. Consequently, all of the sample population are over thirty-five years of age. One participant was excluded from the sample group because it turned out that she had only recently been diagnosed and had given little thought to the disease or treatment. A longitudinal study tracking an individual's experience of hepatitis C from diagnosis would have been better in this regard. However, since many people with the disease do not experience symptoms for up to twenty years after infection, such a study is well beyond the scope of this thesis.

## **Interviews**

After I received Human Ethics Committee approval, I contacted participants recruited from my social network or through the Hepatitis C Resource Centre (the printed advertisements came later) to arrange times and locations for the interviews. On this occasion the participant's rights, my responsibilities, and the general aims of the study were explained verbally. The interviews were held in a place of the

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<sup>24</sup> This may be indicative of the general population in New Zealand. In a random study of ninety seven Christchurch residents, Broom (2002:9-11) found that a "large proportion" of people favoured the use of both alternative and conventional medicine.

<sup>25</sup> I interviewed five people who have exclusively or predominantly used conventional Western medicine, two people who have predominantly used traditional Chinese medicine, and three people who have used herbs and supplements. Four of the participants had not undertaken any form of treatment for hepatitis C.

participant's choice and at a time convenient to them. When necessary, a room was made available to me for interviews at the Hepatitis C Resource Centre.

Taped semi-structured interviews lasting between one to two hours were conducted over a period of six months with fourteen participants. During the interviews, these participants were invited to tell me the story of their lives with hepatitis C. This usually constituted the bulk of the narrative component of my data collection. Sometimes the storied aspects of living with hepatitis C were further stimulated by anecdotes I provided from my own experience, by the drawing process, or through photo elicitation. However, because of the qualitative nature of the interviews, and because they were taped and transcribed (by me); a reconstruction of each participant's illness narrative was possible regardless of where it appeared. I had a list of questions that acted more as a guide for me during the interview than a questionnaire for the participant.<sup>26</sup> In most cases I began the interview by turning on the handheld micro cassette recorder and asking the participant if they could tell me how they first found out they had hepatitis C. This often had the effect of stimulating a narrative account that included the participant's response to being diagnosed, whether they had been ill, the forms of treatment they had sought, and why. If this information was not forthcoming, I would ask questions such as, "and how did you come to try acupuncture?" Following the advice of Howard Becker (1998:58), I tried to avoid the word *why* in my questions in order to elicit longer and more informative answers. Even so, some people were more reticent than others, and I had the feeling in more than one interview that I was trying to pull 'hen's teeth'.

Upon transcription, it became clear to me that by combining several methods it was possible to collect data that would have been missed otherwise. For example, Nina had previously overlooked telling me about Reiki massage, a treatment that was central to her views on illness and treatment, until she began her drawing. My aim was to position the participants as experts in the area of their own health, and when necessary I mentioned that I was not interested in obtaining the 'right' information

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<sup>26</sup> See appendix B, for a copy of this sheet.

according to some a priori standard, but rather that the participants themselves were the only ones qualified to tell me what I wanted to know.

### **The production of visual texts**

After all the questions pertaining to the illness narrative section of the interview had been addressed to some degree, I asked each participant if they could draw the way they visualise hepatitis C in their bodies. I then produced a set of sixteen coloured felt tip pens and handed them a clipboard with A4 sheets of paper. I mentioned that they could take their time and draw as many pictures as they liked. Although many of the participants mentioned that they were not good at art, only one of them refused to actually draw a picture. Instead she invoked the image of the 'hungry enzymes' from the *Drive* laundry detergent commercial, and wrote the words: *Hungry enzymes eating away at the liver.*

To allow the participants to concentrate while they drew, I did not initiate conversation. However, few people remained silent as they drew, and in many cases, the drawing process evoked a different form of communication from them. Some made jokes about their pictures, and some explained what they were drawing in a stream of consciousness manner. It is tempting to suggest that the act of drawing may allow people to access thoughts and feelings that would otherwise remain dormant. But at least, as Wakefield and Underwager (1998:186-187) found in their work on child abuse investigations, the process of drawing can help to "...build rapport and encourage narrative accounts".

### **The veracity of visual texts**

The possibility that participants may not have the ability to faithfully draw the way that they visualise disease in their bodies was raised by one of my colleagues. When discussing the uses of images in anthropology, Marcus Banks (1998:15) raises the same issue when he states,

Claims to veracity - or image as evidence - presume complete and authoritative control and intention lying with those who produce the image,

and who have faith in their ability to record reality or their vision of reality convincingly.

This is perhaps of particular importance, as several of the people participating in the drawing exercise mentioned that they were not good at drawing. I address this issue by pointing out that the drawings were treated as visual texts from which certain discourses regarding medical treatment and embodiment could be read. These images are not therefore used as evidence in the conventional sense. As such, there is no need for them to faithfully represent 'reality'. It is also worth noting that many people are not particularly good at articulating their thoughts verbally. By asking the participants in my study to draw, as well as express themselves verbally, I was making an allowance for the possibility of limitations in these areas.

When the participant indicated that they had finished their drawing, I asked them what was depicted in it to clarify possible anomalies. They were asked to identify the elements present in their representations (such as virus, liver, immune system, treatment intervention) as well as the nature of the relationship between them (is it antagonistic, complementary, dominant and/or submissive). I then asked participants if they could identify any material such as medical texts, practitioner explanations, anecdotes, metaphors or even television programmes that might have influenced the way they visualise hepatitis C and the inner workings of their bodies. By asking this question I hoped to ascertain something of the socially constructed nature of hepatitis C. In many cases, the participant had volunteered some information regarding influences earlier in the interview, but by asking the question directly I often received either clarification, or sources not previously mentioned.

### **Photo elicitation**

In a study of changing public attitudes about health and illness, Emily Martin and her team of researchers showed the people they interviewed a set of four photographs depicting various aspects of the immune system interacting with bacteria and cancer cells (1994:14,264). I used a similar form of photo elicitation

with participants who had difficulty visualising/imagining the relationship between hepatitis C and their bodies. I used images from *Newsweek* of the progressive stages of liver damage caused by HCV.<sup>27</sup> I also showed a picture of the ‘sleeping dragon’ symbol used by the Hepatitis C Resource Centre in Christchurch. Although I was aware that the ‘authority’ of these images might have influenced the participants’ conceptions, on several occasions these prompts stimulated their own unique responses. For example, when one participant (Juan) saw the sleeping dragon image, he associated it with his Celtic heritage. He told me that in Celtic myth the dragon is a symbol of healing rather than danger. Juan then went on to explain that, in his view, all ancient cultures possessed methods of healing equivalent to that of traditional Chinese medicine.

In hindsight, my use of photo elicitation/visual prompts was probably the most underdeveloped method in the study. By the time I had realised the potential of showing images to elicit responses, it was too late to include more images or incorporate the method as a standard interview practice. I think the inclusion of other pictures, such as an electron micrographic view of the virus, as well as an image of Drive’s hungry enzymes would have worked well.

## **Methods of analysis**

Broadly, my analysis focused on the two types of data collected. These are the illness narratives (narrative texts), and the drawings (visual texts) produced by participants. This analysis was informed by the literature I was able to locate regarding both narrativity and participants’ illustrations as research methods. As mentioned in chapter two, there was no one formula available to me regarding the analysis of participant’s drawings of the relationship between their bodies and disease. The methods I have used began developing when I was presented with the

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<sup>27</sup> Kuchment, A. (2002). Hepatitis C: The Spread of a Killer Virus. *Newsweek*: 20 may, pp.40-43.

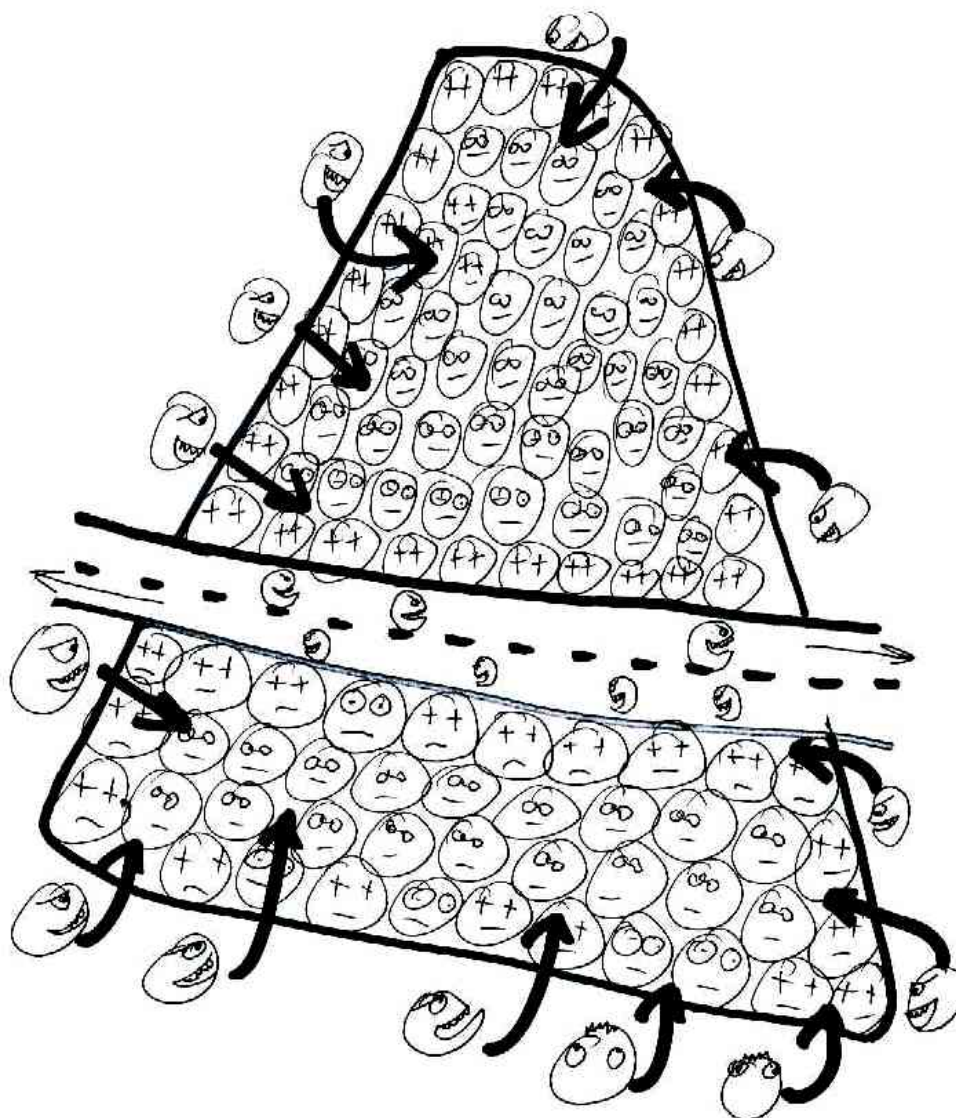


task of analysing the drawings produced by the participants of my pilot study. A discussion of some of the pilot study material is therefore presented below.

### **Content**

When discussing the analysis of visual texts, Howard Becker recommends a comprehensive and methodical approach; "...a naming of everything that is seen with the object of making the taken-for-granted rise to the surface, breaking down the privileging of the central image..." (Bolton et al 2001). I started with a content analysis of each drawing that noted what was included, what was excluded, and the apparent relationship between them.

This was then combined with the narrative information about the participant and *their* explanation of the drawings content. A content analysis of the picture below *without* such information might be reduced to: numerous faces within a triangular shape that is bisected by what appears to be a road on which there are faces in profile with their mouths open. Outside the triangle there are more of these faces attached to arrows pointing inward.

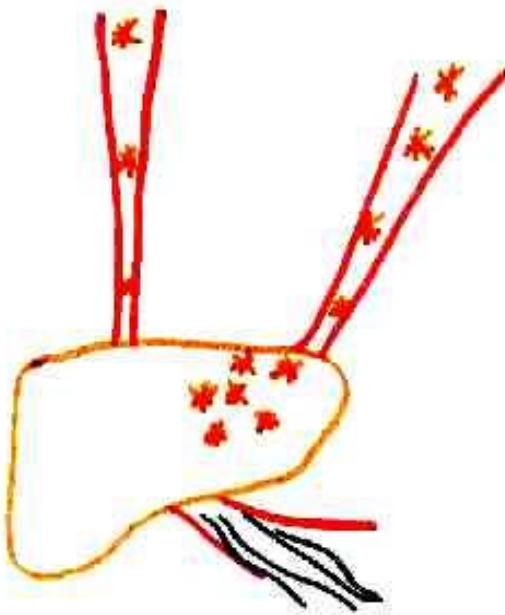


Removed from the context of an interview about hepatitis C, this content of this image makes little sense. However, given that this participant (Rob) firmly believes that Western biomedicine offers the best treatment available for hepatitis C, and that he has undergone an unsuccessful course of interferon, this drawing is particularly telling. Coupled with Rob's explanation, the faces within the triangle are revealed as cells trapped within an outline of the liver while malevolent hepatitis C virions with open jaws and jagged teeth surround them. A highway runs right through the middle of the liver allowing rapacious hepatitis C virions resembling 'Pac-man' or *Drive* washing powder's hungry enzymes to enter at will. Most of the liver cells alongside the highway, and those around the edge of the liver have already been killed. This is

indicated by their having crosses instead of eyes. The cells that remain alive appear to be terrified or at least anxious. To allay any doubts about hepatitis C's murderous intent, Rob has drawn thick black arrows reaching from the virions into the liver. Rob's visualisation does not so much present a battle between HCV and his body, as a massacre. While he drew, Rob explained that "the liver has no defence against hep C...the virus is like a wolf in a sheep pasture; whenever it's hungry it just grabs another sheep." His liver cells are trapped and powerless.

### **Brainstorming**

Content analysis combined with participants' illness narratives and their own explanations of their drawings gave me some substantial material in terms of analysis, but at the pilot study stage I still lacked confidence in my interpretations. The visual texts produced by the participants of my study are polysemous and therefore open to many readings. For example, the following drawing of hepatitis C in the liver reminded me of a textbook picture of the internal workings of a combustion engine. To me this indicates a mechanistic view of the body. To another person the same image may have quite different connotations. In order to keep my readings in check, and to gain the insight of others, I showed some of the drawings I had collected to my honours class. Before doing so, I contacted the participants concerned, and was granted permission to display their drawings in this manner.



After briefly describing the nature of my project, I held up the drawings, one by one, and asked the class (including my supervisor) what each of the images suggested in terms of the treatment undertaken by their authors. I then asked the group if they thought they could identify any inherent discourses regarding medicine or the body. This form of collective analysis proved to be useful in several ways: Firstly, on a personal level it was encouraging to see the interest generated by the drawings, and also that it was taken seriously as a research method. Secondly, some of the readings made by members of the group matched mine closely enough to be supportive of my analysis. Thirdly, and perhaps most importantly, a wider variety of readings was generated. Some of these led me to incorporate ideas that I would not have come to otherwise. In the case of Rob's drawing, I was alerted to the fact that there were no colours used, and that the liver cells appeared to be passive victims of the virus. I related both of these observations to the dualistic assumptions underlying the biomedical treatment he had undergone.

When it came to the visual texts produced for my masters' study, I was alerted to one of the limitations of brainstorming as method of analysis. For the pilot phase I only had seven pictures to show, and this worked well. However, for my masters'

there were over thirteen visual texts, and while enthusiasm and ideas flowed freely for half of these, the viewers' interest fell away noticeably after that. On the two occasions that I tried this method with the images from my master's research, the same phenomenon occurred. In the future, I think that organising two viewing times in which half the images are shown at each session would be a way of getting the most from the brainstorming strategy. Alternatively, one could reserve this method only for the visual texts that prove to be the most difficult to interpret. Nonetheless, these sessions still proved to be supportive of my own analysis, and they provided me with readings that had not occurred to me previously. This is particularly true of Wesley's text, where his own explanation of his drawing had blinded me to other possibilities.



While Wesley was drawing this picture he mentioned that he thought of himself as someone who smiled a lot, and that he didn't know how he could make the smile in his drawing any bigger. However, one of the members of the brainstorming group

read the stance of this figure as frustrated and angry. This reading was much more consistent with Wesley's narrative of uncertainty about his condition than his own description. As a consequence, I decided to override Wesley's comments in favour of the 'frustrated and angry' interpretation. With interest, I awaited Wesley's response to this preliminary analysis.

The first 'brainstorming' group of my masters' research was conducted with members of a discourse analysis study group. This group had a stated interest in elaborating on semiotic and narrative research strategies, and as such, the members provided me with a wealth of useful interpretive material. The second group was made up of several local artists of my acquaintance. The input from this group tended to be intuitive rather than theoretically informed, and this inspired a number of my less conservative readings of the visual texts. I chose these two groups in order to gain insights from an academic, as well as an artistic perspective. Once again, I sought permission from participants before these sessions were held.

### **Participant check**

An important part of my methodology involves showing the participants of my study a provisional analysis of the material they provided. Doing so allowed participants to check my interpretation of their illness narratives, and particularly their visual texts, for fidelity. A further meeting or telephone conversation with participants also provided me with an opportunity to collect additional data.

After conducting an initial analysis of data and two brainstorming sessions, I contacted participants and asked if they were comfortable with my sending them a provisional analysis of the interview material, either by post or e-mail. I consider this to be an important ethical consideration given that an unanticipated disclosure of a stigmatised disease might result from 'a third party's' opening and reading the provisional analysis. All the participants I approached agreed to this means of

communication.<sup>28</sup> I then arranged a time to phone or meet them in person to discuss their response to my interpretation.

As mentioned earlier, the drawings produced by participants are open to multiple readings, and in some cases I feared that I might have stretched the material too far in my analysis. After talking to participants I was pleased to discover that, according to them, this was not so.<sup>29</sup> Wesley, for example, was not displeased with the way I emphasised his frustration about the uncertainty of living with hepatitis C. He only asked that I change several words that he thought inaccurately described his attitude in other areas. I believe his suggestions have improved my final analysis of the material he provided. On the whole I have attempted to err on the conservative side with regard to my interpretive analyses, and this is perhaps reflected in the positive responses of participants. Presenting conservative, and thus less closed-off interpretations, of my preliminary analysis allowed room for participants to further contribute information and also to take part in the analytical process. In this way an ongoing dialogue and generation of meanings between researcher and participant was facilitated. In terms of the final analyses of visual texts presented in this thesis, I have attempted to guide the viewer/reader towards a certain way of seeing the relationship between disease, the body, and medical treatment. In making conservative readings, I have attempted to leave the visual texts produced by participants open to further interpretation.

### **Summary of methods in practice**

Using personal contacts, printed advertisements, and a snowball sampling method, I recruited fourteen hepatitis C positive participants for my study. My initial plan to recruit people who had undergone either interferon therapy or traditional Chinese medicine was complicated by the messy reality that few of the participants in my sample group had undertaken either one treatment or the other. Consequently, I

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<sup>28</sup> One participant did stress the importance of clearly addressing the envelope to him in particular because he shared a mailbox.

<sup>29</sup> It must be noted however, that participants did not have the opportunity to view my final analysis as it appears in the thesis.

expanded my definitions to include people who had undergone naturopathic remedies, as well as those who demonstrated a pragmatic and eclectic use of a variety of treatments for hepatitis C. Four people who had not undergone medical treatment were also included. I selected participants who were over thirty-five years of age because I wanted to talk to people who had been living with the disease for some time in order to gain a sense of their illness trajectory.

As an integral part of my research strategy, I asked participants to draw a picture of how they visualised hepatitis C. During the interviews, I also asked them to tell me the story of their lives with the disease. After transcribing the interview tapes, I constructed an illness narrative from each of the stories. This usually followed a linear trajectory from initial illness or disease diagnosis, right up to the time of the interview.<sup>30</sup> While charting this trajectory, I noted which aspects of living with hepatitis C were represented in the visual texts. I then arranged and conducted two brainstorming sessions; the first being with members of a discourse analysis group and the second with a small number of local artists. After a preliminary analysis of the data, I sent participants a copy by e-mail attachment or through the mail. I then arranged to meet the participants or contact them by telephone, to discuss their responses. This final stage of my fieldwork was for the most part reaffirming of my analytic interpretations. It also furnished me with some extra information with which to begin the write-up of my substantive chapters.

The following chapter is the beginning of the analytical section of my thesis. I begin by introducing the reader to the notion that biomedical treatment for hepatitis C can potentially colonise the everyday lifeworld of those undergoing it. The existential condition of uncertainty common to the participants in my study is then discussed as a prelude to a brief explanation of the uncertain workings of interferon therapy. This then leads to an analysis of the visual texts and narrative accounts of three participants who have undergone at least one course of this interferon. Here I

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<sup>30</sup> Because each participant's story is uniquely different, a presentation of their illness narratives might breach the anonymity guaranteed them. As an ethical consideration, full presentations of participants' illness narratives do not appear in this thesis.



suggest that an uncertainty/control dialectic inherent in both Western culture and biomedicine, might predispose people with hepatitis C to interferon therapy. I then focus on the development of interferon technology; a promising, but ultimately disappointing, cancer treatment that found its place in medicine with the discovery of hepatitis C. The reader is left to judge whether this is an example of how corporate interests and biomedical practices might colonise the lifeworld of patients.

## CHAPTER FIVE

### Medical treatment and the lifeworld

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Just as political and economic colonialism took over geographic areas, modernist medicine claimed the body of its patients as its territory, at least for the duration of treatment...Modernity did not question this reduction because its benefits were immediate and its cost was not yet apparent. The colonization of experience was judged worth the cure, or attempted cure. But illnesses have shifted from the acute to the chronic, and self-awareness has shifted

(Frank 1995:10-11).

#### Colonisation

The term colonisation is most commonly used to describe the process of settlement and exploitation of foreign territories in the interests of economic and political expansion. This usually occurs with military coercion and results in the subjugation of the indigenous population (Johnson 2000:50). Sandra Harding (1998:40-43) writes that voyages of discovery and colonisation, beginning in the late 1400s, set out from Europe in search of riches. Harding explains that the colonies provided Europe with precious metals and raw materials for industry, while the colonised provided a cheap labour source. What resulted was a flow of resources to Europe that left the colonies ravaged. Writing as a person whose land has been colonised, Linda Tuhiwai Smith (1999:20) explains that European expansion in the South Pacific not only decimated the indigenous populations through introduced diseases, but also led to a crippling loss for the peoples whose identity is inextricably bound to the land that was removed from them. In the same century that Māori land was being systematically accumulated by colonial interests, so too were the Mexican people “swindled” out of the land they legally owned (Anzáldua 1987:7-8). In an attempt to justify such colonisation and secure imperial interests, the coloniser often re-wrote the history of the colonised (Tuhiwai Smith 1999:22). In the hands of the coloniser, indigenous history was often erased, or framed as superstition and myth. In some cases, the religious practices of the colonised were decreed devil worship (Anzáldua 1987:7-28).

### **Colonisation and the lifeworld**

Borrowing the notion ‘colonization of the everyday lifeworld’ from Jurgen Habermas, Arthur Frank (1995:146) argues that Western biomedicine has the potential to turn people into patients and their bodies into cases, thus robbing them of their personhood and subjective experience of illness. According to Habermas (1987:154,196), the progressive rationalisation involved with modernity has led to a profound separation of administrative systems driven by economic interests (such as biomedicine), from the everyday lifeworld of embodied experience (Kelleher 2001:129; Frank 1995:146). For Habermas, the lifeworld is a shifting site or forum where issues concerning personal and public wellbeing are experienced and discussed (Nørager 1993:162-65; Habermas 1987:126). With regard to health, Habermas fears that an uncoupling of expert systems and the lifeworld will lead to situations where the appropriateness of medical interventions, for example, will be decided in isolation from those undergoing them. The integration of lifeworlds and systemworlds is an essential requirement for challenging medical definitions that inevitably affect the wellbeing of patients (Kelleher 2001:129-30). Without lifeworld/systemworld integration, the patient’s body is vulnerable to medical regimes where the success of treatment is defined by interests other than wellness (*ibid*). Later in this chapter, I re-tell the history and development of interferon technologies. To what extent this is a story of colonisation, is perhaps best judged by the reader.

While there are similarities between the way the ‘new world’ was colonised, and the way biomedicine might colonise the lifeworld of patients, I do not mean to suggest that these respective colonisations are in any way comparable in terms of suffering or injustice. Instead, my use of the ‘colonisation of the lifeworld’ concept has more in common with Foucault’s account of the ways knowledge and power are deployed through discursive practices (Penna and O’Brian 1996:52). Here the inner worlds of people with hepatitis C are vulnerable to colonisation by dominant discourses, narratives, and metaphors of disease and the body that circulate culturally. In

addition to these cultural influences, the patient undergoing interferon therapy is also subjected to a regimen of drug administration. Speaking as someone who has undergone biomedical treatment for cancer, Frank (1995:41) argues that the “single-minded pursuit” of such a regimen

...transforms the body into “it” to be treated; the self becomes dissociated from this “it.” A self dissociated from its body will rarely seek and discover terms of association with others, so the disciplined body becomes monadic (1995:41).

The mind/body split that Frank refers to, and the consequent social isolation, is particularly apparent in the case of one of my participants (Ryan), who underwent a forty-eight week course of interferon. However, as my examples show, the participants of this study are also actively involved in the negotiation and resistance of biomedical colonisation.

In chapter two I discussed the practices of biomedicine, and to some extent, traditional Chinese medicine and naturopathy for treating hepatitis C. I also touched upon some of the major ontological assumptions underlying these practices. In this chapter I look at how these assumptions are manifested in participants’ accounts of their lived experience while undergoing these treatments. I begin this chapter with a discussion of uncertainty as an existential condition for those living with hepatitis C, and look at how this condition relates to their treatment decisions. I then move to a short explanation of how interferon, traditional Chinese medicine, and naturopathy work in theory, before introducing some narrative accounts of how these treatments have been experienced by participants. Finally, I re-tell the story of the changing fortunes of the drug interferon, from its early pseudo-scientific status, to its position as a possible cure for hepatitis C. In doing so, I explore Frank’s contention that medical treatments, particularly interferon, have the capacity to colonise the lifeworlds of those undergoing them.

## Uncertainty

One thing that all the people I interviewed have in common, regardless of treatment intervention, or lack of it, is *uncertainty*. The exact workings of the virus have confounded scientists and virologists alike. The same can be said for the way interferon and other treatments might work to benefit sufferers. People living with the virus are like the Protestants of Max Weber's classic study who believed that nothing they did could assure them of salvation. In the face of this uncertainty, these Protestants sought out signs that might give them some indication of their status with regard to the afterlife (Weber 1958:105-115). This is also the case for many people with hepatitis C, who, faced with the uncertain efficacy of treatment, place a great deal of importance on the classification of their viral subtype or genotype as a sign. This is particularly the case for the people I interviewed who decided to undertake interferon therapy.

In Western scientific terminology, hepatitis C is known as an RNA virus. RNA viruses have an unstable genetic structure, which means that viruses such as HCV mutate rapidly into different strains or 'quasispecies' as they replicate (Petro Roybal 1999:13). Because of this, the hepatitis C virus essentially defies classification. No two people can even be said to have the same disease (Bowker and Star 1999:90, 98; Askari 1999:143; Dolan 1997:104). This seems to fly in the face of biomedicine's penchant for singular diagnoses. Nonetheless, these multifarious strains have been classified *very broadly* into six genotype categories, of which there is any number of quasi species. Many doctors "suspect" that a patient's hepatitis C genotype has a bearing on their prognosis and their chances of a successful outcome through interferon therapy (Dolan 1997:14-15).

Implicit in uncertainty is a lack of control. From the Enlightenment onwards, the scientific project, particularly with regard to the body, has been concerned with prediction, regulation, and ultimately control (Birke 1999:86, 97, 134; Kleinman 1995:29, 33). When faced with a phenomenon, such as hepatitis C, that evades regulation and control (Crofts *et al* 2001: xviii), science in the form of biomedicine

attempts to isolate, divide, and classify the subject of scrutiny. In their study of classification and its consequences, Geoffrey Bowker and Susan Leigh Star (1999:13,15) explain that in this way some appearance of order is established, even if it means little in terms of “pure” science. They point out however, that virus classification is practically essential for the project of science. Without such a taxonomy it would be difficult to make comparisons, write scientific papers, or provide indexing and keywords (1999:98). In other words, the classification of viruses, and particularly hepatitis C genotypes, must be considered too vague to be meaningful in terms of making treatment decisions. Nonetheless this technoscientific illusion of control (Bryld and Lykke 2000:6) is seductive to those suffering from the existential uncertainty of hepatitis C. The lifeworlds of patients that come to see themselves in terms of their assigned genotype classification are arguably colonised to some extent by the practices of biomedicine. This is suggested by some of following accounts of participants in this study.

As people with hepatitis C have very little else to go on when making decisions about treatment and weighing up their chances of recovery, it is perhaps not surprising that they often put a great deal of stock in their genotype. Ryan explains, for example, “there’s a 39% chance that the hepatitis will come back after this interferon, cos I’ve got genotype one which is the hardest to get rid of”. Owen, on the other hand, has genotype three, and according to one specialist the chances of someone with this genotype achieving a sustained response through interferon are favourable. Owen considers this a good omen in terms of his odds of attaining a cure. He does observe, however, that compared to cancer, hepatitis C is a “newfangled” disease and that “nobody really knows how it works, or what it does, or how long it takes to do it”. Owen goes on to point out that, in a year’s time, scientists may discover several new subtypes of the genotype that he has, and it may turn out that his particular strain is resistant to interferon therapy. So in the end, undergoing treatment adds up to a great deal of uncertainty, regardless of genotyping. Owen has reframed this as a big gamble - a chance to beat the odds. He explains: “I realise there’s no concrete way of dealing with it [HCV]...if I fall within

the lucky twenty percent, or whatever it is, then I'm lucky. If I don't, at least I can say that I had a go". So although Owen recognises genotype classification as valid, in the sense that hepatitis C can be identified as a disease entity, his awareness of biomedicine's knowledge deficit with regard to the disease, has prevented him from firmly anchoring his faith in his genotype as a fortuitous sign. While Owen's attitude to interferon may seem somewhat fatalistic, he has negotiated, and to some extent resisted, the possible de-personalising or colonising effect of biomedical classification.

Fran has been told that she has an uncommon genotype of the virus. This, and the fact that she has no idea how she contracted hepatitis C, has resulted in her feeling different from most other people with the disease. Although Fran has been told that interferon is particularly effective against this genotype, she has many financial commitments and cannot afford to take time off work because of side effects. She has also found that naturopathic herbs have improved her health without deleterious side effects. Fran has been asymptomatic, and she thinks of herself as fortunate compared to many others with hepatitis C. However, like most people with the disease, she cannot be sure about how she will fare in the future: "Maybe it hasn't kicked me in the ass properly yet. Maybe I've still got that to come...who knows? There is no way of knowing!" Although Fran has decided not to undertake interferon therapy at this stage, the prerequisite genotype testing for this biomedical treatment has colonised her lifeworld to the extent that she feels alienated even within the marginalised community of people with hepatitis C.

Of all the participants, Glenda is probably the least reassured by her genotype classification. Like Fran, she does not know how she acquired the virus and the disease has resisted all forms of treatment. Glenda tells me she has non-specific genotype one, and hastens to add that this means that "...they don't really know what it is". Because she had a particularly adverse reaction to acupuncture and Chinese herbs, Glenda views interferon as her best treatment option. Even though she remained non-responsive to a previous twelve month course, she persisted, and

was finally accepted as part of the pegulated interferon trial being staged by Roche.<sup>31</sup> Like several other participants, Glenda visualises the virus as *Drive's* hungry enzymes, progressively eating away at her liver. Although she is unwilling to draw a picture, Glenda says:

You know in that Drive advertisement where you see all of those things going munch, munch, munch, munch?...Well I can see that just all sort of going round the liver doing that all the time. That's how I reckon it's working on my liver all the time. I wouldn't know how to draw that; I don't know what your liver particularly looks like.

Glenda was hopeful that her first course of interferon would have “poisoned” the virus, thus eliminating it, but now she simply hopes that the interferon will arrest the munching progression of the disease during treatment. Glenda's understanding that her condition is the result of a non-specific and uncertain disease entity, as classified by biomedicine, has left her with little confidence about her chances of wellness. Interestingly, the way Glenda visualises hepatitis C, is in itself, a picture of colonisation congruent with the biomedical view of viral infection. Her internalisation of the perception of having been invaded by a hostile disease entity has, in turn, colonised her lifeworld. Given her way of visualising hepatitis C, it is perhaps unsurprising that she is inclined towards the form of treatment that has defined the disease. When I asked if she had considered naturopathy, Glenda says: “No, I don't think anything but interferon could completely get rid of it...I don't want to live with the virus, I want to beat it”.

The above examples suggest that, like the Protestants of Weber's classic study, the uncertainty of living with hepatitis C leads people with the disease to look for signs that might indicate their chances of eliminating the virus through medical treatment. In this case, the signs take the form of the genotype classification assigned to them by biomedical technologies. However, by visualising the disease as something identifiable as singular as a genotype classification, these participants are in a sense allowing their experience of hepatitis C to be framed within a biomedical paradigm

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<sup>31</sup> The pharmaceutical company Roche has been carrying out global trials to test the safety and efficacy of their version of pegulated interferon, which is called Pegasys (Franciscus 2002:1). In New Zealand, participation in these trials has been free to those who meet the criteria.



that prescribes only one form of treatment for the disease. This can be seen as one way in which the everyday lifeworld is colonised by an engagement with medical practice.

In this light, the view of disease offered by biomedicine (or any other treatment modality) can be seen as a potential form of colonisation. It is at this level that my study is mostly concerned. In the next section, the reader is introduced to the theory behind interferon treatment and the language used to explain it. Following this, participant accounts of interferon therapy as they pertain to uncertainty and the dualistic assumptions underlying Western culture are discussed. The tacit prevalence of these ontological assumptions is proposed as a major influence on the treatment decisions made by some of the participants of this study.

### **Interferons and interferon**

A comprehensive understanding of the immunological role of interferons is still incomplete and research findings have tended to be speculative rather than conclusive (Dolan 1997:107). When addressing the question of how interferon works, Alan Franciscus of the *HCV Advocate* (2002:9) writes, “Our immune system naturally produces a variety of different interferons to help *defend the body against invaders*” (My emphasis). Interferons protect “healthy uninfected cells from being *attacked* by the virus” (My emphasis).<sup>32</sup> According to the Schering-Plough guide to interferon combination therapy, their interferon (Intron A) is a synthetic version of a type of interferon that is naturally produced by the body’s immune system. It is genetically engineered to “mimic” the body’s naturally produced interferons (Franciscus 2002:9). Intron A, and interferon generally, works by boosting the body’s own “defence system”, so that the activity of “natural killer cells” is increased to “destroy foreign cells” such as HCV. As interferon is a protein, it would be destroyed by the digestive system if it were swallowed. Instead interferon is self-

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<sup>32</sup> Interferon is so called because it interferes with "...viral protein synthesis" and inhibits the "...uncoating of viruses within cells" (Franciscus 2002:9). For a more detailed and technical explanation of interferon therapy and hepatitis C from a biomedical perspective see (Sievert 2001:140-154; Bowen *et al* 2001:59-81).

administered three times a week by injection under the skin. Ribavirin pills, when taken in combination with interferon, have been shown to increase the overall efficacy of anti-viral therapy. Ribavirin is a drug that prevents the correct viral replication of HCV (Dolan 1997:107).

Ribavirin, in combination with interferon, has now become standard practice in the biomedical treatment of chronic hepatitis C infection (Mijch 2001:121). However, the action of combination therapy for hepatitis C is poorly understood (Davis 2001:1141). The language and metaphors used to explain the action of interferons and interferon to people with the disease is nevertheless clear cut, with the ontological assumption of a distinct and antagonistic *self* and *other* dichotomy in which defence and attack are naturalised. The sociological implications of this naturalisation are picked up on in the next chapter.

One of the interesting aspects of interferon therapy is that it falls somewhere between cytotoxic, treatment where healthy as well as infected cells are destroyed, and many alternative therapies where the immune system is stimulated to ward off disease. Patients undergoing interferon therapy certainly suffer from many of the same side effects that are produced by cytotoxic or chemotherapy.<sup>33</sup> At the same time interferon therapy focuses on an immunological mechanism that alternative treatment, such as naturopathy, attempts to elicit from the body's own immune system.<sup>34</sup> Technoscience has successfully cloned and synthetically reproduced part of the human body's interferon response so that it can be administered in large doses for an intended therapeutic effect.<sup>35</sup>

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<sup>33</sup> These include hair loss, lowered white cell count, as well as mood, skin and gastrointestinal disorders (Richards 1991:210; Dore 2001:173). While the extent of these varies from person to person they are often so severe that treatment must be terminated.

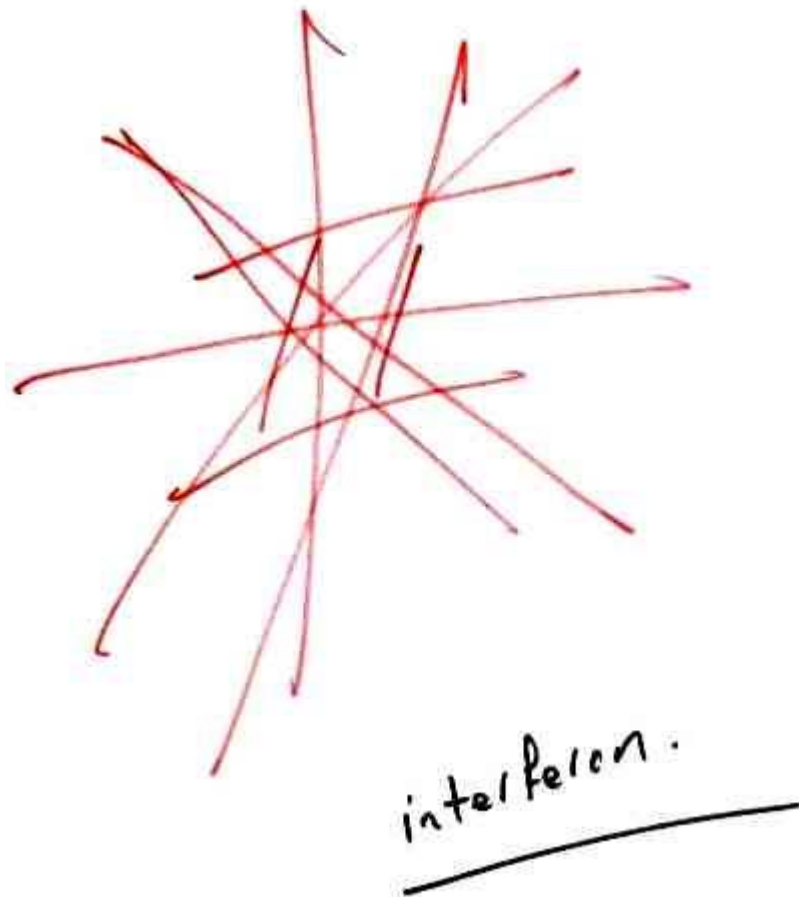
<sup>34</sup> For example, Echinacea is often prescribed by naturopaths to stimulate natural interferon response (Dolan 1997:151).

<sup>35</sup> However, there is some debate as to whether interferon produced by recombinant technologies is comparable in terms of therapeutic value to that produced naturally in the human body (Walsh 1995:194-5).

### **Cultural predisposition to Western biomedicine**

In this section I will pursue the theme of uncertainty and biomedical treatment, as it has been illustrated in the illness narratives and visual texts of people living with hepatitis C. Here I argue that the pervasive dualistic assumptions of Western culture predispose certain people to seek interferon treatment despite adverse side effects and the presence of alternative treatment options.

I think so much of hepatitis C is the way you picture it. I mean, you're onto it anyway, and that's why you're asking us to do pictures...but I think instead of getting me to do the interferon picture, you should have given me an axe. I think if you're looking for images or metaphors for interferon treatment then it really is an axe...the longer I'm away from it, the more I realise that.  
(Wesley)



This quote by Wesley suggests that interferon treatment enters into the lifeworld as more than just a medical intervention. With a view to identifying possible dualisms inherent in interferon treatment, Wesley's use of the axe metaphor leads one to think of something heavy and sharp that has the capacity to split and penetrate; something created by humans (technoscience) to dominate nature (HCV). The uncertainty of living with hepatitis C rendered Wesley open to treatment for a disease that he cannot even be sure he has suffered from. Nevertheless, he met the criteria for treatment and was advised, in his doctor's words, that a course of interferon would amount to a "pre-emptive strike" that would "drive" hepatitis C from his body. And so Wesley underwent a six month course of interferon therapy and found that he did have more energy afterwards. However, he is not sure whether this can be attributed to the treatment, as there were other significant factors at work in his life at the time. For Wesley, the uncertainty of living with hepatitis C extends also to the efficacy of the treatment he has undertaken for it. One thing he is sure of though is that interferon is a profoundly debilitating treatment. As such it penetrated his lifeworld for the duration of treatment and even afterwards. Wesley explains while he draws a picture of interferon:

...it's an extremely difficult drug. Anyone who says it's not a difficult drug...wants to be in a John Wayne movie.... If it was just the physical symptoms, I think you'd be alright, but it's the emotional thing of interferon...it's like being in the winter...at the end of it, it's like somebody switches on a light and you walk away from it, but it takes you a long time to adjust even afterwards. It's thoroughly confusing because you're never quite sure how you're going to wake up. Some days you feel absolutely normal and positive and you want to do things, and there are other days when you wake up and you can't get out of bed... The thing is that when you're having one of those bad days there is nothing that makes it better. You might have a headache, and itches, and diarrhoea, and any number of other symptoms, but that's nothing compared to the emotional desolation...the day after your shot you feel sick, the next day you're starting to come right, and then it's time for the next shot. And there's no way you can get any pleasure out of that shot.

Wesley goes on to tell me that one doctor referred to the therapy as "inhumane" and "akin to leeches", and his own allusion to John Wayne suggests that interferon is indeed *heroic* medicine. When explaining how interferon works, Wesley says it

“drives” hepatitis C out of the blood. He uses the term *drives* several times and the drawing of how he visualises interferon looks to me like blood that has been shot against a white hospital wall at high velocity. When asked about why he uses the word *drives* repeatedly, Wesley explains:

Because it's a very, very strong drug, and you soon get that idea. It makes people depressed...you can think that you did it to yourself, and that you're taking this treatment for it, and it's horrible, and even though you're taking responsibility, you don't have the wherewithal to stand up and be strong with that information...the first thing about interferon is that it is fatiguing, and if you start feeling bad about yourself when you're on the treatment it's very easy to go all the way down the slope.

Wesley found that with this treatment there was no redemption for his taking responsibility for his own health or previous risk-taking behaviour. As with most people who undergo six months of interferon combination therapy, Wesley found that although hepatitis C was *driven* from his blood during treatment, the virus once again returned several months afterwards (Davis 2001:141-42).



The frustration involved in living with the uncertainty of hepatitis C is eloquently stated in Wesley's drawing. This is an angry stance. His hands can be read as both fingerless, and thus incapable of grasping his condition, or as clenched fists. The fact that his feet and hands are not connected to the rest of him also seems to indicate a lack of agency or powerlessness over his prognosis. Within his body there is nothing to indicate the presence of a progressive disease – no blood to carry it, no liver for it to inhabit, and no symptoms to betray its existence. Here there is nothing but a great yellow question mark. Wesley's identification of the colour yellow with disease suggests that the uncertainty associated with hepatitis C may in itself be pathological.

Although Wesley has no plans to undergo interferon therapy again at this stage, the results of the latest pegulated interferon trials seem promising, and the lure of gaining more energy through being ‘cured’ still beckons him. Wesley does not suffer from any symptoms that cannot be attributed to other factors such as stress and overwork, but the spectre of hepatitis C still looms at times, particularly when he reads something, or sees a report on television about it. Recently he underwent another biopsy in an attempt to find out his HCV status. He was disappointed to find out that the condition of the liver estimated through a biopsy depends on the time of day it was taken, the site it was taken from, and food eaten the day before. Wesley says, “...if I’d known that beforehand, I wouldn’t have bothered – what’s the point?”

The desire to know, to be certain, to have some control over his body and the disease is a reoccurring theme in Wesley’s narrative. Lynda Birke (1999:110) explains that control of the body is also a powerful imperative in Western culture generally. This urge to control the body certainly resonates with Cartesian dualism or mind/body split inherent in Western thought. It is not surprising then that Wesley pursued biomedical treatment, which is primarily based on Western science’s preoccupation with ordering, prediction and control. Since undergoing interferon therapy, Wesley has tried traditional Chinese medicine in the form of herbs and acupuncture, but his inability to comprehend the logic behind this treatment led him to doubt its potential effectiveness. He says:

I think there’s this exotic attraction, like with ethnic foods, but I have to suspend disbelief when he puts those pins in me...it’s like voodoo...Part of me hopes that something in it [traditional Chinese medicine] will drive the hepatitis from my system.

The fact that interferon therapy failed, and that biomedical technologies proved to be inconclusive in terms of his condition, has certainly not reaffirmed a world-view consistent with biomedical practice. While he is now deeply sceptical of biomedical authority, Wesley is prevented from wholeheartedly pursuing traditional Chinese medicine because the workings of acupuncture and herbs are based on an ontology

that is incoherent to his cultural worldview. As he is asymptomatic, traditional Chinese medical treatment offers him no comprehensible standards by which he can judge the efficacy of the treatment.

### **John's search for a cure**

John is similar to Wesley, in that he also discontinued traditional Chinese medical treatment even after interferon had proved to be unsuccessful. However, unlike Wesley, John's account of interferon is un-dramatic. Although he concedes to suffering some side effects, it seems they were not particularly severe in his case. John had read in some of the hepatitis C literature that traditional Chinese medicine was becoming a popular alternative to interferon. As conventional Western medicine had nothing else to offer him at the time, John decided to "give it a bash". He made an appointment with a Chinese doctor who informed him that he had successfully cured a patient of hepatitis C using traditional Chinese methods.<sup>36</sup> It was with such a cure in mind that John pursued traditional Chinese medicine. According to my findings, the desire for a cure is predominantly associated with the pursuit of biomedical treatment for which John is apparently predisposed.

For almost a year John had acupuncture and took Chinese herbs twice a day. He describes acupuncture as "quite relaxing". In contrast to interferon, the herbs he took had no unpleasant side effects. Nonetheless, John was disgruntled about the fact that his doctor gave him no indication of how long the treatment would go on for.

He just said that we would have a PCR test after a while and if it was still positive we'd just carry on [with the treatment]...but I couldn't go on...without any idea of how long it would last.

John was also upset that the ingredients of the packages of herbs that he was given were entirely written in Chinese. Without knowing what he was taking, John had no reference to its possible efficacy. Having not felt noticeably better (or worse) because of the acupuncture and herbal preparations, John was not prepared to take it

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<sup>36</sup> This practitioner of traditional Chinese medicine is perhaps unusual in that he uses the PCR test as a diagnostic tool to determine whether a patient is 'cured' of hepatitis C.



on faith that they were of significant benefit to him. Without the familiar illusion of certainty afforded by biomedicine, John stopped using traditional Chinese medicine after a year. When asked how he thought Chinese medicine might work, John said:

I figure it's probably basically the same way as interferon, but it's natural so it's not as nasty as far as side-effects go, but it's probably a lot less effective over the same period of time...from my own experience it is a lot less severe. The side effects of interferon are obviously a shock to the system, but you are prepared to put up with that if you think it's going to work...it's a bit of a trade off...chances are it will do something.

In John's comparison of treatments, there is a parallel between the efficacy of treatment and the severity of side effects. When referring to the workings of traditional Chinese medicine, John does not mention yin and yang, Qi, or meridian channels, and there is no indication that the ontological assumptions behind this treatment have challenged his understanding of embodiment or disease. John's visual text is also devoid of any apparent reference to an 'alternative' influence.<sup>37</sup> Had he been 'cured' (according to biomedical diagnostic technology) by Chinese herbs and acupuncture, John might have been open to another understanding of the body, disease, and society, but as it is, his ontological default setting remains distinctively Western. Several years after his experience with Chinese medicine, John was accepted for the pegulated interferon trial. He tells me that if this is unsuccessful he may try naturopathic herbs to keep his liver in good condition until the technologies of Western biomedicine discover a cure. Here John is making the distinction between biomedicine as cure, and alternative treatments as maintenance. In many ways, John's treatment decisions exemplify Ursula Sharma's contention that most patients initially try alternative remedies as part of a problem-solving process after orthodox biomedicine has failed to help (1995:38-44). Although it seems that John is culturally predisposed to Western biomedicine, he is not ideologically opposed to non-orthodox treatment such as traditional Chinese medicine and naturopathy.

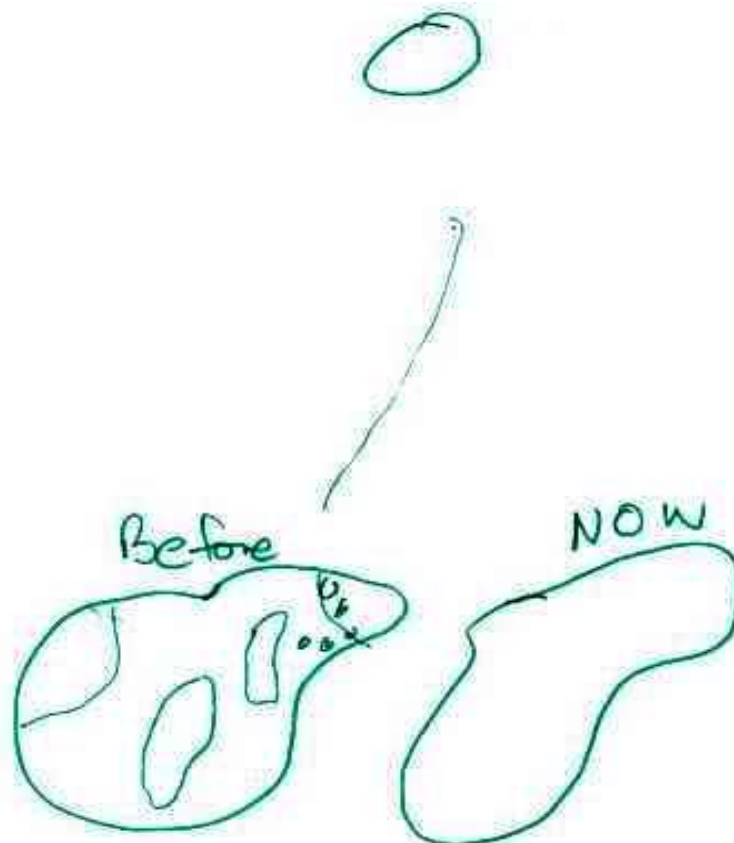
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<sup>37</sup> John's visual text appears on page 103 and appendix A on page 182.

### Ryan's interferon experience

“In many ways, the last eleven months has been the worst time of my life.”

In the above quote, Ryan is referring to his experience of pegulated interferon. Like Wesley and John, Ryan underwent combination therapy for six months and then relapsed. Several years later he was offered a place on Roche's pegulated interferon trial, which he took up in the hope that this treatment would cure him of hepatitis C. At the time of our interview he had just had the last interferon injection of his eleven-month course. Ryan was extremely confident that pegulated interferon, along with a technique of positive visualisation, had successfully eliminated the virus from his body. According to Ryan, “you've just got to believe that interferon is the best thing that modern science has to offer”. Ryan's belief in the power of his mind over his body, as well as the power of science (as culture) over hepatitis C (as nature) had probably never been stronger. This is clearly illustrated in his visual text.



Ryan has drawn a line that stretches from a diseased liver up to a roughly drawn circle representing his mind at the top of the frame. He has also drawn a fully functional liver next to the scarred one. Above it he writes NOW to indicate that his liver has been restored to health by a combination of interferon, positive visualisation, and diet. This picture shows that, in Ryan's view, the liver damage caused by hepatitis C also affects his mind. Nonetheless, his mind with the help of interferon is triumphant. The line indicating the link between the mind and body is broken. It is a hesitant line; drawn more faintly than the rest of the picture. It does not connect the two. This can be seen as the mind/body split of Western culture. As illustrated in Ryan's visual text and narrative account, hepatitis C has been overcome with the help of biomedical technology and the dualistic relationship between mind and body has been restored according to the dominant ontological assumptions of Western culture.

However, Ryan's account of the drug's side effects was not so positive. Although he has experienced chronic fatigue because of hepatitis C, this was minimal compared to the side effects of interferon. The drug affected his cognitive ability as well as his physical and emotional state. In particular, interferon inhibited him socially. He explains:

I haven't been able to function in society on this stuff. I've had to remove myself. I don't want to see people I know while I'm on this, cos I'm out of it. They can't comprehend what I've been going through; they'd think I was a fucking nutter... I've had no choice but to remove myself for the last eleven months. I don't want people to see me when I'm wazzed-out.

Biomedical treatment colonised Ryan's lifeworld to the extent that he felt the need to sever social ties. His reliance on the inadequate support of biomedicine thus intensified. Eventually this lack of support and his growing sense of isolation led him to seek psychotherapeutic counselling at great personal financial cost. Ryan maintains however, that this counselling kept him sane during the desolation he attributes to interferon therapy. Nevertheless, like John, Ryan equates the drug's power to "defeat" the virus with how much it knocks him around. When asked how he thinks interferon works, Ryan said, "It's so powerful in the mind that I think of it

as a mind drug". Here the power to dominate is once again associated with the mind while the body is relegated to little more than the battle scarred territory that hosted the dualistic victory. Ryan goes on to describe interferon by saying:

When you inject it, you're squeezing this liquid in and I think of it going to my liver and giving it a dose; all those bacteria or whatever it is causing the problem. I see it freezing them; dealing to them; grabbing them all up into a bunch and killing them...And then the next week you have another lot [of interferon] and deal to them again. It just beats them down, continually, beating them down till they give up... [Interferon is] defeating it for you, and with your mind you can imagine it happening.

Although this evocative description is quite different from a technical biomedical explanation of how interferon works, it does have similarities with an interpretation of specific disease aetiology in which the specific disease agent held responsible for hepatitis C is targeted with the aim of eradication (Dubos 1995:6). Both Wesley and Ryan visualised the drug as something cold and metallic, which seems indicative of technoscience being enrolled against the recalcitrant and threatening natural world. For Wesley, interferon is like an axe that cleaves the lifeworld, exposing the uncertainty that he hoped would be diminished. For Ryan, the same treatment cut him off from much of his social lifeworld support, while ultimately reinforcing the mind/body dualism of Western culture. In John's case, the cure he was searching for eluded two courses of interferon and twelve months of traditional Chinese medicine. He is nonetheless confident that technoscience will eventually deliver him from hepatitis C.

Using the above examples I have attempted to address my initial research question, which is, what might lead people with hepatitis C to pursue interferon therapy despite the severity of side effects and poor prognosis in terms of improved health. Secondary to this is the question of why, after undergoing this treatment without the desired outcome, people remain unwilling to pursue alternatives that may at least alleviate their suffering. Although these questions are far too big to be satisfactorily answered here, I hope that I have alerted the reader to the possible role of the

ontological assumptions inherent in both Western culture and biomedicine regarding these questions. The biomedical emphasis on control resonates deeply with those for whom the uncertainty of hepatitis C means a lack of such control (Birke 1999:110). In the following section I tell a story of interferon that demonstrates how corporate and political interests enter into the lifeworld of people living with hepatitis C.

### **The story of interferon**

In New Zealand, interferon therapy is the only officially recognised and fully subsidised treatment available for hepatitis C. The major pharmaceutical company, Roche, has also provided free trials to certain HCV positive individuals as a way of testing new forms of interferon in combination with other drugs such as Ribavirin.<sup>38</sup> Dolan (1997:101) argues that obtaining official sanction for a drug treatment such as interferon requires enormous financial investment by pharmaceutical companies. These companies are anxious to see some return for such investment, and Dolan explains that this situation has led critics of pharmaceutical company policy to suggest that drugs such as interferon are *treatments in search of a disease* (1996:101). One such critic, Evelleen Richards, states:

There can be no doubt that as far as the pharmaceutical industry was concerned, Interferon *had* to work. A 1982 survey of American corporate investment in interferon research and development reported the involvement of six multinational pharmaceutical corporations and a ‘multitude’ of small companies  
(1991:212. Emphasis in original).

The virologists Alick Issacs and Jean Lindenmann are credited with the discovery of interferon in 1957. Since then the clinical efficacy of interferon has been the subject of much controversy. Initially a small number of virologists and biochemists had high hopes that, as a protein appearing to inhibit viral replication, interferon could be refined and produced for therapeutic use in humans (Cantell 1993:62). However, this proved to be so prohibitively time-consuming and expensive that no human trials

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<sup>38</sup> The manager of the Christchurch Hepatitis Resource Centre, Bill Jang, gave me this information in a phone conversation on 29 January 2003.

were carried out. Many in the scientific mainstream were sceptical of interferon's value and viewed research into interferon disparagingly. Interferon was referred to by some as "misinterpreton" and "imarginon" (Cantell 1993:66). When tracing its history, Evelleen Richards (1991:206-15) claims that the only reason interferon remained on the research agenda is that it was found to have a "modest" anti-tumour effect on mice in 1967. It was as an anti-cancer drug that interferon first received serious scientific attention. But once again its limited supply and exorbitant cost hampered research. Kari Cantell, a scientist who believed in the therapeutic potential of interferon, recalls that support for the drug was at its lowest ebb in the early 1970s (1993:62,108).

### **Genetic engineering**

Then the fortunes of interferon changed with the advent of recombinant DNA technologies, which made large-scale production of a genetically engineered cure for cancer seemingly possible. In the early 1980s, large pharmaceutical companies such as La Roche and Shering-Plough made huge investments in research, in a bid to be the first to patent a genetically engineered interferon (Richards 1991:207; Walsh 1995:194). Richards explains that in 1980

...it was estimated that interferon had a potential world market of around three billion dollars by the end of the decade, and that its use by cancer patients alone would represent a market value of around \$270 million per year  
(1991:207).

The stakes were high, and the potential profits for whichever company successfully cloned and patented the interferon gene promised to be astronomical. This is a prime example of medical science being driven by commercial interests above a dispassionate search for 'truth'. This is not to say that the medical community fell in line silently behind corporate interests. There was strong opposition to interferon in some quarters, particularly from established oncologists committed to cytotoxic treatment. However, in spite of the enormous investment and enthusiasm, interferon repeatedly demonstrated disappointing results as a cancer treatment (Dolan 1997:102). Nevertheless, those supporting interferon were well connected, and with

considerable public as well as private resources, research into the drug continued (Panem 1984:20-21, 23). Both Schering-Plough and Hoffmann-La Roche successfully cloned the human interferon gene amid much publicity and frenzied Wall Street speculation in 1980 (Richards 1991:208; Walsh 1995). Interferon even featured on the cover of Time magazine, which was illustrated with "...cannonball-like viruses bombarding anachronistic modern-day cell 'factories', with a pistol brandishing Paul Revere galloping between them" (Richards 1991:214). Richards claims that the ability of interferon technology to fit into the warfare imagery characteristic of media representations of Western biomedicine went a long way to ensuring its support over other cancer treatments, such as vitamin C, that may have been more effective (1991:214).

In spite of unprecedented support from corporate, government, and private sectors, interferon proved to be ineffectual against all major forms of cancer. It was also found to cause considerable "deleterious" side effects (Richards 1991:208). During the 1970s, attempts to expose interferon's iatrogenic effects were successfully hushed up for fear that these reports would reduce popular support for the drug. However, in 1982 when four patients died of heart attacks while undergoing interferon treatment, it was admitted that tolerance to the drug was not as good as was previously thought. A growing debate arose as to whether it was ethical to perform large scale experiments on human subjects until more was known about interferon (Panem 1984:30-31). Nonetheless, interferon was licensed by the Federal Drug Administration in 1986 to treat a rare form of cancer called hairy cell leukaemia (*FDA Consumer* 1991:3). Richards (1991:214-15) argues that interferon was lifted from the status of "pseudoscience" to "officially credited cancer treatment" because its advocates were able to deploy "...powerful rhetorical, economic and political resources" to this end. She also maintains that, as a treatment controlled by the medical profession, interferon therapy fits neatly alongside other biomedical modalities.

Although continuing research into various combinations of interferon and other drugs as therapeutic agents became an industry in itself, pharmaceutical company expectations and investments have never been fully realised (Richards 1991:212; Panem 1984:32). After failing as a cancer cure, interest in interferon subsided significantly (Dolan 1997:102). Then in 1986 ten patients suffering from hepatitis non A non B (later to become hepatitis C) were found to have improved liver functions during interferon treatment. Following this, larger trials were conducted, and, in the early 1990s, interferon was officially approved for the treatment of patients with hepatitis C in Europe and the United States (Davis 2001:1141). The controversial drug once again had a reversal of fortune. This is perhaps best summed up by the title of an article about hepatitis C in the *New York Times* from 1989, which read:

### **At Last, a Place in Medicine for Interferon**

The title of this article suggests that interferon was indeed a treatment in search of a disease. In hepatitis C, pharmaceutical companies discovered new territory for a drug that had failed to live up to their expectations.

At first, a six month course of alpha interferon monotherapy was used to treat people with hepatitis C. When this proved to be disappointing in terms of sustained viral response, the course of treatment was extended to twelve months.<sup>39</sup> Given a longer period of treatment, the sustained response rates in patients rose to just above ten percent (Davis 2001:1141; Sievert 2001:146). In 1999 the combination of interferon and ribavirin was approved for treatment, and this combination therapy is currently the standard biomedical treatment for hepatitis C (Sievert 2001:142). Although standard interferon treatment has shown to be “only partially effective” for achieving sustained viral responses in patients, it is an improvement on monotherapy (*Connexions* 2002:15). A more recent biomedical development in anti-viral therapy

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<sup>39</sup> A sustained viral response means no detectable level of HCV in the blood as determined by a PCR test.



is pegulated interferon. This form of interferon has a polyethylene glycol (PEG) molecule added to it, which means it has a longer half-life in the bloodstream (*Connexions* 2002:15). When combined with ribavirin, pegulated interferon is considered to be the most promising treatment technoscience has for hepatitis C (Franciscus 2002:7; Sievert 2001:148).<sup>40</sup> Ryan, John, Glenda, and Owen have participated in the Roche clinical trial for this drug. At the time of writing, Owen is still undergoing this treatment. Unfortunately, Ryan, John, and Glenda have not achieved a sustained viral response as a result of undergoing pegulated interferon therapy.<sup>41</sup>

Successful treatment outcomes depend very much on how such outcomes are defined. Whether or not interferon therapy can cure hepatitis C is very much dependent on the definition of the term ‘cure’. If a sustained viral response six months after completion of treatment is defined as a cure, then interferon can be said to cure a percentage of patients. This percentage varies from study to study, but it is probably somewhere between twenty to eighty percent (Davis 2001:1142). If on the other hand, a cure is defined as a complete eradication of hepatitis C from every area of the body for a period of several years, few if any patients can be considered cured as a result of undergoing interferon therapy (Sievert 2001:153; Dolan 1997:97).

Successful treatment intervention using interferon is defined by scientists and biomedical clinicians. Not by patients. With reference to Habermas’ (1987) concept of the lifeworld, there has been an uncoupling of the systemsworld and lifeworld in which expert medical decisions affecting the health and wellbeing of people with hepatitis C are conducted outside the lifeworld of biomedical patients. Nevertheless, as participants’ accounts show, these lifeworlds are penetrated and colonised on many levels as a result. The history and development of interferon technologies

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<sup>40</sup> There are two major forms of pegulated interferon currently available. The first on the market, Peg Intron, produced by Shering Plough, is no more effective than standard combination therapy. Roche invested more time in developing their version called Pegasys. Trials have shown Pegasys interferon to be 61% effective in terms of a sustained viral response in patients (Franciscus 2002:7).

<sup>41</sup> I am pleased to report however, that one of the participants of my pilot study has no detectable level of HCV in his blood six months after completing a forty-eight week course of pegulated interferon.

demonstrates that pharmaceutical company investment and interest in profit played a major role in the drug's establishment as a cancer treatment. Here interferon's effectiveness in treating cancer was arguably of secondary importance (Richards 1991:212). Could it be that, in hepatitis C, pharmaceutical companies have found a 'new world' to colonise in the form of patients' bodies?

### **In summary**

Although the colonisation of the new world cannot be compared to the colonisation of patients' lifeworlds in terms of suffering or injustice, there are some similarities as pointed out by Arthur Frank (1995:10-11). I began the chapter by introducing uncertainty as an existential condition that renders the lifeworld of people with hepatitis C vulnerable to colonisation. This colonisation may occur after a patient is advised by clinicians that the viral genotype assigned to them through biomedical technologies responds well to biomedical treatment. Even if the prognosis is poor, the mere fact that a patient thinks of their condition as something that can be classified as *single disease entity* makes them arguably more inclined to pursue a form of treatment aimed at eradicating that entity. This may be even more likely if the patient views hepatitis C as something foreign and hostile that has entered their body. Because many explanations of biomedical treatment for hepatitis C frame the relationship between disease and the body in these antagonistic terms, such a view is very common, as the visual and narrative texts of participants attest. However, as I mentioned in chapter two, there are other ways of visualising the disease, and these are related to other forms of medical treatment, such as traditional Chinese medicine. For several of the participants I interviewed, the experience of undergoing interferon therapy can be seen as analogous to a lifeworld colonisation. In Ryan's case, the interferon drug regime led to physical and emotional disability, social isolation and despair. For others, such as John and Owen, undergoing interferon therapy was more of a minor inconvenience.

If the dualistic assumptions inherent in biomedical practice could be shown to *cause* a profound split between the mind and body, this could then be seen as a similar violence to that suffered by indigenous people when they are dispossessed of their land. However, since the participants of this study who have undertaken interferon therapy probably inherited something of a mind/body dualistic assumption culturally, undergoing biomedical treatment can only be said to have reaffirmed or challenged such an assumption. In ‘new world’ regions, colonisation severed identities that were rooted in the land, whereas for people with hepatitis C, biomedicine may colonise the lifeworld experience of illness by defining the disease in such a way that interferon seems like the only logical form of treatment.

While the uncertainty associated with the disease and treatment outcomes has left some of the participants vulnerable to lifeworld colonisation, others, such as Owen and Fran, have in various ways negotiated biomedical treatment and discourses in their pragmatic attempts to solve their health problems. Wesley and John both sought out traditional Chinese medicine as part of their problem-solving exercises and found the logic of this system impossible to comprehend. John finally abandoned Chinese herbs and acupuncture for another course of interferon, while Wesley continues to suspend his disbelief in the hope that something in traditional Chinese medicine will rid him of hepatitis C.

The examples of Wesley, John, and Ryan go part-way to answering my question as to why people continue to pursue interferon therapy in spite of previous treatment failure and the severity of side effects. It seems that these participants are *culturally predisposed* to Western biomedicine due to its ontological and epistemological congruence with their own understandings of the body, treatment and disease. The biomedical emphasis on control, for example, resonates deeply with those for whom the uncertainty of hepatitis C means a lack of such control (Birke 1999:110). For Wesley, John, and Ryan, for whom interferon therapy was not successful, there have been some challenges to the ontological assumptions that underlie biomedical

treatment. However, the embeddedness of these participants in a culture that supports such assumptions has constrained any apparent shifts in world-view.

The story I told about the development of interferon is an example of how ‘value neutral’ scientific enquiry can be subverted by corporate interests. As part of the systemsworld, these corporate interests, along with technoscience and biomedicine, have penetrated the lifeworld of many people with hepatitis C, thus leaving them open to colonisation at a physical, emotional, and psychic level. Here I have left the reader to judge the extent to which colonisation is an appropriate term for biomedical intervention for hepatitis C.

In the next chapter, the dualistic assumptions of Western culture and biomedicine are further examined as they appear in public health and immune system discourses. Here the focus shifts to the political nature of epidemics as they apply to the collective social body or body politic. I then narrow the lens to show how the culturally circulating metaphors, narratives, and images of disease and the body are drawn upon, experienced, and internalised by those living with hepatitis C. I conclude the chapter by proposing a way of re-envisioning the relationship between disease and the body informed by some of the narratives and visual texts produced by the participants of this study. Here an attempt is made to avoid the self and hostile other distinction as well as the warfare metaphors common to biomedical explanations.

## CHAPTER SIX

### Immune system imagery, metaphor, and discourse

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Not all metaphors applied to illnesses and their treatment are equally unsavory and distorting. The one I am most eager to see retired – more than ever since the emergence of AIDS – is the military metaphor... [T]he effect of the military imagery on thinking about sickness and health is far from inconsequential. It overmobilizes, it overdescribes, and it powerfully contributes to the excommunicating and stigmatizing of the ill...We are not being invaded. The body is not a battlefield. The ill are neither unavoidable casualties nor the enemy. We - medicine, society - are not authorized to fight back by any means whatever (Sontag 1988:94-95).

A theme common to most of the narratives and visual texts of participants is that of *self* and *other*. In fact within Western biomedical discourses, particularly immunology and virology, it is difficult to even talk about disease without invoking a self and other distinction (Birke 1999:142). According to Lisa Weasel (2001: 29, 31), the self/other dichotomy is “essential” to orthodox immunological theory. In the hands of translators of Western biomedicine, this distinction commonly leads to the use of militaristic metaphors to explain both disease and treatment (Martin 1994:53, 96). As I have shown previously, hepatitis C is no exception. It is perhaps not surprising then, that someone who visualises their body as invaded by something which is perceived as hostile or threatening, is willing to take up biomedical arms against it. However, as Martin points out, there are biological anomalies that severely trouble the idea that the immune system operates according to a distinction between self and non-self. For example, a pregnant woman’s immune system does not attack the foetus within her, even though it is essentially made up of foreign tissue that has grafted itself to her womb like a tumour (Weasel 2001:32; Martin

1994:59).<sup>42</sup> Along with the cultural predisposition to Western biomedicine discussed in the previous chapter, I contend that the adoption of the *self* and *hostile other* dichotomy of immune system discourse, as a way of visualising disease, is a major factor relating to treatment choices made by people with hepatitis C.

In this chapter I look at how self/other distinctions and warfare metaphors are manifested in the narratives and visual texts of people living with hepatitis C. After an example of this manifestation, I outline some of the ways in which the body and disease have been visualised over time in Western culture during the 20<sup>th</sup> to 21<sup>st</sup> century. I then briefly discuss the metaphors and images that have been used in traditional Chinese medicine. In doing so, I hope to further illustrate that ideas and understandings about the nature of the relationship between the body and disease, are not only culturally, but also historically, contingent. I then introduce the idea that when an epidemic is declared, the individual diseased body often becomes a metaphor for the social body, or body politic. In this analogy, a person infected with a disease such as hepatitis C, is classified as *other* in the social body. Here there are some remarkable similarities between contemporary immune system discourse, and the notion of the body politic. The social implications of this confluence with regard to people living with hepatitis C are then discussed. Following this, the way that stigma and discrimination are internalised along the lines of a purity/pollution binary is examined with reference to the visual texts and narratives produced by participants of my study. Here I argue that the dualistic assumptions inherent in biomedical discourses help to perpetuate stigmatisation and discrimination against those living with hepatitis C. I propose that this perpetuation, in turn fuels the epidemic by promoting shame, secrecy, and unsafe drug injecting practices.

Warfare metaphors in which the body is a *battlefield* no doubt serve to make complex medical knowledge comprehensible to the lay person, but do such frameworks not also limit our capacity to visualise other methods of healing?

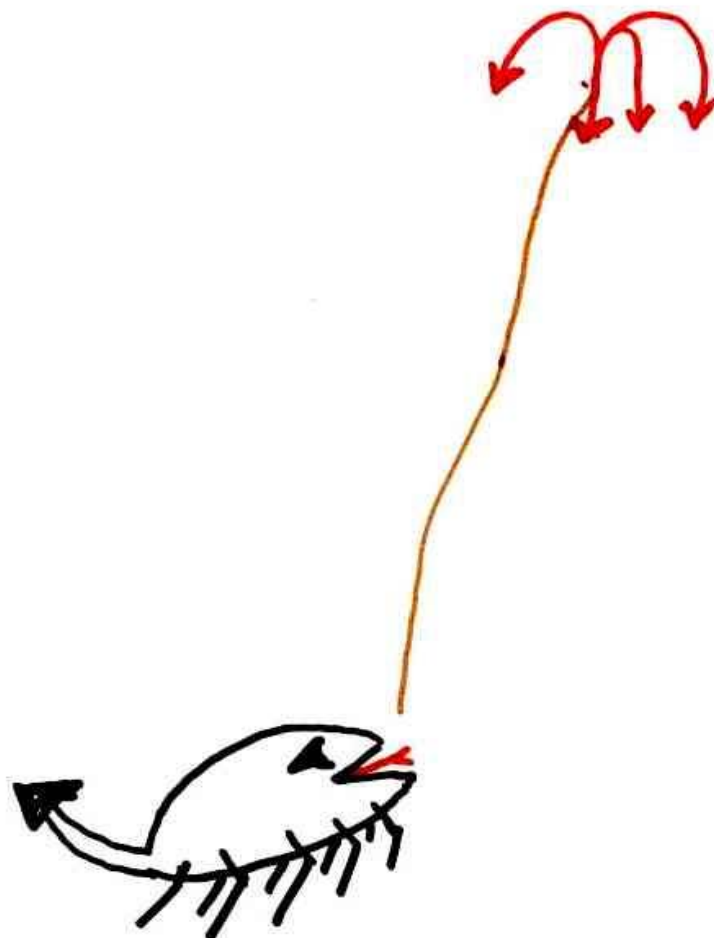
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<sup>42</sup> An alternative model of how the immune response functions has been proposed by Bonney and Matzinger (1997, cited in Weasel 2001:33). In this model, an immune response is mounted against that which presents a danger to the organism, rather than that which is recognised as non-self.

Visualisations and metaphors of the interaction between viral actors and the body do not simply arise in a vacuum. Medical texts and educational tools are replete with images and analogies that inevitably contribute to the way we visualise the relationship between our bodies and disease. Donna Haraway (1992:319-320) has shown how the technologies of “biomedical visualisation” have played a role in determining our notions of what is *self* and what is *other* within our bodies. Colourful photographs revealing the strange creatures that either threaten or protect the integrity of our inner spaces serve to enhance the image galleries of our visualisations.

In the visual text and narrative account produced by John, the influence of biomedical visualisation is quite apparent. Here the limiting potential of this visualisation, in terms of other methods of treatment, is also exemplified. John explains that he imagines the hepatitis C virus to be something like a dust mite that has been magnified by technoscientific tools of visualisation. He says:

Well I suppose it's an invasive type of thing that is trying to bowl your liver off. Something that's getting in there and doing a bit of damage...I kind of visualise hooks. Hooks and arrows...like a grappling hook. There's a little bug there somewhere and he's not very peasant looking...black has got to come into it [black for the bug]...something that looks pretty nasty. Like a dust mite...lots of legs. It looks like a cockroach...a little devil tail...eyes...snake tongue.



...the bug's getting into your liver and being very hard to remove. They are obviously very small and they stick like shit to a blanket basically. That's the hooks.... I see them in my liver. I think of my liver as being invaded type of thing, and not being able to shift them. I say to my partner, we've got to try and get those bugs out of there somehow, so I suppose that's how I think of it. They're in there and they're not coming out.

The positioning of the virus in the lower left hand corner of his picture is suggestive of a bottom dwelling deep-sea creature; something that lurks unseen but for technologies of visualisation. However, the creature itself has eyes signifying malicious intent. This composite of evil signs is not connected to the barbed grapple issuing from its mouth. To me this indicates that while hepatitis C is difficult to remove, it is not entirely impossible.

When looking at the way John visualises the hepatitis C virus, the self/other duality is quite apparent. As this dualism is also central to the practices of Western



biomedicine it perhaps not surprising that John abandoned traditional Chinese medicine in favour of another course of interferon.

John thinks of his liver as been invaded by something hostile, tenacious, and *other*, and he has been twice prepared to undergo arduous treatment specifically designed to eradicate the foreign pathogen. Congruent with a biomedical view, John's picture represents the hepatitis C virus in complete isolation from his body. Despite undergoing a lengthy course of traditional Chinese medicine, John's way of visualising hepatitis C appears to be firmly aligned with the ontological assumptions of conventional Western medicine. In John's case, the biomedical framework in which he is situated seems to have limited his capacity to visualise other methods of healing.

Haraway (1992:324) indicates that the way we visualise the workings of our body will have wider implications for social action, and Weasel (2001:30) stresses the importance of critically examining the discourses associated with the body and disease for how they might "...reinforce prevailing social and cultural stereotypes, making them appear 'natural'". In which case, how might the *self* versus *hostile other* metaphor serve to perpetuate the xenophobic notion that anything different or foreign is naturally threatening? In the next section I explore the way in which Western ideas about the relationship between the body and disease have shifted over time, and how the images and metaphors used to describe this relationship have been shaped by technology and dominant social values. This is not intended to be an account of how medical knowledge is progressively revealing the 'true' nature of the body and disease, but rather to show the unstable and socially constructed nature of these categories (Nettleton 1995:17). Following this, I turn to a discussion of the images and metaphors used in traditional Chinese medicine to refer to health, illness, and the body. Finally, I return to the accounts and visual texts produced by participants as they relate to the culturally available discourses, narratives, and metaphors of disease.

In a historical overview of the way disease and the body have been visualised, Emily Martin (1994:23-44) demonstrates that, in the United States during the 1940s and 1950s, the body was often depicted as a fortress. The fortress's walls represented the body's skin; its primary protection against germs and disease. In this view, the body's defence was compromised at openings such as the mouth and nose, or if the skin was damaged. At these points of entry, the vulnerable interior of the body was exposed to infection. Consequently, vigilant hygienic practices were promoted to protect the body's exterior surfaces (fortress walls). Martin suggests that the fortress analogy reflected middle class anxieties and the cold war mentality of the time (1994:24-32). After the 1950s, the fortress imagery was still prevalent in popular texts, but from this time onwards, more and more attention was focused inside the protective walls, where an interior army was increasingly seen to fight off germs and disease (Martin 1994:34-35). As theories about the immune system developed in the 1970s, visuals of the body's interior defences intensified and the primacy of exterior hygiene subsided (Martin 1994:32, 33).

### **The immune system, flexible specialisation, and interferon**

Martin (1997:352) and Helmreich (2000:487) argue that the orthodox biomedical view of the body's immune response to disease tends to be consistent with late capitalist modes of production such as 'flexible specialisation'. Flexible specialisation is a term used to describe a form of production that can respond quickly to ever-changing market demands. Aided by the speed of internet technologies, which makes global market information instantly accessible, flexible specialisation is replacing Fordist modes of production characterised by the routine of assembly-line mass production (Sennett 1998:51-53). Martin (1997) suggests that the immune system, as a highly complex and flexible network, has become not only a measure of health, but also a metaphorical standard by which to evaluate employees in an increasingly team oriented and insecure workplace. Like the immune system, the ideal employees of late capitalism are those with the flexibility to respond at a moment's notice to their employer's wishes (1997:351, 355). This mode of production tends to exclude people with chronic illness and people

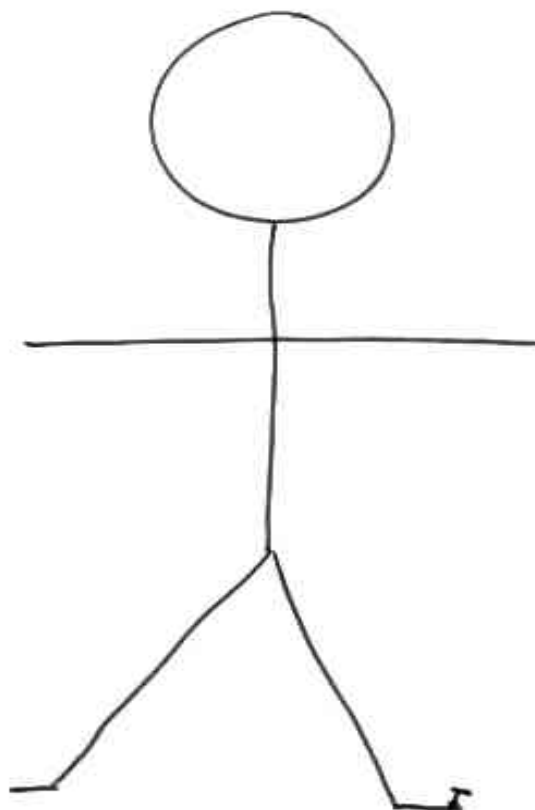
committed to staying in one particular place. In their study of hepatitis C and quality of life, Conrad *et al* (2001:191) explain that anxiety and uncertainty about their future ability to earn a living is common among HCV positive people. Participants such as Owen and Wesley who are concerned about keeping up with contemporary labour force demands, cite this as a reason for undertaking interferon therapy, which simulates a hyper-boosted immune system response. Wesley explains:

...things have changed so much in the last ten years and I think that everybody is looking for energy to rise above it. The promise for me with interferon was more energy. At the time I wanted to think that my life to come would be better than my life that had gone...I wanted to live, and if you think that hep C is keeping you from a better life then you want to take care of it.

Owen thinks that the odds of being cured by interferon are remote, but he is nonetheless keen to take a chance, particularly with the prevailing labour market in mind. “You’ve got to do it” he says, “it’s a lottery; if you win you win”. Owen uses the metaphor of ‘treatment as a gamble worth taking’ repeatedly throughout the interview. He explains:

It’s the same as buying a lottery ticket. People buy lottery tickets with the hope that they’ll win, but with the knowledge that the chances are pretty slim. But actually I’ve got a much better chance of a cure out of this than buying a lottery ticket and winning the big one, so the odds are pretty reasonable.

‘Life as a gamble’ seems to be the guiding metaphor of Owen’s biographical narrative of self. Although there are lucky breaks in life, there are no “free rides” according to Owen. He thinks that the chances of his “walking away” from ten years of hard drug use without being damaged in some way would be “one in a million”. There is therefore, no sense of self-pity in the story Owen tells of his life with hepatitis C. Nevertheless, Owen thinks of hepatitis C as impeding his chances of getting ahead under the new labour market demands. In his visual text, Owen represents himself as entirely symmetrical except for a thorn that is lodged in the end of his left foot. This is hepatitis C; the only obvious legacy of his previous way of life. He refers to the thorn as a “hindrance”. “If I could take it out then I’d be totally free to move on”. The ability to be mobile, a central



prerequisite for success in flexible specialisation, is denied to Owen because of his hepatitis C status. The body depicted here is unencumbered by flesh, organs, or social relationships. It can be viewed as the ideal body of late capitalist modes of production except for the hepatitis C, which remains as a legacy of Owen's deviation from legitimised forms of inebriation. Although Owen describes hepatitis C as a thorn, it was mentioned in both of the brainstorming sessions that the thorn looks more like a nail, pinning him down and thwarting his mobility. The disease is always insidiously at the back of Owen's mind, and he is currently undergoing interferon because he thinks his chances of "fighting" the virus off with the drug are better while he is still relatively young and healthy.

Not all biomedical clinicians are limited to warfare imagery. A doctor that Owen spoke to explained that interferon therapy was like throwing water on a fire. In some cases the embers would flare up again, and in some cases they would not. Owen then

extended this analogy when explaining his decision to undergo a second and longer course of interferon by saying, "...it seems to me that if you could pour water on a fire for longer there'd be more chance of it not flaring up again". Although Owen admits that this is an extremely simplistic metaphor for anti-viral therapy, it certainly made more sense to him than all the "techno-speak" he read in medical textbooks. This example of the use of metaphor in clinical practice also addresses my initial research question, which is, what leads people with hepatitis C to undergo a second course of interferon after the first one failed. In Owen's case he was provided with a metaphor that made sense of such an undertaking.

### **Traditional Chinese medicine and metaphor**

While there is no concept of the immune system, as such, in traditional Chinese medicine, the wellbeing of the body is directly related to the even flow of Qi through invisible meridian channels in the body. When this flow is obstructed, illness occurs (McNamara and Xuan Ke 1995:27; Dolan 1997:118). The even flow of Qi is impeded by any imbalance of yin and yang. Such imbalances are referred to using climatic analogies. In traditional Chinese medicine, the condition of hepatitis C may be described as an overabundance of *damp heat* in the body, as opposed to an *invasion* by a *foreign pathogen* (Dolan 1997:123). Paul Unschuld (1992:55, 56) points out that militaristic terminology and metaphor have appeared in Chinese medical literature. In these accounts the appropriateness and quality of both military and medical interventions are stressed. However, these accounts drew criticism from conservative medical representatives of the time, who claimed that notions of warfare and destruction deviated from the correct understanding of medicine's purpose (1992:55, 56). A far more common metaphor to describe the workings of the body in traditional Chinese medicine is that of climatic conditions. Here the body is visualised as subject to internal weather, which is affected by diet and exercise, and also to external weather conditions (McNamara and Xuan Ke 1995:27-29). Health is thus contingent upon the interrelationship of inside and outside. This is in accordance with the traditional Chinese cosmology of relational interdependence of elements in seasonal cycles (Vercammen 1996:166; Leslie and Young 1992).

Having once again illustrated the unstable and culturally constructed nature of health, illness, and the body, I will now continue to examine the extent to which the imagery and language of warfare has been adopted or resisted in the material contributed by the HCV positive participants of this study. Here the ubiquitous public narrative of *battling* disease is introduced as a dominant media representation of the experience of illness that circulates widely in Western culture. Following this, I discuss Juan's unique way of visualising hepatitis C as an alternative to imagery associated with warfare. I then introduce the reader to the 'body politic' analogy in order to explore the themes of stigma, discrimination, purity and pollution, as they have arisen in the accounts of participants of this study.

With the exception of Juan, all of the participants viewed the relationship between themselves and the virus as hostile to some extent. Even Maria, who was relieved to have a clinical explanation for her condition, and whose life has been enriched because of treatment, referred to the virus as "eating away" at her. A determined mobilisation of willpower and treatment in order to *fight* or *beat* the virus is a position that was taken up by Fran, Ryan, and Glenda. Glenda states, "I am determined to beat it somehow". There is a long tradition of fighting disease in Western culture, particularly battling cancer. This is perhaps because within dominant biomedical discourse, the healthy body is deemed normal whereas the diseased body is an abhorrence that must be cured or sequestered. In secular Western culture, life is of primary value and death is often thought of as a kind of failure (if it is thought of at all) (Giddens 1997:40-41). The battle with cancer is commonly fought using chemotherapy, which has much in common with interferon therapy. For example, in 1999 and 2000, the popular prime-time talk show host Paul Holmes was featured on the cover of the *New Zealand Woman's Weekly* publicly vowing to *beat* cancer for his children. Inside the magazine, Rowan Wakefield (1999:4-5) describes the disease as "...the most important *battle* of his life", and Holmes himself says "...I have this cancer – *this evil thing* growing inside me... [and it] has got to be *destroyed*" (my emphasis). Although none of the above three participants

alluded to such illness narratives, the ubiquitous nature of their cultural presence renders these stories a public resource to be drawn upon in the face of hepatitis C.

By contrast, Juan visualises the hepatitis C virus as something that has become part of him. He says, “it’s not like some sort of enemy has invaded me...I’m the virus and the virus is me”. For him, declaring war on the virus would be tantamount to declaring war on himself, and this is something Juan is not prepared to do. Given his attitude, it is perhaps not surprising that Juan has avoided interferon therapy with all its allusions to conflict between self and other. In terms of treatment for hepatitis C, he wants to explore other avenues besides fighting. Juan explains:

If I fight I’m sending negativity, and with that comes bad energies; stress, battling with myself...there must be peace for healing energies to flow...because that’s the barrier – fear and hostility towards your virus.

Consistent with these ideas, Juan’s text contains a forearm reaching out of the middle of a chaotic and visceral surround. At the end of this arm a hand can be made out that cradles the virus. Juan’s text can be read as the harmonious relationship he currently has with the hepatitis C virus. This relationship is the outcome of the violent emotional struggle that has been his life.



Up to this point in the chapter, I have discussed conventional immune system discourse as a powerful influence on the way some of the participants in this study visualise the relationship between their bodies and disease. I have also used examples of participants' accounts and visual texts to illustrate how late capitalist modes of production, combined with immune system discourse, can be seen as a factor in the decision to pursue interferon therapy. By exploring the imagery and



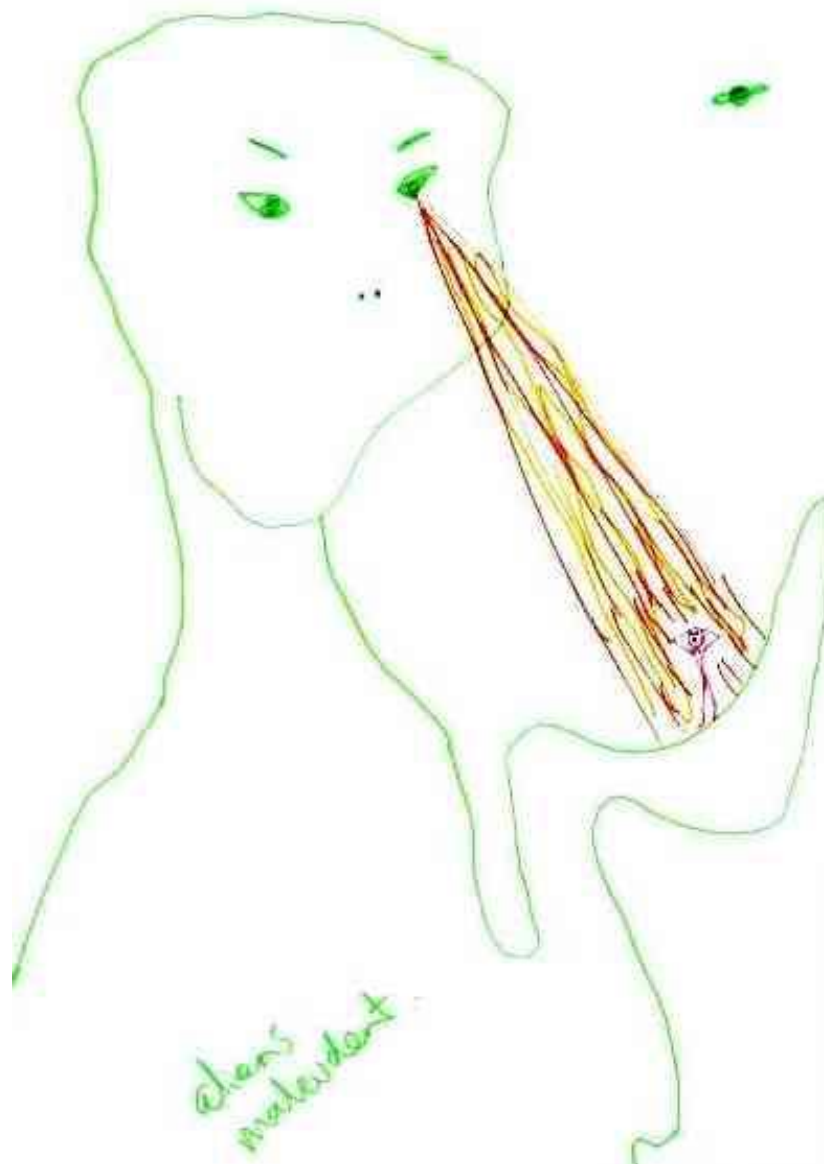
metaphors used in traditional Chinese medicine, I have attempted once again to disrupt any ideas the reader might have that there is a universally accepted way of understanding health, illness and medical treatment. Juan's unique visualisation of hepatitis C serves as an example of one of these alternative perspectives. I now turn to some of the social implications of the way in which epidemic diseases are experienced.

### **Epidemics, the individual and the body politic**

The [military] metaphor implements the way particularly dreaded diseases are envisaged as an alien "other," as enemies are in modern war; and the move from the demonization of the illness to the attribution of fault to the patient is an inevitable one, no matter if patients are thought of as victims. Victims suggest innocence. And innocence, by the inexorable logic that governs all relational terms, suggests guilt (Sontag 1988:11).

In much of this thesis I have examined what it means for people to have hepatitis C on an individual, or micro, level. In the following section, I attempt to extrapolate from these personal accounts to take in the hepatitis C epidemic on a collective, or macro, level. Because of the silent nature of this epidemic, little has been written about it to date. I therefore draw on material concerning HIV/AIDS and the 'body politic', as the hepatitis C epidemic has been said to be comparable to the HIV/AIDS epidemic in terms of discrimination as well as in its economic and social consequences (Puplick 2001:196).

Catherine Waldby (1996:1) argues that when an epidemic is declared it is synonymous with a declaration of war. War is declared on the viruses and bacteria that threaten the ontological status of humankind by colonising the human body. In binary terms, science as *culture*, particularly biomedicine, is mobilised against *nature* in the form of microbial invaders. In keeping with the B grade science fiction narrative suggested by Waldby, one participant in my study (Kerri) visualised the hepatitis C virus as a frightening alien presence over which she was powerless:



Kerri explains the origins of this imagery:

...if I feared anything with an absolute passion, it's aliens, of all the weirdest things, and I think I got it from watching creepy, creepy alien movies when I was a kid... You know, the ones where people get abducted and get things stuck in their brains and their noses. I was thinking that y'know, maybe there's a parallel here, y'know, cos I have aliens inside my body...And um, so I guess there's a kind of parallel there because I do have up till now, really, felt quite a strong sense of powerlessness around my prognosis and y'know the cure and so on.

Given the way Kerri visualises the virus, it is perhaps not surprising that she has put herself on the waiting list to have interferon therapy. Just as Kerri has felt vulnerable to malevolent aliens, so too is the individual human body vulnerable to HCV or HIV when the protective borders of that body are compromised by the introduction of a ‘foreign’ object, such as a needle or penis capable of transmitting the virus. In public health terms, an epidemic occurs when too many bodies have had their protective borders compromised. When this happens the entire population or *body politic* is threatened by social disorder.<sup>43</sup> Waldby (1996:88) describes the body politic as “...a term which implies imagining the nation or some governmental unit along anthropomorphic or bodily lines”. This, in turn, has some unfortunate social consequences for the viruses’ human hosts, particularly those infected with HCV or HIV/AIDS. Because of their sexual preference or risk-taking behaviour, these people have contravened the social contract and thus forfeited their rights to full citizenship. With reference to the HIV/AIDS epidemic, Waldby (1996) writes:

The same idea of infection presides over the particular body and the social order, and the HIV infected person is thus assimilated to the position of the virus in the body politic. Similarly the bodies of ‘risk groups’, with their dangerous permeability, are assimilated to the position of fluid transmission points for the virus’s progress through the body politic (1996:15).

In Mary Douglas’ work on purity and pollution, the same theme of the body as a model for the social system is explicated. The boundaries of both the body and the social system are threatened at the margins (1984:115). People infected with HCV or HIV, as well as those engaging in behaviours considered to put them at risk of infection, are at the margin. Risk behaviour includes historically stigmatised activities such as drug taking, prostitution, and casual sex. Interestingly, having blood transfusions or dental surgery are not considered risk behaviours, even though transmission of HCV is possible as a result (MacDonald *et al* 2001:209-217). People at the margin constitute the permeable skin of the social body. Waldby argues that

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<sup>43</sup> The term body politic is derived from the political theories of classical liberalism, with their roots in the work of philosophers such as Thomas Hobbes, John Locke, and Jean-Jacques Rousseau. Very generally, these men argued that in order to attain some form of individual liberty and protection, citizens must agree to a tacit social contract. Anyone refusing to enter into this contract must be forced to do so by the entire social body or body politic (Tauber 1994:151; Pateman 1988 55, 56).

such people "...have passed irrevocably over onto the side of the inhuman, the side of the virus, the side of death, and have thus become enemies of the medical campaign to contain viral spread" (1996:4). This marginalisation is doubly acute for people who have already suffered negative legal and social sanctions for their drug use or sexual preferences.

### **Immunology and the body politic**

The immunological view of the body has some remarkable similarities with the body politic analogy. Cindy Patton (1990:9) explains that the interior workings of the immune system, as revealed by new imaging technologies, allowed a far more sophisticated and interior vision of the body to emerge. With the advent of these new technologies, the dominant metaphors of the body and disease also shifted. Since the late 1970s, the body's ability to protect itself against disease has been increasingly attributed to the immune system in popular texts informed by immunology (Tauber 1994:186).

The contemporary view of how the body protects itself from disease has moved from primary defence of the body's exterior to a complex rearguard action on the inside (Martin 2000:127; Birke 1999:142; Patton 1990:9). Patton (1990:9-10) explains that things were no longer as black and white once it was discovered that bacteria could also be beneficial, and that hideous subterranean entities such as macrophages were the 'good guys'. The body's interior defence in the form of the immune system became seen to operate by making fine distinctions between what is *self* and what is *other*. According to Patton, "...it was not so much about Other with a capital O as about the marginally different that had already been admitted to close proximity" (1990:9-10). In terms of the body politic, the marginally different other is the intravenous drug user and the homosexual who in most respects appear to be 'good' citizens. The category of the *marginally different other*, that nonetheless threatens the social body, naturally extends to include those living with hepatitis C.

## Stigma and discrimination

The average punter thinks of it [HCV] as AIDS. They don't know any different...it doesn't bother me most of the time, but I guess it all goes into the subconscious...each little bit; it all adds up and batters away at your self-esteem  
(Ryan).

Helene Joffe (1997) argues that plagues and epidemics have historically been linked to foreignness, and the morally questionable behaviour of certain out-groups in society. In the nineteenth century, for example, syphilis was identified with black women, prostitutes and immoderate sexuality (Gilman 1985, cited in Joffe 1997:136). Similarly, typhus was thought to have been introduced into Britain by Irish refugees (Morris 1976, cited in Joffe 1997:136). In her study of how AIDS is represented cross-culturally, Joffe found that three-quarters of the 'white' lay respondents thought that AIDS originated in Africa. A majority of these people, linked the spread of the disease to "alien practices", such as bestiality or voodoo rituals (1997:138-39). The HIV/AIDS epidemic has also been strongly linked to homosexuality. In fact, the disease was initially called Gay Related Immune Deficiency (Patton 1990:8). The above quote, by Ryan, suggests that hepatitis C has inherited much of the stigma of AIDS in the public imagination. However, the current hepatitis C epidemic, is primarily associated with another marginalised group - intravenous drug users.

During his summary of the stream highlights at the third Australasian conference on hepatitis C, Professor Robert Batey explained that hepatitis C was thought of as *an illegal virus* due to the illegal route of transmission commonly associated with it. He went on to say that this perception inevitably led to the stigmatisation of those living with the disease. This stigmatisation results in a sense of social isolation and a dependence on allopathic medicine, which is not known for its person centred approach. At the same conference, Dr. Alex Wodak argued that the major barrier to preventing the spread of hepatitis C is an entrenched commitment to drug prohibition. Not only does discrimination against intravenous drug use push this

activity underground, but it also results in the imprisonment of large numbers of this marginalised group. The prevalence is disproportionately high in penal institutions, and transmission due to the sharing of drug-injecting equipment and unsanitary tattooing practices is common (MacDonald *et al* 2001:210-11; Crofts and Wodak 2001:348). Wodak argues that keeping intravenous drug users out of prison is one of the best defences against hepatitis C transmission.

Chris Puplick (2001b), the president of the Anti-discrimination Board of New South Wales, states that discrimination is in itself a disease of epidemic proportions. Puplick argues that:

Any disease, particularly an epidemic one, is as much a sociopolitical phenomenon as it is a medicoscientific one. Any illness, disease, or disability which results from acts of personal behaviour, especially if the dominant paradigm defines that behaviour as 'deviant', is as much a moral phenomenon as it is a health one  
(2001:194b)

Puplick (2001:198b) contends that the stigmatisation and discrimination of people with hepatitis C prevent the best public health policy outcomes, by making these people less likely to come forward for testing and treatment. The negative social and legal sanctions against intravenous drug users also fuel the hepatitis C epidemic by making it difficult for these people to access clean injecting equipment. If imprisoned, intravenous drug users are far more likely to contract and/or transmit hepatitis C than they would otherwise be (Crofts and Wodak 2001:348).

Most of the people I interviewed no longer use drugs, and some of them never did, but their HCV positive status still links them to the stigma of this demonised activity. For Kerri, this stigma, compounded with the symptoms of hepatitis C, has left her feeling isolated, depressed, and without the energy to maintain the very relationships she needs for support. The clinical encounter with biomedical specialists is mentioned by many as a location where they felt particularly

stigmatised and discriminated against.<sup>44</sup> Glenda for example, had a hospital appointment rescheduled when she mentioned to a nurse that she had hepatitis C. Instead of being first on the list, Glenda was moved to the very end. This experience made her feel as if she was a “leper”. After Fran was told she had contracted hepatitis C, she left the doctor’s surgery feeling “...sort of dirty, yucky...it was like I didn’t belong; an alien; like I was from another planet”. Fran’s relationship with the social world was suddenly changed by news of her HCV positive status.

When Fran finally saw a biomedical liver specialist, she was appalled by the treatment she received. To begin with, she was made to wait in a corridor facing a wall like a naughty schoolgirl waiting to see the headmaster. Fran felt intimidated and self-conscious about clearly being on display as someone with hepatitis C. Then to make matters worse, the specialist repeatedly insinuated that she was a drug user.

He kept asking me had I been taking drugs. I said no, and he’d leave it for a bit and then he’d come back to it. In the end I said, “Look, how many times do I have to tell you, I have never taken drugs”. I think he’s of the opinion that I’m a drug user; that I did it to myself and it serves me right.

In Fran’s account, the connection between having hepatitis C and the stigma of drug use is quite apparent. This then leads to the discriminatory notion that drug users deserve the disease. Similarly, Wilma felt “dirty” and stigmatised during the biomedical encounter. She thinks that people with hepatitis C are viewed negatively by others as the unworthy victims of their own choices. She thinks that through public ignorance, having hepatitis C is strongly associated with AIDS, homosexuality, drug addiction, and prostitution. Like Fran and Wilma, Nina also had the impression that a public hospital liver specialist viewed her as someone that had been using hard drugs for years; a deserving victim. She says:

I would rather trust people I know [regarding hepatitis C] than the specialists at the hospital...he didn’t give me any information, and he certainly didn’t make me feel any better about myself – he could have at least done that. I just

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<sup>44</sup> Most of these people referred to a particular specialist, and biomedical practice *per se* cannot be judged by this one practitioner. However, Puplick (2001:196b) cites a study that found discrimination to be pervasive throughout the health sector.

had the feeling he was getting two hundred dollars an hour for seeing me; that I was just another number he didn't give a fuck about.

### **Blood, purity and pollution**

Joffe (1997:144) argues that linking diseases with particular out-groups has the effect of forging and sustaining a positive self-identity for members of dominant social groups. In the light of this argument, stigmatising intravenous drug users and people with hepatitis C can be seen as a social strategy to reaffirm an identity as a member of the in-group. This strategy also reaffirms normative social conventions regarding behaviour. In this way, people involved in behaviour that is thought to threaten the health of the body politic are identified and ostracised. This process is not dissimilar to the way biomedicine describes the workings of the immune system. In many of these accounts, anything recognised as non-self, or *other*, is attacked as part of the immune response (Weasel 2001:29-31; Tauber 1994:184). The body politic analogy and immune system discourse are thus remarkably similar.

Historically, a purity and pollution dichotomy has been used as a strategy in identity formation. For example, Stalleybrass and White (1986:145-48) argue that nineteenth century English bourgeois identity was, in part, created and maintained by a censorship of behaviour and language associated with the lower parts of the body, particularly bodily wastes. Bourgeois identity was thus fashioned in opposition to the lower classes who they increasingly identified with lower body activity such as sex, excrement, and consequently, disease. Bourgeois anxiety (and fascination) at the time was particularly focussed on ways in which the boundaries between clean and dirty, and high and low class, might be transgressed. Stalleybrass and White identify the *rat*, the *pig*, and the *prostitute* as vectors of disease that moved between areas of the city inhabited by the dirty lower class and the respectable neighbourhoods. In so doing, the *rat*, the *pig*, and the *prostitute* threatened the binary distinction between purity and pollution upon which middle-class privilege and identity was based. To bourgeois society, the rat, the pig, and the prostitute were symbolic mediators between what they imagined themselves to be,



and their imagined 'others', the dirty, disease ridden, lower class. Similarly, the intravenous drug user and those infected with hepatitis C can be seen symbolically as a possible bridge between viral invaders and humankind; conduits between nature and culture that threaten the integrity of the body politic.

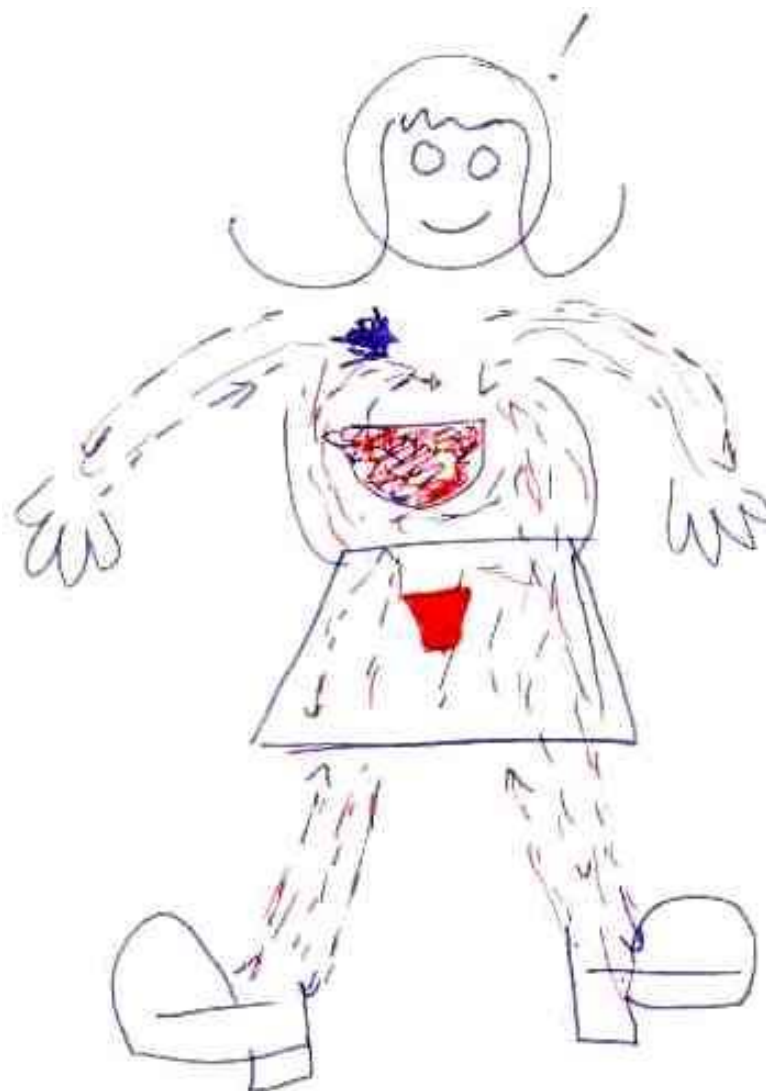
In her discussion of medical discourse in late Victorian England, Anne Scott (1996:100-07) suggests that in the middle-class society of the time, 'decent' women were considered to be something of a bulwark between nature and culture. Scott writes:

Through their sexuality, women were perceived as one of the primary links between man and nature; the force of the tame/wild split fell heavily on them. A deeply sexualised polarity between madonna and whore – or between the white English lady and the black foreign woman – developed. Blood and sewage, both products of the untamed body, became potent symbols of this division, and served to demarcate the two categories of women. Prostitutes for example, were metaphorically seen as conduits between civilised society and the wild, untamed, underworld.  
(1996:102-03)

However, even 'decent' middle-class women were deemed a potential threat to the male world of civilised rational endeavour (culture) because of their closer association with bodily activities such as reproduction (nature) (Shildrick 1997:26; Scott 1996:106). These dualistic assumptions were very much influenced by a popular interpretation of Darwin's evolutionary theory that positioned men as more evolved than women, and middle-class women as more evolved than prostitutes, lower-class women and women of colour (Gilman 2002:392-400; Scott 1996:102-103). Much of the responsibility for delineating and containing the threat of social disorder posed by women was claimed by the medical profession, many of whom argued that independence, education, and competition were unsuitable pursuits for women. It was thought by these men that if women were to engage in such activities, hysteria caused by menstrual disorder and nervous breakdown would result (Shildrick 1997:26; Scott 1996:106). In this analysis, it is women, as well as the rat, the pig, and the prostitute, that were perceived of as conduits between nature and culture; disease and health; pollution and purity.

Margrit Shildrick (1997:27) argues that the clinical encounter is still a site where male power is exercised to control the perceived irrationality of women, which is inextricably linked to menstruation and the corporeality of reproduction. It is in the clinical encounter that the gendered experience of hepatitis C and biomedical treatment becomes apparent. As participant accounts earlier in this chapter demonstrated, several women felt dirty, diseased, and alien during clinical encounters. None of the men I interviewed expressed this response. This finding suggests that the gendered experience of disease and biomedical practice is related to the dualistic assumptions inherent in both Western culture and biomedicine. These dualisms align the category of male with mind, rationality, culture and control, and female with body, irrationality, nature and chaos (Brown and Jordanova 1995:510; Spelman 1982:109-11).

Nina's chief concern when she found out that she was HCV positive was that she might infect her partner during sex, particularly if she was menstruating. Nina eventually found out that there was virtually no chance of this occurring. Nevertheless, her concern about her blood and sexuality as vectors of pollution and contagion is apparent in her visual text:



Barely contained within the perimeters of Nina's body we can see the flow of blood and hepatitis C circulating. The vagina area is coloured in solid red indicating both blood and danger. The only organ depicted is her liver; the headquarters and generator of the disease. As the blood goes through Nina's liver it becomes polluted with hepatitis C. The virus then transgresses the boundaries of her body during menstruation. The most extreme example of internalised stigma that I have heard is the story of an Australian woman with hepatitis C, who became so fearful of her menstrual blood that she had a hysterectomy performed. While this example is anecdotal, it illustrates the profound and tragic effect that stigmatisation can have. It also illustrates something of the gendered nature of embodiment and disease.

However, the issue of gender as it relates to embodiment, disease, and medical treatment cannot be done justice in this thesis. I have only touched lightly on this area in order to demonstrate how social stigma has become internalised in the case of several of the women participant of my study. The gendered aspects of medical treatment for hepatitis C is nonetheless a promising topic for further research.

### **Juan and pollution**

The cyclical traffic of the virus across bodily borders during menstruation is not part of the male experience of living with hepatitis C. Nevertheless, men do internalise stigma along the lines of purity and pollution. The hepatitis C virus had only just been isolated when Juan was diagnosed. As the ‘host’ of a new disease, Juan was treated as a medical curiosity (albeit a dangerous one) and was studied as such within the biomedical framework. Although he was pleased to be given time out from a rehabilitation centre to have a number of tests, Juan was unhappy about being treated as a “diseased person”. He remembers being in a room with a bright red sign on the outside of the door to indicate his infectious status. Gloves and masks were worn by the clinicians who attended to him and his room was mopped out regularly to prevent the contagion inside him from polluting those on the outside. He feels that this had the effect of doubly compounding his stigmatisation as a “junkie”.

When Juan did stop using heroin, he hoped that the stigmatisation and discrimination associated with this activity would cease. However, he was saddened to find out that this was not the case. After his young son inadvertently mentioned at school that his daddy had a virus, Juan felt that some of the teachers and other parents began to view him differently. He says: “I felt judged, contaminated...like I was less than the other dads”. Although Juan has come to accept the hepatitis C virus in himself, his initial experience of being labelled infectious, coupled with his recent experience of stigma, has left a strong impression on him. This is particularly evident when he talks about physical interaction with his young son.

I’ve got to think about educating him. He already knows not to touch me if I’m bleeding...he’s aware of blood. He’s aware to stay away from blood and he makes it conscious to me when I’m bleeding.

In saying this, Juan constitutes himself as a possible threat to his son if his infected blood transgresses the boundaries of inside and outside. While Juan's blood is contained discretely within the boundary of his body, those on the outside remain safe from its polluting potential. However, Juan does not propose quarantine as a solution to the hepatitis C epidemic. "It's too late", he says, "The virus is here...Now we have to decide how to deal with it". He states that we are living in the age of blood borne viruses. Whether it is HCV, HIV, or Ross River Fever, Juan suggests that maybe the world needs these diseases to "wake up to itself"; for people to take responsibility in a social and spiritual sense; to educate themselves and others in order to avoid a global catastrophe. Juan appeals to the community to "de-stigmatise" and accept people with hepatitis C. This is in accordance with his own acceptance of the disease within himself. In Juan's narrative, an implicit connection is made between the way disease is visualised in the body, and the way people with hepatitis C are tolerated in society.

### **Chapter summary**

In this chapter, I have pursued my critique of biomedicine further, by arguing that the self/other distinction of immune system discourse compounds the notion that the relationship between the body and disease is necessarily one of conflict. I have attempted to trouble this notion by showing how visualisations of the body and disease have changed over time, often reflecting social values. I then referred once again to traditional Chinese medicine, in which the images and metaphors used to describe treatment are not based on dualistic assumptions. Following this, I looked briefly at how in the prevailing labour market, employees are judged by their ability to respond to workplace demands in a similar fashion to the way the immune system is thought to operate. Using the accounts provided by Wesley and Owen, I proposed that the desire of these participants to compete in the current labour market, is one of their major reasons for undertaking interferon therapy.

I then introduced the idea that, when an epidemic is declared, the individual diseased body often becomes a metaphor for the social body, or body politic. Here there are some remarkable similarities between contemporary immune system discourse, and the notion of the body politic. The social implications of this confluence with regard to people living with hepatitis C were then discussed. After pointing out how stigma and discrimination work to fuel the epidemic, I discussed the way that stigmatising people with hepatitis C can be seen as a positive identity-building strategy for in-groups. Following this, the way that stigma and discrimination are internalised along the lines of a purity/pollution binary was examined with reference to the visual texts and narratives produced by participants of my study. Here the gendered nature of living with hepatitis C was lightly touched upon to illustrate how the biomedical encounter is laden with cultural values. Once again, the nature/culture, mind/body, male/female dualisms inherent in Western culture and biomedicine were identified. Finally, using Juan's account of his initial, and then more recent experience of stigmatisation, I showed how the strategies used by some members of society to build a positive self-identity, can have a negative effect on others. The chapter finished with my articulation of Juan's view that the way we visualise disease in the body is not only related to the treatment we seek, but also our wider social relations.

## CHAPTER SEVEN

### **The chronic illness trajectory and narrative reconstruction**

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#### **The chronic illness trajectory: embodiment, dys-embodiment, re-embodiment**

While the vicissitudes of mind and body can be traced back to antiquity, a basic dualistic imagery has nonetheless remained fairly constant within Western thought. Within this scheme of imagery, dominant themes have included the body as alien, the body as confinement and limitation, the body as prison of the soul, the body as enemy, the body as the locus of all that threatens our attempts at control, and the body as machine (Williams 1996:23).

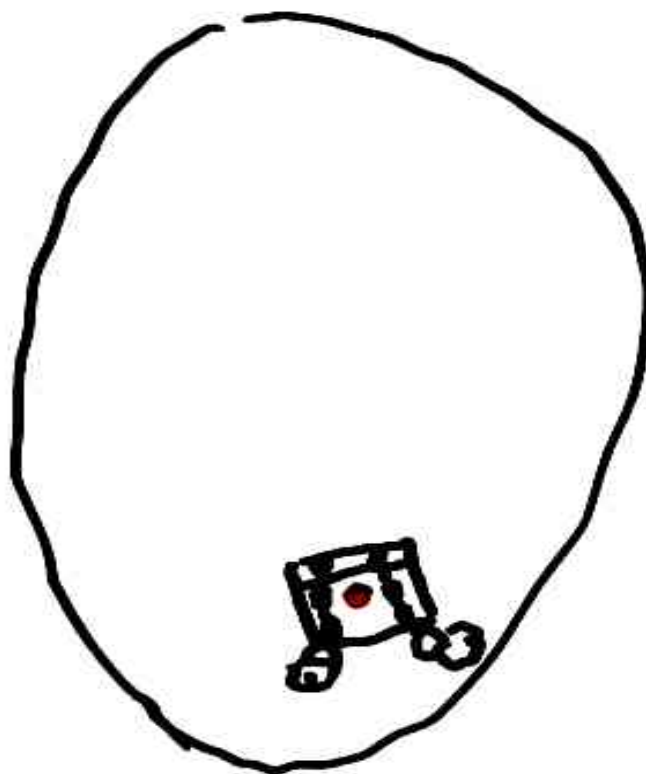
In this chapter I follow up on a theme mentioned earlier in the thesis. That is the potential of the tacit ontological assumptions inherent in treatment interventions for allowing or constraining transformations of the world-views of those undertaking them. With the ‘illness narratives’ presented to me by participants I attempt to track the transformative possibilities of different treatment interventions using Simon Williams’ (1996) concept of ‘the chronic illness trajectory’ as an analytical framework. I then incorporate the idea of ‘narrative reconstruction’ to demonstrate how the stories of people’s lives disrupted by a diagnosis of hepatitis C are ‘re-told’ in a meaningful way that accommodates the disease.

According to Simon J. Williams (1996:37), chronic illness is typically characterised by a trajectory that moves from an original state of embodiment “...to a subtle, complex and sophisticated oscillation between states of *dys*-embodiment and attempts at re-embodiment.” Drawing upon writers such as Leder (1990) and Merleau-Ponty (1962), Simon Williams uses the term *embodiment* to describe the body un-beset by illness or disability. Here the body is taken for granted and only “marginally present” (Williams 1996:24). Nonetheless, there is an implicit dualism

of mind over body at work. This dualism is not obvious because for the most part, the body complies with the mind's wishes with little or no resistance.

### **Peter: the embodiment of Cartesian dualism**

In Peter's case, the asymptomatic nature of his condition allows the mind/body dualism to remain intact. Peter explains that he has used the power of his mind to keep the hepatitis C in his body under control. To him the fact that he has experienced no symptoms of the disease is a testament to the mind's power over the body. The mind/body dualism inherent in his narrative remains unchallenged due to his continued state of embodiment. The mechanism by which he controls hepatitis C is illustrated by his visual text:



Here we can see the disease, represented by a small red dot, safely contained and padlocked within Peter's liver, which is otherwise free of any blemish or pollutant. Peter's use of red to distinguish the virus certainly suggests a self/other binary, and,



in fact, when his greater illness narrative is considered, an overarching mind/body dualism is apparent in the account of his life with hepatitis C. As with the biomedical view of disease, the virus is isolated and abstracted from the rest of Peter's body in this picture. Rather than hyper boosting his immune system with interferon to destroy the hepatitis C, Peter keeps the disease harmlessly contained with the power of his mind over his body – I think I am well, therefore I am. The Cartesian dualism mobilised by Peter to keep the disease at bay remains unchallenged by hepatitis C.

Anne Scott (2001:8) argues that the form of unproblematic embodiment inherent in Peter's narrative and text is consistent with dominant Western notions of individuality and self. Simon Williams' state of embodiment is the 'normal' body of Western biomedicine. Peter's friend Shona on the other hand, experiences a body that deviates from this norm.

### **Shona: the dys-embodiment of duality**

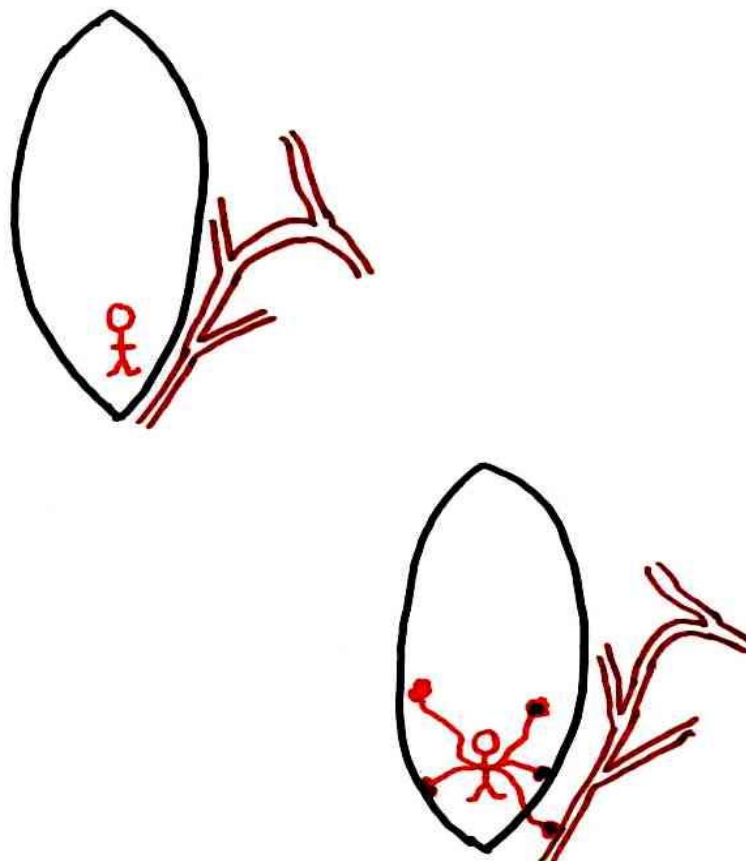
Simon Williams argues that the pain and disability associated with illness can present a profound challenge to the dualistic relationship maintained by embodiment. He calls this interruption of the embodied state *dys-embodiment*.<sup>45</sup> In such cases, the body overrides the mind's previous apparent domination. This situation is exemplified in Shona's illness narrative and visual text. Shona is Peter's friend, and although she tries to share Peter's faith in the power of positive thinking, this is only possible for her when she is well. The dys-embodiment associated with the symptoms of hepatitis C has led her to question the mind's dominance over the body. She says:

I try to share Peter's positive thinking outlook, but it's hard when you get sick all the time. I do believe in the power of the brain cos we only use a small percentage of what we can tap into...I do try to use the power of positive thinking but my body tells me differently.

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<sup>45</sup> While the body cannot be taken for granted during the experience of this *dys-embodiment*, in some cases the mind/body dualism may actually be reinforced. Simon Williams explains that illness may in fact result in a further estrangement of the body, particularly if this body is seen in painful opposition to pain-free aspirations (1996:26-27).

Because Shona's symptoms come and go, her narrative and text exemplify the "vicissitudes" of embodiment as proposed by Simon Williams (1996).



In Shona's drawing both her embodied state and her dys-embodied state are depicted. Although Shona's text has much in common with Peter's, there are several distinctive differences that relate to her very different experience of living with hepatitis C. Shona's first drawing represents a point in her chronic illness trajectory when she is not suffering from any symptoms. Here her relationship with the virus is similar to Peter's; it is confined to a small area in her liver with perhaps the power of positive thinking. Note however, that the virus takes a human form and it is neither contained nor locked. There is considerably less self/other dualism apparent in Shona's text. Adjacent to her liver is an open ended vein to carry viral traffic to the rest of the body. During Shona's dys-embodiment, the little figure morphs into an alien-like creature. Here its arms branch into tentacles that stretch out to the vein

where the disease is taken to other areas of her body and experienced as illness or dys-embodiment. Shona's lower picture represents the failure of her mind and/or body's ability to contain the virus.

Unlike Peter, Shona's experience of *dys*-embodiment does not allow her to fully use the power of positive thinking discourse as part of a positive narrative reconstruction of self. If she were to do so, each new bout of sickness on her chronic illness trajectory would effectively signal a failure of her will. Shona's recalcitrant body therefore denies her recourse to the Cartesian dualism that works so well for Peter. Shona is excluded from interferon treatment because of her continuing drug use, and she will not undergo traditional Chinese medicine because she has heard that endangered animals are often killed to make up Chinese medicines. She says:

I'm a wee bit biased when it comes to Chinese medicine because of the animals they use. I do believe that there is something in Chinese medicine though. They're such an old culture and they were well ahead of their time. I just don't want to support the Chinese herbal market because of the endangered animals.

Shona has been effectively denied interferon treatment and her concern for endangered animals has ruled out traditional Chinese medicine. Her fluctuating health and the influence of Peter's evident success with willpower has left her to think that her body's inherent weakness and the failure of her will is responsible for illness related to hepatitis C. This has exacerbated a mind/body dualism in which her body is experienced at odds with her mind's desire for wellness.

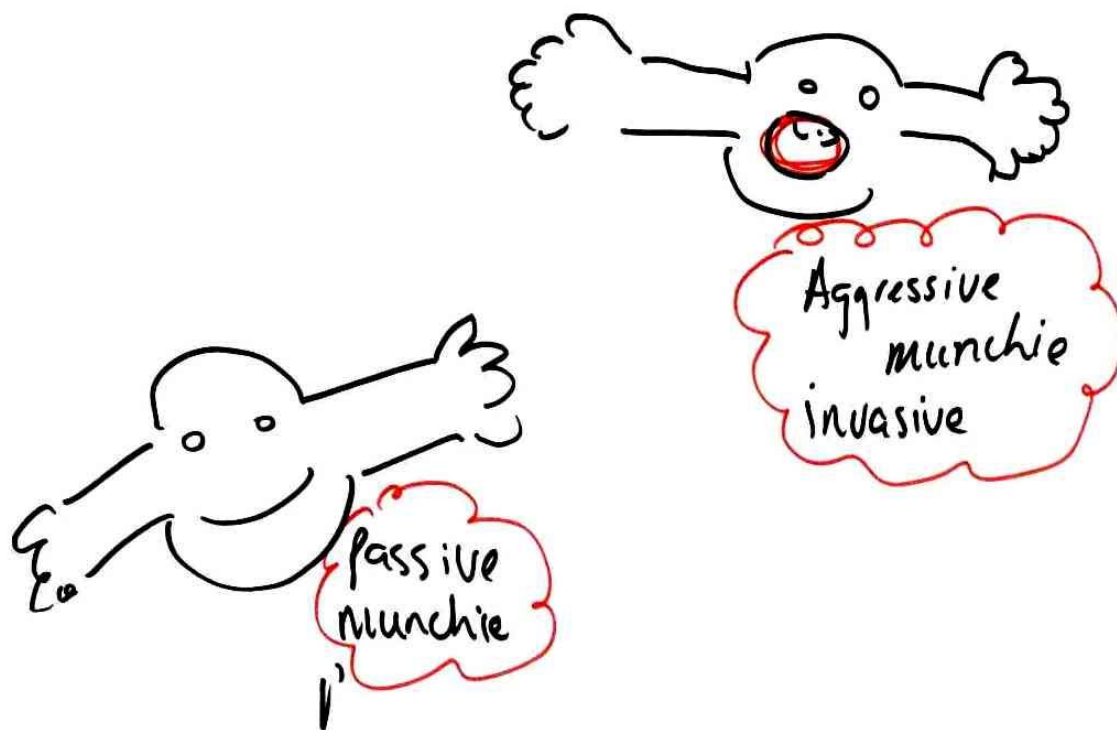
### **Wilma: dys-embodiment to re-embodiment**

I was devastated when I found out I had hepatitis C. I thought I was going to die... I thought there were all these little invasive munchers mutating through my body... You know, like those *Drive* enzymes; chomp, chomp, chomp, chomp. That's what I used to think, and I still think like that sometimes when I get things like the flu. I kid myself I'm doing really well and I'm on top of this and then I get a little gentle reminder that they're still munching. That they're still there.

Wilma's ideas about hepatitis C have changed considerably since she was diagnosed ten years ago. She no longer thinks that the disease will kill her. Wilma now leads a full and active life. For the most part she is fit and healthy, but as the above quote

suggests, any change in her health status can be a reminder of the disease's presence and the uncertainty that is living with hepatitis C. Literature from the Hepatitis C Resource Centre led Wilma to try herbs to treat the disease and she has continued to take these even though a liver specialist told her that they would not get rid of the virus.<sup>46</sup> However, since she has been taking the herbs, her liver function tests have improved considerably. Although she is sceptical of Western medicine, Wilma is not closed to undergoing interferon therapy. At this time however, she is not prepared to jeopardise her wellbeing with six months of the drug's deleterious side effects.

Like Shona, Wilma visualises the virus in two ways as shown in her visual text. She has conveniently labelled these as the *invasive aggressive munchie* and the *passive munchie*.



When she was first diagnosed as having hepatitis C and thought that the disease was terminal, Wilma visualised the virus as one of *Drive's* hungry enzymes with

<sup>46</sup> Wilma takes Milk thistle and Siberian Ginseng.

outstretched grasping arms and an open mouth. This is also how she thinks of the virus when she is ill. The passive smiling munchie on the other hand, appears to be floating or gliding rather than grasping. According to Wilma, the passive munchie best represents the way she visualises hepatitis C when she is feeling well, which is most of the time. This is her *re-embodied* condition. In Williams' chronic illness trajectory, re-embodiment is either an approximation of the original embodied state or "negotiated settlement" in which the disruption to one's sense of self caused by chronic illness is accommodated. The state of re-embodiment is nonetheless precarious and constantly threatened by *dys-embodiment* created by further symptoms (1996:37).

In Wilma's re-embodied state, the aggressive munchie and its attendant symptoms (dys-embodiment) have become pacified by the herbs she takes. She even imagines this version of the virus to be humming contentedly. Interestingly, Wilma also visualises the passive version of hepatitis C becoming the aggressive one if it were taunted by interferon. For Wilma then, the nature of the virus is related to the form of medical intervention undertaken. "I couldn't live with the aggressive munchie" she says, "but I can live with this one". Most of the time Wilma's negotiated settlement with chronic hepatitis C allows her to live unimpeded by the virus and there is no imperative for her to go to war with the disease using biomedicine's big guns. The herbs have transformed hepatitis C into an innocuous entity that hums rather than chomps. Although a self/other dichotomy is present in her illness narrative, Wilma's relationship with the 'other' is remarkably different from that of the participants who have used interferon. Wilma views the other as a 'moral' being that is somewhat similar to her in that a mutual arrangement between them is possible. She does not attack the virus/munchie with interferon, and it does not attack her. Instead, Wilma feeds it with herbs and the disease does not bother her. This is not a dualistic relationship informed by the ontological assumptions of biomedicine, but rather a *negotiated accommodation*. As such, her relationship with hepatitis C is more in line with the naturopathic philosophy that the body will

balance and heal itself, if it is given the opportunity (Woodham and Peters 1998:118).

### **Limitations of the chronic illness trajectory**

Not surprisingly, the chronic illness trajectory as an analytic framework is better employed for those who have experienced the vicissitudes of embodiment across the trajectory of their illness. That is, a vacillation of symptoms that allow for the stages of embodiment, dys-embodiment, and re-embodiment to be charted. As people with hepatitis C can remain asymptomatic for twenty to thirty years, this framework will be limited in these cases unless a longitudinal study can be sustained for that period of time. Of the eighteen people I have interviewed, six can be possibly described as asymptomatic. However, the nature of hepatitis C symptoms can make it impossible to say for sure, and here the element of uncertainty comes into play once again. As Wesley puts it:

I've certainly had the biopsies and the interferon treatment, but I'm not sure what's brought on by hepatitis and what's brought on by fatigue, personal problems, neuroses...I think the world is a perplexing place if you've come out of a previously destructive lifestyle and you have relapses in your mind and you think I've got hep C, I might as well give up. Today I would probably say that I haven't been ill because of hepatitis C, but if you'd asked me three years ago when my life was thoroughly perplexing I would have most probably said that having hepatitis C was a real bitch and give me the sickness benefit now.

Like Wesley, Owen cannot say for sure that he has not been ill because of hepatitis C. Their reasons for undergoing interferon therapy have less to do with illness than a desire to free themselves of the legacy of intravenous drug use so that they can close that particular chapter of their lives and move on. This has more to do with a process of *narrative reconstruction* in which past behaviour associated with stigma and discrimination does not feature. However, the uncertainty of living with hepatitis C does not permit such a re-telling of one's life. This is arguably one of major attractions of a treatment that has been claimed to cure hepatitis C.

## **Narrative reconstruction and hepatitis C**

Unlike the chronic illness trajectory, ‘narrative reconstruction’ can be applied to all of the participants of my study. Whether they have been ill or not, the diagnosis of being hepatitis C positive and the stigma and discrimination associated with it is something that must be negotiated and accommodated to some extent. In an article that has become something of a citation classic in the sociology of health and illness, Gareth Williams (1984) introduces the term ‘narrative reconstruction’ to describe the way people make sense of lives that have been disrupted by chronic illness. With reference to Margret Sommer’s contention that narrativity is an ontological condition of social life, we come to understand ourselves and our relation to society by situating ourselves in narratives that circulate throughout culture (1994:613-14). With the onset of chronic illness, the stories that have previously served to order and make meaningful our day to day lives, often require re-working, or narrative reconstruction, to accommodate the illness (Williams 1984:178). This narrative reconstruction necessarily occurs in relation to official definitions of the disease and the medical treatment undertaken (with its tacit ontological assumptions) (Williams 1984:180).

To illustrate how the participants of my study have engaged in the process of narrative reconstruction using the resources made available to them through treatment interventions they have undertaken, I have selected several accounts and visual texts that best exemplify this process.

### **Maria’s illness trajectory, treatment, and narrative reconstruction**

Although illness is generally thought of in negative terms, it can prove to be a catalyst for positive changes that have a beneficial flow-on effect in other areas of our lives (Williams 1996:32). Before being diagnosed with hepatitis C, Maria felt that the dys-embodiment she experienced was due to her contravention of society’s mores. Instead of being a hard-working career woman, as well as a wife and mother, Maria was an ‘unemployed’ sole parent reliant on welfare. Once diagnosed, however, she realised that her chronic fatigue and depression were directly related to

having hepatitis C. She then felt that she had some agency regarding her condition and began taking naturopathic herbs and practising Qi gong. As a consequence, her health improved and she developed a new outlook regarding her body and her relationship to the social world. Maria no longer thinks of herself as just “a bum on the dole”. In fact, she now devotes much of her new found energy to educating others about hepatitis C and the treatment options available. In the reconstruction of her biographical narrative, the treatments she has pursued are an integral part. When referring to the transformation that occurred after she began taking herbal medicine Maria says:

It's hard to explain, but things were just working better.... it's magic really. As a result I had more energy, and I could take on a bigger workload, and I was getting out of the house and I wasn't getting really low and helpless when it came to the depression side of hep C. It wasn't a hopeless situation; like looking in the mirror and thinking “oh you're sick”, which is what I used to think.

The way Maria visualises hepatitis C is certainly not a picture of sickness and depression. Maria represents herself with a big smile and arms stretched optimistically wide. Within the outline of her entire body there are numerous little red dots that indicate that hepatitis C is present throughout the inner spaces of her body. However, the disease is not apparent in her heart, which radiates golden light of universal energy. This healing energy is generated by Maria's Qi gong practice. The red squiggly lines in her hands, under her arms, and around her eyes represent the symptoms of hepatitis C that she experiences, particularly if she is under stress. Both her feet are pointing right, which indicates a positive forward movement. In the typology of illness narrative genres mentioned by Bury (2001:280), Maria's narrative is ‘progressive’; a positive reconstruction of a narrative disrupted by illness.





Maria also represents hepatitis C as butterflies. She tells me they signify the metamorphosis she has undergone since being diagnosed. In her text there are internal and external butterflies. The butterflies inside her body are transparent and vague suggesting the uncertainty involved with identifying symptoms of the disease. Nonetheless, these butterflies are less troubling to Maria than the external ones. She tells me that she is not obsessed with clearing the virus and doesn't mind if she dies with it. She explains: "I've never really been looking for a cure. That would be asking a bit much; like trying to be perfect – it's unattainable really". The external butterflies, on the other hand, signify the social aspects of living with the disease such as stigma. There are more of these butterflies and they appear more substantial with their darkly coloured purple wings. Maria hopes that with time and public

education, the ignorance and fear she claims is responsible for the stigmatisation of people with hepatitis C, will be diminished.

In Maria's drawing there is a distinction between inner and outer, the individual and the social. There is also an inclusion of the metaphysical in the form of golden healing light or universal energy. This energy can be seen to radiate from Maria's heart into the universe, just as it can be seen to enter her body from a universal or external source. In this way, there is a dynamic relationship going on between the personal and the universal, the physical and the metaphysical, the individual and society. And this relationship is mediated by the practice of Qi gong. Juan also draws upon this golden healing light in his visual text. Both of these participants have eschewed biomedical intervention and, in doing so, have resisted the obvious self/other distinction apparent in many of the other accounts I have analysed. Of course it would be naïve of me to suggest that it was as straightforward as this. While medical intervention, or lack of it in Juan's case, can be seen as an influence on an individual's world-view, there is no doubt more going on here, not the least being a possible predisposition to these ways of experiencing disease due to other life experiences. Nonetheless, the examples of Wilma, Maria and Juan are congruent with the exploratory premise of this thesis. That is, that medical treatment intervention for hepatitis C carries inherent ontological assumptions that may challenge or reinforce the world-view of those undergoing them. In resisting interferon therapy, these three participants have all challenged the dualistic 'othering' process that seems to stem from the ontological assumptions of biomedical treatment.

In the case of Maria and Juan, it is the ontological assumptions inherent in traditional Chinese medicine that relate more closely to the visual texts they have produced. The golden healing light present in both texts can be seen as Qi. The Qi flows throughout the universe and also the body connecting both in an interrelated and dynamic whole. While both texts include hepatitis C, it is not represented as the specific and causal disease entity of Western biomedicine. Neither Maria nor Juan is

concerned about eliminating the virus, nor do they invoke warfare metaphors when speaking of treatment. This is in spite of the fact that both of them have been ill while living with hepatitis C.

The story of Maria's life with hepatitis C demonstrates how treatment for chronic illness has the potential to affirm, and to some extent, transform one's worldview. Although she maintains that she has always had a predilection for "natural remedies", it was not until Maria found out that she had hepatitis C that she fully actualised this by taking herbs and practicing Qi gong. As a result her health has improved and she has a positive outlook informed by the philosophy that grounds traditional Chinese medicine. In her own words:

In conjunction with the herbs, I think it [Qi gong] has affected my internal outlook - my personality. I feel more hopeful because I've found this nice wee thing that I can do on my own...it's just so simple and loving. As far as hep C goes, well Qi gong masters claim it can cure anything. But short of a cure, it can move energy blockages, like acupuncture does.

For Maria, chronic illness has been a catalyst for positive changes. The use of naturopathic herbs and Qi gong has allowed her a narrative reconstruction of self that may not have been possible had she undergone another form of medical treatment. She now has a feeling of agency and purpose, and she no longer thinks of herself as a "bum on the dole". In the words of Simon Williams, there has been a "...realignment between mind and body, self and society" (1996:31).

### **Kerri's story: from monstrous to manageable**

Kerri's life with hepatitis C is also an example of progressive narrative reconstruction related to treatment intervention. However, there is an unexpected twist in her story. Kerri has been very ill because of hepatitis C, and for many years she felt quite hopeless about her condition. The first picture she produced of the way she visualised the disease expressed her feelings of terror and powerlessness about hepatitis C. In it a tiny figure, representing Kerri, is being held under the searing beam of a monstrous alien. This imagery comes from B grade science fiction movies

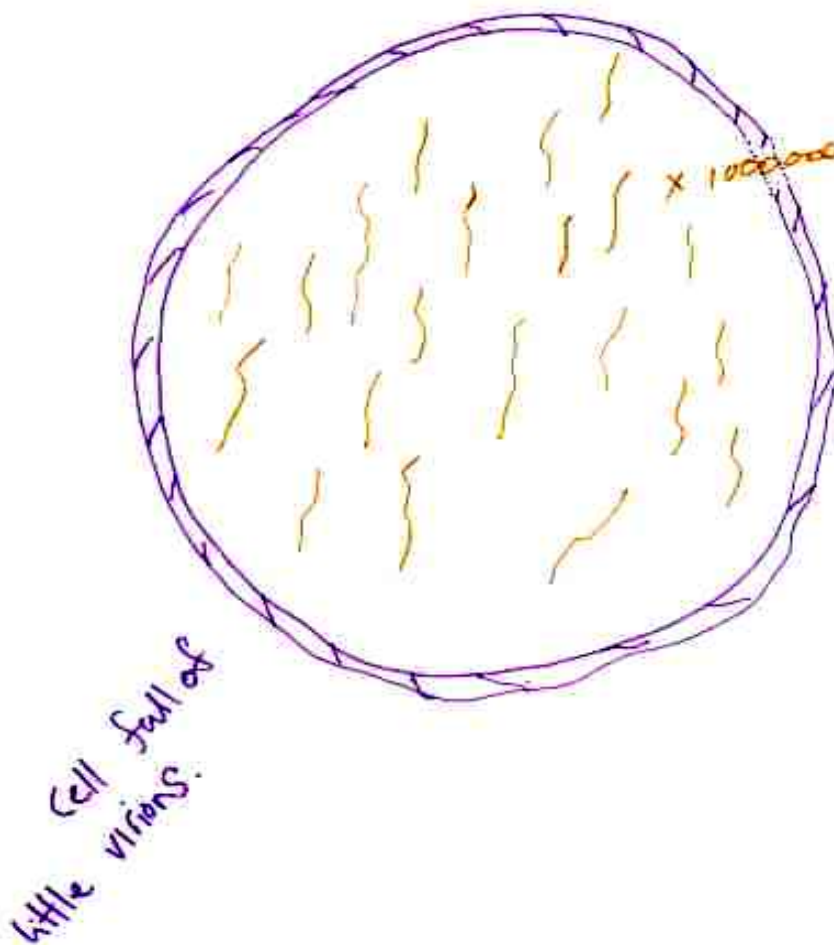
that have terrified Kerri since childhood. So despite her background in biological science, it is these images that she drew upon to represent hepatitis C.



Then, inspired by material that she was exposed to at a spirituality workshop, Kerri realised that she could take responsibility for her illness and even be cured. She believes that this is possible using a holistic approach that takes into consideration the physical, spiritual, emotional, and mental aspects of healing. I was therefore surprised to learn that she was on the waiting list for interferon therapy. Kerri told me that this had been recommended not only by a liver specialist, but also at the College of Natural Medicine. She produced a second picture of the way she visualised hepatitis C in the light of her realisation. However, rather than drawing golden healing light, or something associated with New Age thought, Kerri drew a liver cell enclosing a number of hepatitis C virions that appear to swim together in languid harmony.<sup>47</sup>

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<sup>47</sup> Virus particles are known as virions (Dolan 1997:13).



As such, the virus is perhaps an easy target for anti-viral therapy in the form of interferon. Kerri's second way of visualising hepatitis C is a far cry from the first terrifying spectre of the disease as a malevolent alien. The "cell full of little virions", as she calls it, has stripped the disease of its personal connotations. This is the biomedical view; isolated from the person and abstracted from the body. In embracing this vision, Kerri has reduced the virus from the monstrous to the manageable. Here there is also less of a self/other dichotomy. By depersonalising the virus, it is no longer 'other' to the same degree as in the first picture.

Kerri assures me that interferon is only one aspect of her healing and she fully intends to pursue Qi gong and other alternative methods to address the spiritual, emotional, and mental aspects of hepatitis C. Her narrative reconstruction of self

accommodates both the disease and treatment, and is an example of the eclectic use by participants of biomedicine and alternative practices without adhering to partisan distinctions. In other words, a variety of different treatment practices with their underlying discourses and ontological assumptions are pragmatically mined and negotiated by people with hepatitis C in their attempts to maximise their chances of wellness and make meaningful their condition.

## Summary

This chapter began with several examples to illustrate Simon Williams' (1996) notion of the chronic illness trajectory as it relates to people living with hepatitis C. Here I demonstrated the vacillating experience of embodiment associated with chronic hepatitis C with reference to how certain views of the body may be challenged or reaffirmed at differing stages. Shona, for example, is unable to positively situate herself in the mind over body narrative that works to affirm Peter's sense of embodiment. Wilma, on the other hand, has reached a negotiated settlement in which the nature of the hepatitis C virus is transformed by treatment to the extent that she can live with it. Using Wesley's account of the uncertainty of symptoms, I pointed out the limitations of the chronic illness trajectory as an analytic framework for the study of hepatitis C. I then introduced the concept of narrative reconstruction as a process that all people living with hepatitis C have engaged in to some extent. Here I showed how Maria, Juan, and Kerri's illness narratives are constructed in order to accommodate the disease and treatment, as well as make meaning of their condition.

Wilma, Maria, and Juan have resisted interferon therapy and the warlike metaphors and self/other duality demonstrated in the accounts of participants who have undergone biomedical treatment. Instead of attempting to fight or beat hepatitis C, Wilma, Maria, and Juan have come to what I call a *negotiated accommodation* of the disease. As the name suggests, this accommodation is a relationship in which there is no conflict between the individual and disease. Here there is a departure from the dualistic ontological assumptions inherent in Western biomedicine and a movement

towards the plural and relational world-view of traditional Chinese medicine. While the common narratives, images, and metaphors associated with biomedical treatment may arguably work to naturalise xenophobic social stereotypes that lead to hostility, a negotiated accommodation of hepatitis C can be seen as a non-resistant tolerance of the new and different. Future studies in health and embodiment could pursue this notion further by examining the relationship between the way people view disease within the body, and the way these same people regard immigration or ethnic difference.

## CHAPTER EIGHT

### Summary and conclusion

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What I have been arguing in various ways throughout the thesis is that medical practices are inscribed with certain ideas about the relationship between the mind and body, the individual and society. I have referred to these ideas as ontological assumptions because they concern what exists; the nature of these things, and therefore the relationships that are possible between these things. Using people living with hepatitis C as examples, I have shown that, to a greater or lesser extent, there is a relationship between the ontological assumptions inherent in treatment interventions and their associated discourses, and the world-view of those undergoing them. For the most part, I have concentrated on biomedicine because of its hegemonic position in relation to other treatment modalities available for hepatitis C.

I was led to pose the initial question that motivated this research when several people known to me underwent a six month course of interferon therapy that failed to eradicate the hepatitis virus in each case. Although biomedicine had nothing more to offer these people, they were all unwilling to pursue alternative treatments such as traditional Chinese medicine or naturopathy. At the same time, all three of these people expressed that they would be willing to undergo another course of interferon in spite of the debilitating side effects. I was so intrigued by these attitudes about medical treatment that I decided to make a study of the possible social influences that may have led to them. Here I unknowingly engaged with an old debate as to whether people are ‘pushed’ into pursuing alternative medical treatment due to negative experiences of conventional medicine, or whether they are ‘pulled’ into non-orthodox approaches to health by alternative ideological or philosophical convictions. Rather than being pushed or pulled, the hepatitis C positive participants



of my study have generally approached treatment decisions pragmatically as problem solving exercises.

However, this finding in itself does not fully explain why someone, for whom interferon therapy is unsuccessful, would dismiss alternative methods of treating hepatitis C and yet undergo another gruelling course of interferon. To address this question further I have attempted to reveal the ontological, discursive, and cultural resources participants draw upon to inform the decisions they make regarding medical treatment for hepatitis C. I have done this by examining the visual texts and illness narratives produced by participants, to see if there is an apparent relationship between the way these participants visualise hepatitis C and the treatment interventions they pursue, or have pursued. As such, this study is a different take on the push/pull debate. It has led me to view disease, the body, and society in a far richer and more political light. Throughout this thesis I have attempted to share this perspective with the reader.

In chapter two, I introduced the reader to biomedical theory and practice as it is applied to the treatment of hepatitis C. Although there is a great deal of uncertainty within biomedicine about the nature of the disease and the way treatment works, hepatitis C is considered to be caused by a specific viral agent that, once identified through diagnostic technologies, can be targeted with a drug regime called interferon therapy. The aim of this treatment is complete eradication of the pathogen from the body. As my examples of interferon literature show, the language of war is often used to describe the process of biomedical treatment. A distinct binary opposition is set up in this view that pits biomedical technologies against the foreign viral invader. The patient's body, as the host of hepatitis C, becomes a battlefield where the dualistic struggle takes place. In this case, the body is objectified in such a way that it becomes isolated from the patient's social context and lived experience. The suffering of those undergoing interferon therapy becomes 'collateral damage' in the service of a greater battle; the war between science as culture and viral actors as nature.

To show the reader that the putative biomedical view of the body and disease is culturally specific, rather than a universal truth, I then briefly described a typical clinical encounter with a practitioner of traditional Chinese medicine. In this situation an individual with hepatitis C is assessed using the ‘four examinations’. Here his or her overall condition, which includes mental, emotional, and spiritual aspects, is taken into account. The patient is then prescribed a course of treatment specific to their particular ‘pattern of disharmony’. Because of this, it is unlikely that any two patients with hepatitis C would be diagnosed with the same condition or prescribed the same treatment. Traditional Chinese medical practice is based on epistemological and ontological assumptions rooted in Taoist philosophy. Although a binary of yin/yang is central to Taoist thought, this binary is complementary, not dualistic. From this perspective, disease is caused by a disharmony of yin and yang elements rather than a specific hostile agent or virus. Instead of the language of war, climatic metaphors are used in traditional Chinese medicine to describe disease and the body. Here hepatitis C is not so much a virus, as a pattern of disharmony, such as an overabundance of ‘damp heat’ in the body. In this case, herbs and acupuncture may be prescribed to redress the imbalance by drying and cooling.

Despite these obvious differences in practice and ontology, it would be incorrect to represent either biomedicine or traditional Chinese medicine as discrete or unified systems of medicine. The ‘great divide’ often imposed by medical anthropologists between biomedicine and traditional Chinese medicine is effectively straddled in practice by clinicians and patients daily. As the accounts of participants in this study have shown, a practical concern with treatments that ‘work’ is more important to them than making partisan distinctions between conventional and alternative medicine. I have argued however, that because of the radically different ontological and epistemological assumptions underpinning biomedical and traditional Chinese medical treatment for hepatitis C, these two modalities can be treated as distinctly different for the purposes of this study.

Having moved the reader beyond the superficial understanding of what motivates treatment decisions as proposed in the push/pull debate, I explained that asking participants to draw the way they visualised hepatitis C, seemed to me to be a commonsense method for gaining insight into what constituted the cultural ‘toolkits’ that people bring to their pragmatic problem-solving exercises involving health. It also seemed to me that the visual texts produced by participants might tell me more about the implicit ontologies inherent in medical treatment than just a standard interview. However, in order to follow this line of enquiry, I faced the task of fashioning a methodology sophisticated enough to apprehend the information I was looking for. In chapter three, I led the reader through some of the literature I sourced in the development of this methodology. Much of this chapter is devoted to a debate about epistemological validity, between positivistic sociological approaches to research and the approaches of visual sociology and anthropology. By outlining the historical alliance between the social and natural sciences, I have attempted to show the reader that sociology’s romance with science is based on a bid by early sociologists such as Comte and Marx to gain credibility and popular support for their utopian theories. After a critique of the ‘objectivity’ of scientific methods, I concluded that social research based on visual methods is not necessarily any less valid than research using scientific methods.

I then introduced the notion that social life is storied, to the extent that narrative can be considered an ontological condition of human existence. Accordingly, who we are and how we act, as well as our expectations and aspirations, are largely determined by how we situate ourselves in relation to a multiplicity of cultural narratives. From this premise, I argued that in order to gain an understanding of the experience of hepatitis C, it will be important to attend to the stories told by people living with the disease. The major epistemological proposition of my research is that, while there is a very real biological aspect to the body and disease, much of the lived experience of illness is constituted by the narratives, images, metaphors and discourses that are produced socially. As such, I have argued that only a methodology that takes these constituents into account will be sufficient to address

the research questions I posed. These questions concern the implicit ideas inherent in various forms of medical treatment, and the decision making process involved in choosing between these treatments, as they apply to people with hepatitis C. In this chapter I argued that by collecting and analysing both visual and narrative data, and then by checking this with participant's responses to my provisional analysis, I have developed a valid methodology for researching the experience and social implications of medical treatment for hepatitis C. In chapter four, I explicated in some detail how this methodology was applied in practice. The various methods and strategies that I used to collect and analyse information were to some extent evaluated, and some possible improvements were discussed. Here I attempted to provide a 'roadmap' of what I did and how I did it, for others interested in pursuing similar research interests to follow.

In chapter five, I concentrated on the repressive aspects of biomedical treatment for hepatitis C. I did this by incorporating Habermas's concept that as a condition of modernity, the lifeworlds of patients are vulnerable to colonisation from biomedical practice and pharmaceutical company interests. Using the term 'colonisation' as a metaphor to describe the way biomedical practice might penetrate a patient's lived experience of illness, I argued that the uncertainty involved in living with a HCV positive status renders the individual particularly vulnerable to colonisation on several levels. On one level, many people identify very strongly with their genotype classification even though, as an RNA virus, HCV can only be classified very generally. Nonetheless, many biomedical clinicians, as well as patients, see viral genotypes as indicative of treatment prognosis for hepatitis C. A strong identification with this classification tends to reduce the patient's unique experience of illness to a standard type. When patients are advised by clinicians that the HCV genotype assigned to them responds well to treatment, they may then be more inclined to allow their bodies to be colonised by an interferon drug regime which, as participant accounts show, can lead to physical and emotional disability, social isolation and despair.

Colonisation of a patient's lifeworld can also occur on a psychic level where the dualistic assumptions inherent in biomedical practice may reaffirm a profound split between the mind and body. In a sense, this can be seen as a similar violence to that suffered by indigenous people when they are dispossessed of their land. In 'new world' regions, colonisation severed identities that were rooted in the land, whereas for people with hepatitis C, biomedicine may colonise the lifeworld by splitting patients off from their lived subjective experience of illness, and by redefining this experience so that interferon seems like the only logical form of treatment.

In chapter five I also attended to the question of how it is that some people with hepatitis C tend to dismiss, or be resistant to, alternative methods of treatment even when biomedicine has failed to help them. As is demonstrated in the narrative accounts and visual texts of several participants, particularly those who have undertaken interferon therapy, there appears in some people to be a cultural predisposition to biomedical treatment. Here I maintained that the Western scientific aim of reducing uncertainty is synonymous with the aim of many people seeking biomedical treatment for C. Both the scientific project, and the project of these people living with hepatitis C, are concerned with imposing some kind of control on a particularly uncontrollable disease phenomenon. In doing so, both these projects aim to reduce the anxiety associated with uncertainty. This mutual alignment of goals may then predispose someone with hepatitis C to Western biomedicine. The ontological assumptions underpinning traditional Chinese medicine on the other hand, tend to allow for a greater degree of uncertainty as part of the existential human condition. Both John and Wesley appear to be particularly intolerant of the uncertainty of life with hepatitis C. Both of these participants have found the logic of traditional Chinese medicine particularly problematic with regard to uncertainty and control. While John finally abandoned Chinese herbs and acupuncture for another course of interferon, Wesley continues to suspend his disbelief in the hope that something in traditional Chinese medicine will rid him of hepatitis C. I have argued that both John and Wesley exemplify a condition of predisposition to biomedical treatment for hepatitis C.

I then re-told the story of the controversial and uncertain development of the drug interferon. In doing so, I hoped to demonstrate to the reader how the systemsworld, once uncoupled with the lifeworld, has the capacity to colonise the bodies and imagination of people with hepatitis C. The definition of successful and appropriate treatment for this disease has been decided by experts in the systemsworld of technoscience and corporate interest, which is far removed from the lifeworld forum of people living with hepatitis C. While interferon therapy is no doubt beneficial for some people, it has been of uncertain benefit to the participants of my study. However, it must be noted by the reader that the population sample used in this study is too small for me to draw any generalisable conclusions.

The sustained critique of biomedical treatment for hepatitis C, as unfolded in chapter four, brings in elements of the orthodox as well as the Foucauldian medicalisation critiques. At this point the reader could be forgiven for thinking of people with hepatitis C as hopelessly caught in a web of discursive practices that further predispose them to a form of dualistic thinking lending itself to biomedical hegemony and corporate interests. To make matters worse, the side effects of the only treatment offered by biomedicine may be worse than the symptoms of the disease. On top of this, the chances of a patient being cured through interferon therapy appear to be remote. However, this has not been a criticism of biomedicine *per se*, but rather a critical investigation of the ontological assumptions of Western culture as they are manifested in biomedical treatment for hepatitis C. Later in this thesis, interferon therapy is redeemed somewhat as a treatment that, when dislocated from its embeddedness in dualistic thought, can offer much hope to lives once devastated by the HCV.

In chapter six I pursued my critique of biomedicine further, by arguing that the self/other distinction of immune system discourse contributes to the notion that the relationship between the body and disease is *necessarily* one of conflict. Here I outlined some of the ways in which the body and disease have been visualised over

time, within Western culture, during the 20<sup>th</sup> to 21<sup>st</sup> century. I then briefly discussed the metaphors and images that have been used in traditional Chinese medicine. In doing so, I hoped to further illustrate for the reader that ideas and understandings about the nature of the relationship between the body and disease are culturally contingent. In other words, these understandings are mutable and socially constructed. I then illustrated the similarity between contemporary views of the body's immune response and late capitalist modes of production, with accounts articulated in the texts and narratives of participants. For Wesley and Owen, choosing to undertake interferon therapy is related to their anxieties about employment in the current labour market climate.

In order to frame my discussion of stigma and discrimination as it relates to hepatitis C, on both an individual and social level, I introduced the idea that when an epidemic is declared, the infected body often becomes a metaphor for the social body, or body politic. Here I pointed out some remarkable similarities between contemporary immune system discourse, and the notion of the body politic. For example, in the contemporary biomedical view of the body's immune response, internal health is maintained by the immune system's ability to make subtle distinctions between what is *self*, and what is barely distinguishable as *other*. In the body politic, the *barely distinguishable other* is the individual who threatens the population as a whole with infection due to their risk taking behaviour. Within the body politic framework, an ability to *discriminate* socially can be viewed as a public health measure. Referring to literature on the HIV/AIDS epidemic, I argued that this measure can also be interpreted in the light of the dualistic struggle between civilised human endeavour (culture) and viral attempts to compromise it (nature). The logic of these dualistic assumptions positions the hepatitis C positive individual at odds with public health attempts to contain the epidemic.

Following this, I explored the themes of stigma and discrimination as they appeared in the visual texts and narratives produced by the participants of my study. Here I showed how internalised stigma and discrimination can be interpreted along the

lines of a purity/pollution binary. The stigma experienced by people with hepatitis C in the social body is reflected in the way they visualise the disease inside themselves. Nina, for example, emphasises her blood as a conduit for the transmission of HCV/pollution, particularly during menstruation. Similarly, Juan does not consider himself to be a threat to anyone else while his infected blood remains safely contained within his bodily boundaries. However, if these boundaries are transgressed, even his family is in danger of pollution.

In this chapter I attempted to show how immune system discourse, coupled with the doctrine of specific disease aetiology, reaffirms the self versus hostile other understanding of disease and the body. The centrality of these ways of thinking about disease makes it difficult to conceive of methods of treatment other than biomedicine for hepatitis C. I have also argued that the dualistic assumptions inherent in biomedicine may go far beyond the boundaries of the body and work to naturalise xenophobic social stereotypes. The marginally different, in the form of people with hepatitis C, and the obviously different, represented by immigrants and people of other ethnicities, then become targets of stigma and discrimination. Using the body as society analogy, I have attempted to show the reader how our attitudes about something foreign and different inside our bodies might be reflected in our attitudes towards difference and diversity in society. In terms of the hepatitis C epidemic, I have argued in this chapter that the stigmatisation of, and discrimination against, intravenous drug users and people with hepatitis C, work against public health prevention policies and instead fuel the epidemic.

In the final analytical chapter, I acquaint the reader with the ‘chronic illness trajectory’ and ‘narrative reconstruction’ as theoretical frameworks with which to examine the possible transformations in a patient’s worldview resulting from treatment interventions. Here the exploratory premise that tacit ontological assumptions inherent in medical treatment may challenge or reinforce a patient’s understanding of the relationship between body, self and society, was revisited. Using the visual texts and narrative accounts of participants, I introduced the reader



to a way of envisioning the relationship between the body and disease that is more closely aligned to the ontological assumptions of traditional Chinese medicine. I called this relationship a ‘negotiated accommodation’, and suggest that visualising hepatitis C in this manner may allow people living with the disease to avoid the dualistic assumptions inherent in biomedicine. I also argued that, because in most cases hepatitis C is a long term chronic illness, visualising the disease along the lines of a negotiated accommodation might allow for treatment interventions that have ongoing beneficial effects in other areas of a patient’s life.

Finally, using Kerri’s story and visual text as an example, I went some way towards rescuing interferon therapy from its damning association with the underlying ontological assumptions of Western biomedicine. Here the reader was once again reminded that treatment decisions made by people with hepatitis C are predominantly part of pragmatic problem-solving exercises aimed at maximising their health and wellbeing. As such, Kerri was able to incorporate interferon therapy into the range of methods she had been using to improve her health. In the process, Kerri reduced the once monstrous spectre of hepatitis C over which she was powerless, to something she visualised as manageable. In other words, Kerri has successfully negotiated the implicit ontological assumptions and discourses of biomedicine to suit her own treatment needs.

### **Research questions**

I have posed a number of related research questions in this thesis, and these have guided my exploration of the argument that within medical treatment there are certain implicit ideas or worldviews. The initial question that instigated my research was: How is it that people with hepatitis C come to be unwilling to pursue non-biomedical treatment that may ameliorate their suffering, particularly after interferon therapy has failed to help them? My research has indicated that there are a multiplicity of factors involved in such decisions, not the least being the ontological and epistemological assumptions inherent in biomedical treatment.

Given that the participants of this study are primarily motivated by a desire for treatment intervention that ‘works’, I have argued that a method of treatment that can be explained in a way that makes sense to these people is also of importance. The self and hostile other distinction, that arises from both specific disease aetiology and immune system discourse, sets the scene for the warfare metaphors common to biomedical explanations of disease and the body. An understanding of having been invaded by something alien and life-threatening goes a long way to justifying a course of treatment designed to eradicate that *thing*, even if the side effects are severe. For Ryan and John, the very severity of side effects was indicative of the power of interferon to eliminate hepatitis C from their bodies. I have argued that the pervasive mind/body dualism of Western culture has predisposed Ryan and John to biomedical treatment. Both of these participants have twice allowed their bodies to be a backdrop to the showdown between biomedical technologies and the virus.

As well as the language of war, an intolerance of uncertainty is common to those participants who have pursued interferon therapy in favour of other forms of treatment. This intolerance, or desire to control the recalcitrant nature of hepatitis C, is also shared by the scientific epistemology behind biomedicine. I have argued that this shared project also equates to a form of cultural predisposition to interferon therapy. The uncertainty involved with having hepatitis C renders people vulnerable to colonisation by a treatment modality that defines the disease as something that can be eliminated. My analysis of participants’ visual texts and narrative accounts has shown that such colonisation can work to reaffirm the mind/body split, which can then further dispose an individual to treatment based on this dualistic assumption. In doing so, interferon therapy might contribute to making treatment based on incompatible ontological assumptions, such as traditional Chinese medicine, less accessible to the patient in terms of comprehensibility. Finally, by offering the possibility of viral eradication, interferon therapy appeals to people such as Wesley and Owen, for whom hepatitis C is an impediment to their taking part in a competitive labour market that requires flexibility, mobility, and a clean bill of

health. Non-biomedical interventions, such as traditional Chinese medicine and naturopathy, on the other hand, do not specifically target the focus of their anxieties. While scepticism of alternative methods of treatment varied, all of the participants who had undergone interferon therapy expressed the view that biomedicine is better equipped to eliminate hepatitis C. This is in spite of the fact that five of these participants have undergone a course of interferon that did not result in a sustained viral response.

My second set of research questions also concerned the treatment decisions made by people with hepatitis C. These questions, however, were more closely related to the visual component of the methodology I developed for this thesis.<sup>48</sup> Using this methodology, I have broadly identified two different ways that the participants of my study have come to visualise the relationship between hepatitis C and their bodies. The first way of visualising this relationship is very much an antagonistic one. Here the body is host to a foreign viral entity. As illustrated in the visual texts and narrative accounts, this is the predominant view. I have argued that this way of visualising disease is closely related to the biomedical view which features the self and hostile other dichotomy. While I am certainly not claiming that there is a causal relationship involved, *all* of the participants who have undergone interferon therapy visualised hepatitis C along these lines. Only Juan, Maria, and Wilma can be said to have reached an accommodated settlement with the disease. For these participants, the nature of hepatitis C has changed since they were first diagnosed. For Maria and Wilma, this change occurred after they began using non-biomedical treatment. In terms of the participants in this study then, there does seem to be a relationship between the way hepatitis C is visualised, and the treatment interventions undertaken.

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<sup>48</sup> 1) How do the hepatitis C positive participants of my study visualise the relationship between the disease and their bodies? 2) Is there an apparent relationship between the way people with hepatitis C visualise the disease, and the treatment interventions they pursue, or have pursued? 3) What ontological, discursive, and cultural resources are they drawing upon to inform the treatment decisions they make?

I contend that asking the participants of my study to draw the way they visualise hepatitis C in their bodies was a particularly useful strategy for gaining additional insight for a number of reasons. Firstly, the process of drawing enabled participants to use a means of expression other than simply conversation, and this in itself often allowed them to access information and ideas that they had not mentioned verbally. Although many participants mentioned that they were not particularly good at drawing, some of them actually seemed better at expressing themselves through the drawing process than in words. In this event, by giving participants the opportunity to do both, their limitations in one area might have been compensated in another.

The process of producing visual texts also encouraged a different kind of dialogue between me and the participants on many occasions. Some participants joked about their pictures, and some explained what they were drawing in a stream of consciousness manner. When asked to explain various elements of their drawings, and the relationship between them, the participants themselves often became involved in the interpretative process, thus contributing to my own interpretation of the visual texts. In this way, a co-construction of meaning took place that would not occur in a standard interview.

Because of the subtle, complex, and even ineffable nature of much of the information I sought to apprehend in my study, I contend that visual methods are particularly appropriate. Few, if any, of the participants I interviewed could have provided me with the kind of data I was seeking without the aid of visual texts. My exploration of the ontological assumptions inherent in medical practices has been greatly enriched by the traces of binary dualism and the self/other dichotomy apparent in these drawings. Nonetheless, I have attempted to make conservative readings of this data in order for the visual texts to remain open to further interpretation by the reader. While I am satisfied that the collection and analysis of participant's drawings can be a valid and useful method for researching social life, I do not consider this to be a stand-alone research strategy. In terms of this study, the triangulation of additional information gained through narrative accounts and

standard interviewing techniques was essential. Checking my interpretations with some of the participants was also a fruitful strategy. In the final analysis, how well my visual methodology worked in practice is perhaps best judged by the reader.

### **Limitations of this study and future directions for research**

It must be noted once again, that the number of participants involved in this research is not large enough for any generalisations to be made about the experience or efficacy of various treatments available for hepatitis C. While I am sympathetic to medical treatment not based on the dualistic assumptions that underpin interferon therapy, I realise that this form of treatment has offered hope and improved the health of countless people suffering from hepatitis C. However, the visual and narrative texts of the people I interviewed in this study did not reveal interferon therapy in a particularly positive light. Future research in the area might redress this imbalance by focusing on the accounts of hepatitis C positive people for whom interferon has been successful.

Another area of enquiry that the constraints of this thesis excluded is the practitioners of different forms of treatment for hepatitis C. Further research in which representatives of various treatment modalities are interviewed, and perhaps asked to draw how they visualise the disease, might be revealing. It would be interesting to see if there was an apparent relationship between the way practitioners visualise disease, and the form of treatment they practice. A study that looked at the similarities and differences between the way practitioners and patients visualise hepatitis C, might indicate something of the inherent ontological assumptions of medical treatment.

## **Concluding remarks**

Central to biomedical treatment for hepatitis C is the theory of specific disease aetiology and immune system discourse. The centrality of these ways of thinking about disease and the body makes it difficult to conceive of the hepatitis C virus as anything other than alien and hostile. Positioned as such, the virus becomes the target of a drug regime in which the side effects are often worse than the disease itself. The rhetoric of war is regularly used to describe the process of biomedical treatment, and the suffering that undergoing interferon treatment entails, becomes 'collateral damage' in the service of a greater battle; the dualistic struggle between science as culture and viral actors as nature.

But this conflict also exists on a social level, where the infected body of the person with hepatitis C becomes part of the permeable skin of the social body. This threat is then often internalised on a personal level, where the disease exists as a form of inner pollution that must be contained within the body in order to protect one's friends and lovers and children from contamination. At this level, interferon therapy may seem to offer the only possibility of a cure; the only chance to restore the individual autonomy compromised by viral interests; the only chance to remove the final legacy of an illicit past and cleanly move forward. However, as some of the examples set by participants of this study have shown, there are other ways to visualise the relationship between disease and the body. A 'negotiated accommodation' of hepatitis C is one alternative that is more closely related to the relational world-view implicit in the practice of traditional Chinese medicine.

Alternative treatment interventions for hepatitis C, such as traditional Chinese medicine and naturopathy, do offer different perspectives from biomedicine with

regard to the body and its relationship with disease and society. It is my contention that an adoption of these different ways of seeing and understanding may facilitate the development of new possibilities, on both the personal and social levels. However, the hegemonic status of biomedicine, and the persistence of the dualistic assumptions inherent in Western culture, tends to marginalise alternative treatment modalities, rendering them less accessible to people with hepatitis C. As a consequence, biomedicine with its attendant ontological assumptions and discursive practices may remain the primary form of treatment intervention for hepatitis C. The social implications of this may include a perpetuation of intolerant attitudes and violence towards that which is considered foreign and different. At a time when the underlying dualistic assumptions of Western culture continue to serve in the justification of suffering and oppression globally, I hope this thesis contributes in some small way to a deconstruction of these assumptions, allowing room for a vision of negotiated settlement between the body and disease, self and society.

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## **APPENDICES**

## Appendix A

### Brief Participant Profiles

#### **Kerri**

Female

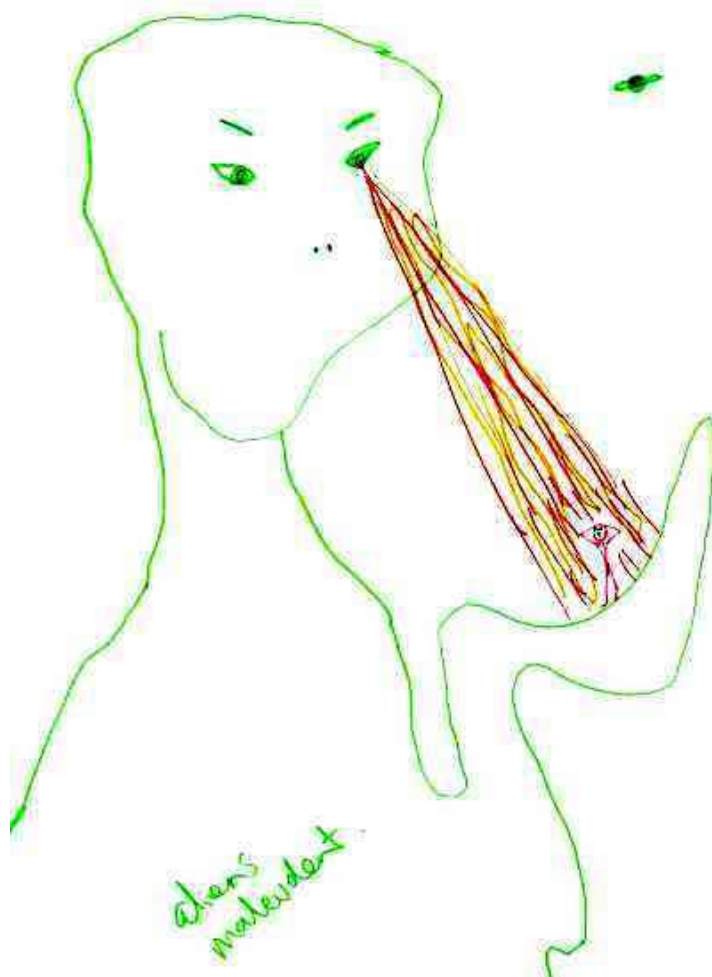
Age 40-45

Living with hepatitis C for approximately 20 years

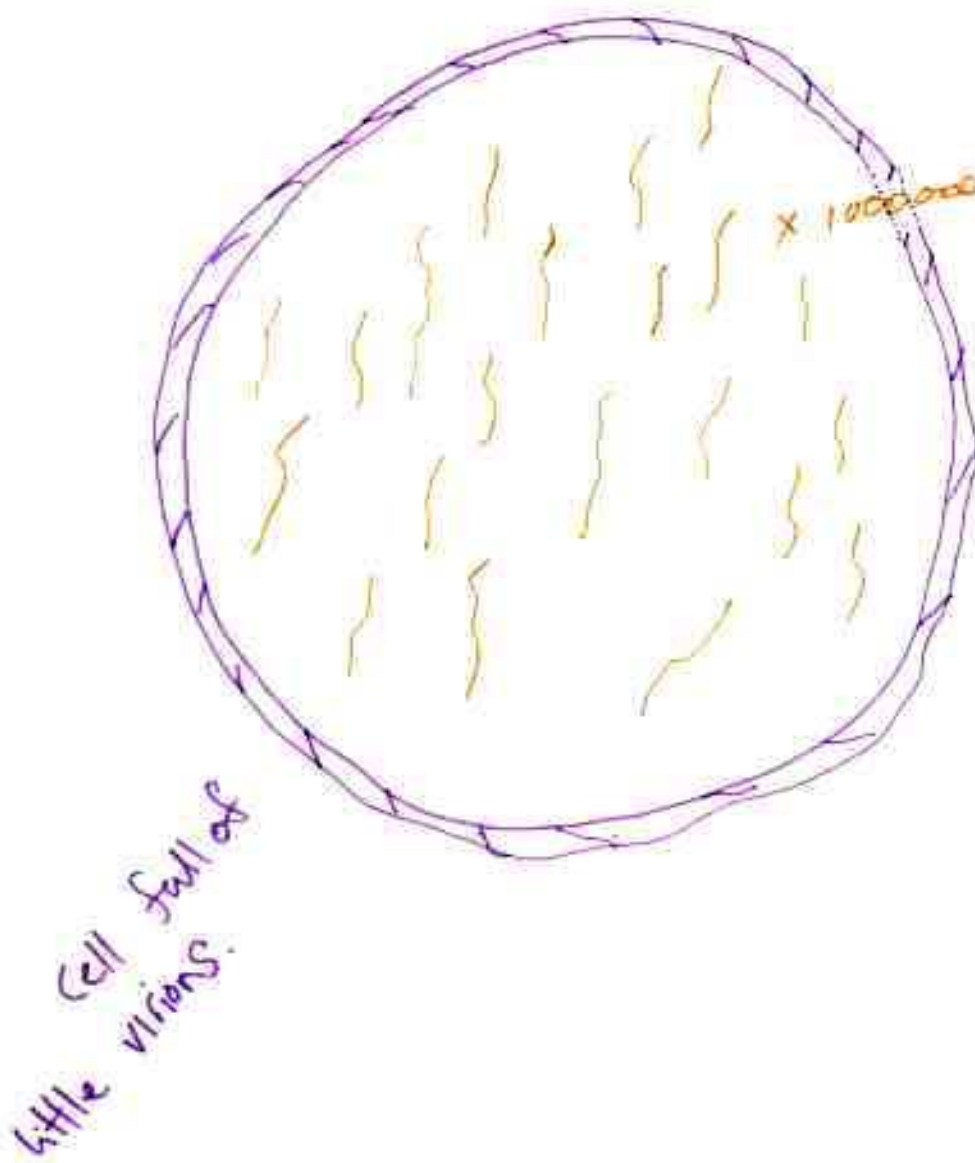
Treatment interventions:

- Vitamins and supplements
- Chinese Herbs
- Spirituality workshops.

#### *Kerri's first visual text*



*Kerri's second visual text*



**Owen**

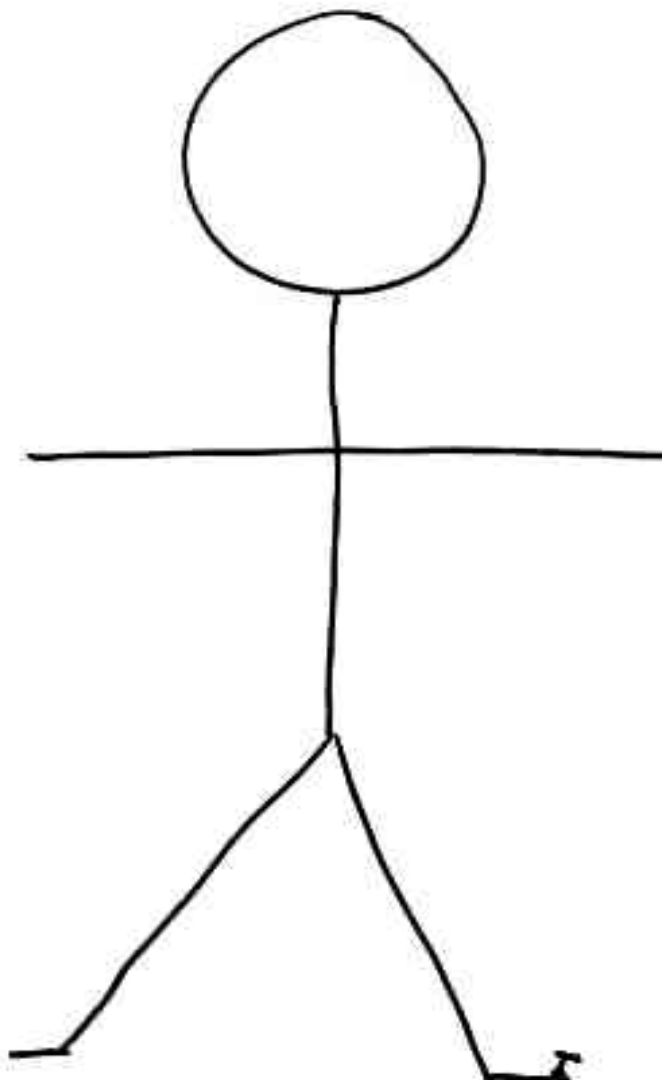
Male

Age 40-45

Living with hepatitis C for approximately 20 years

Treatment interventions:

- Standard interferon combination therapy.
- Pegulated interferon therapy.

*Owen's visual text*

**Glenda**

Female

Age 45-50

Living with the hepatitis C for possibly 15 years, although 2 years is more likely

Treatment interventions:

- Standard interferon combination therapy
- Pegulated interferon therapy
- Acupuncture and Chinese herbs (briefly)

*Glenda's visual text*

Handwritten text in green ink: "Hungry enzymes eating away at the liver."



**Juan**

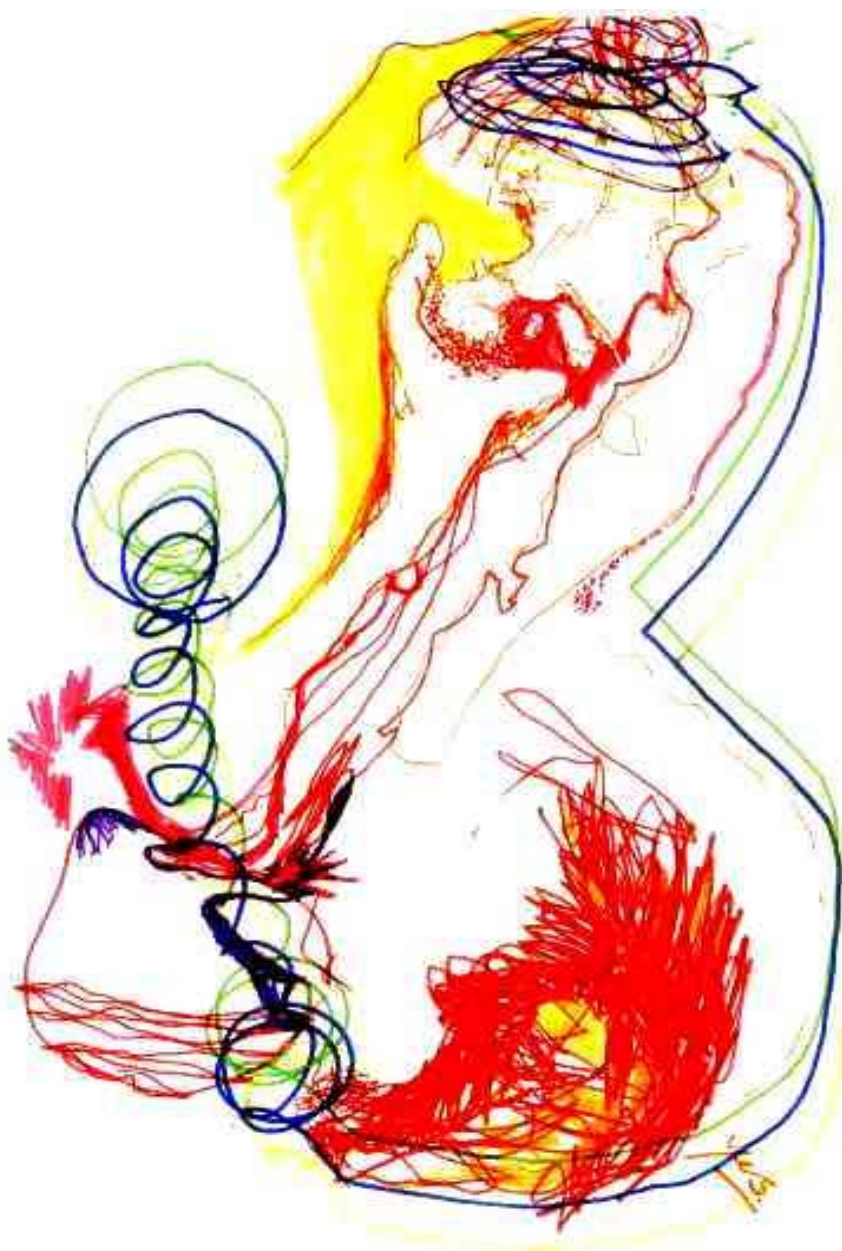
Male

Age 55-60

Living with the hepatitis C for at least 11 years.

Treatment interventions:

- Lifestyle changes

*Juan's visual text*

**Maria**

Female

Age 35-40

Living with the hepatitis C for at least 4 years

Treatment interventions:

- Herbs and Qi gong

*Maria's visual text*

**Nina**

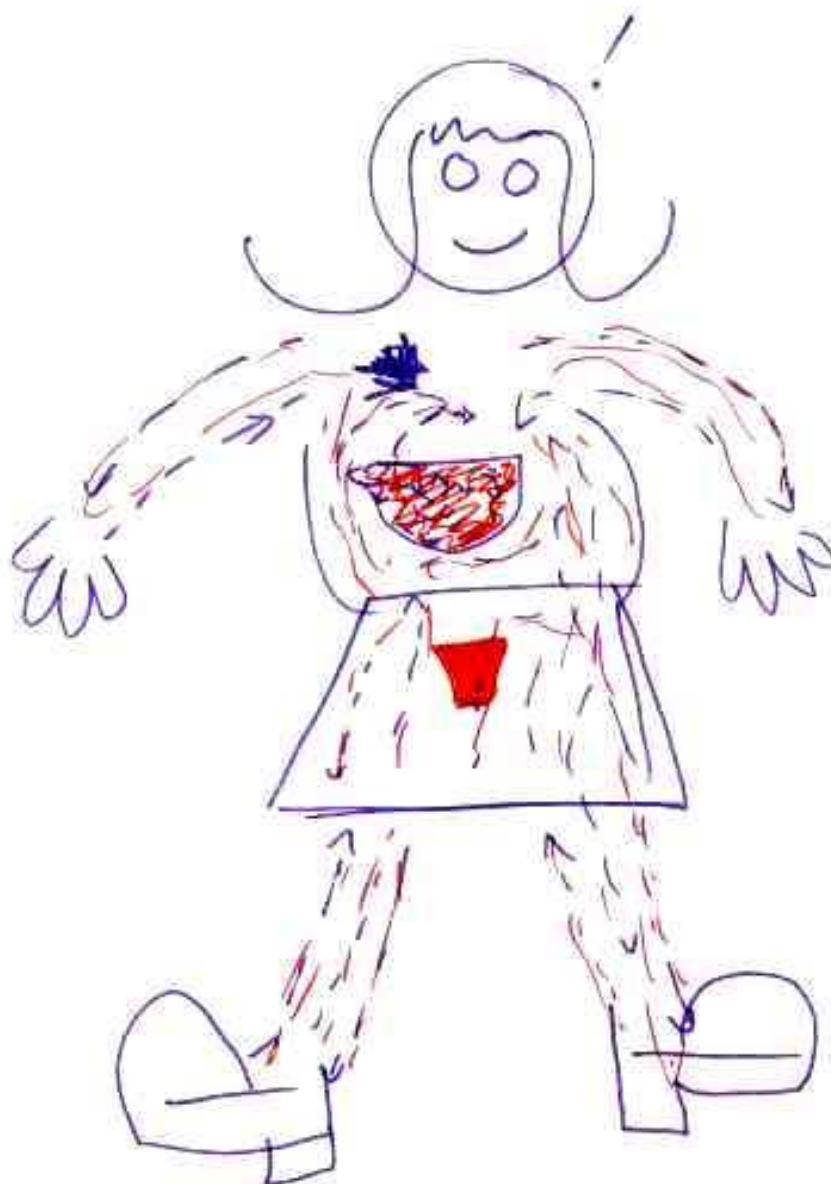
Female

Age 35-40

Living with the hepatitis C for approximately 16 years

Treatment interventions:

- Acupuncture
- Reiki massage

*Nina's visual text*

**Fran**

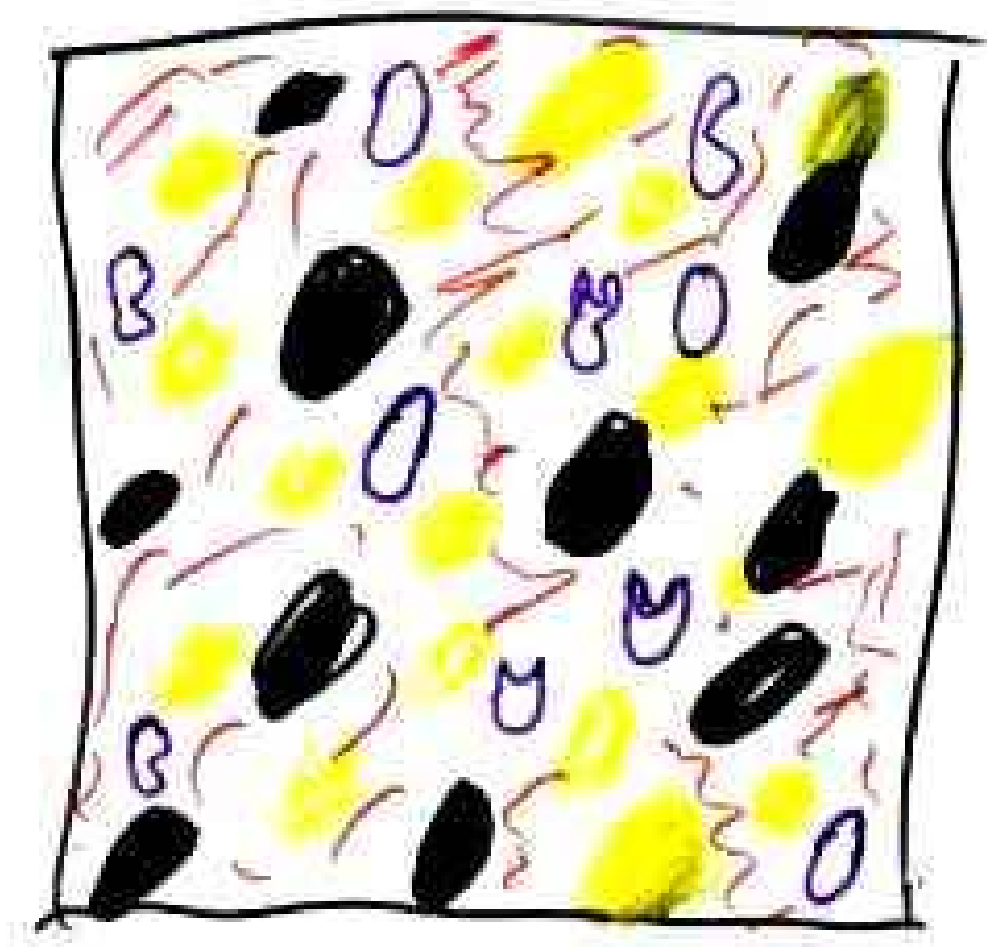
Female

Age 55-60

Living with the hepatitis C for possibly 8 years

Treatment interventions:

- Naturopathic herbs

*Fran's visual text*

**Peter**

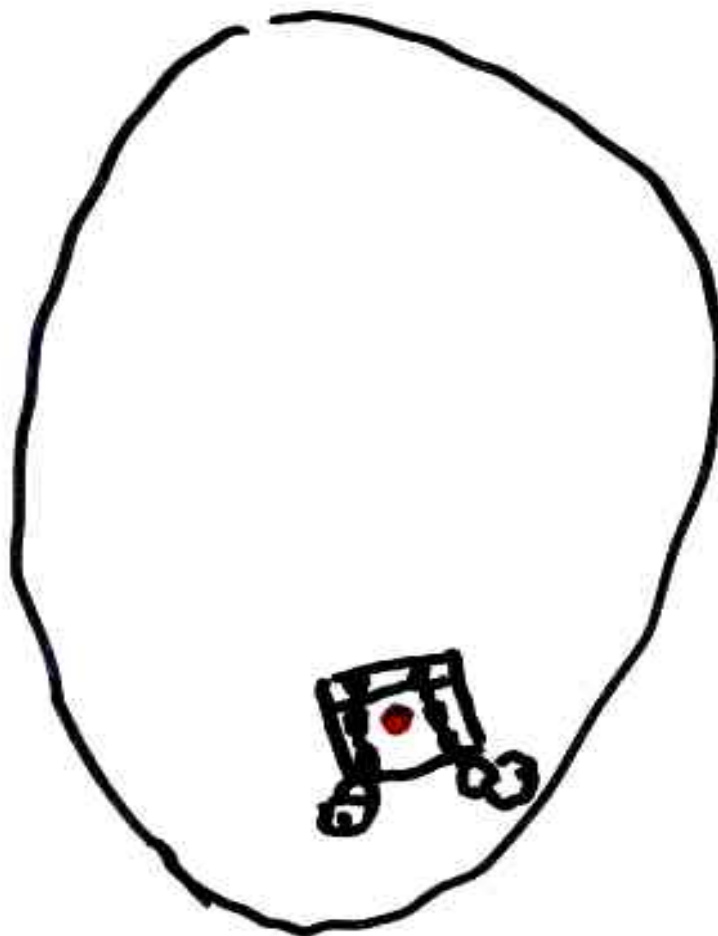
Male

Age 35-40

Living with the hepatitis C for at least 10 years

Treatment interventions:

- None

*Peter's visual text*

**Shona**

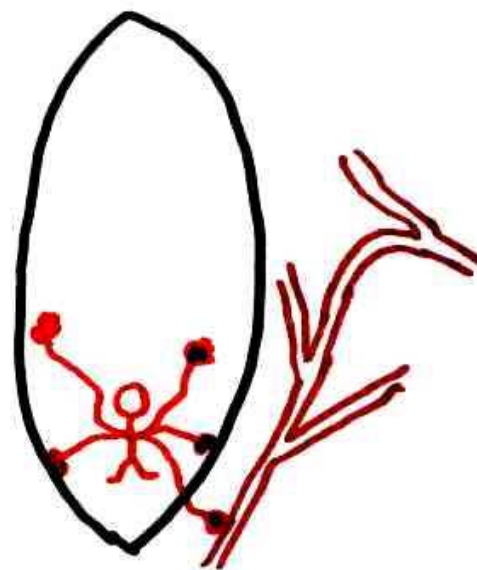
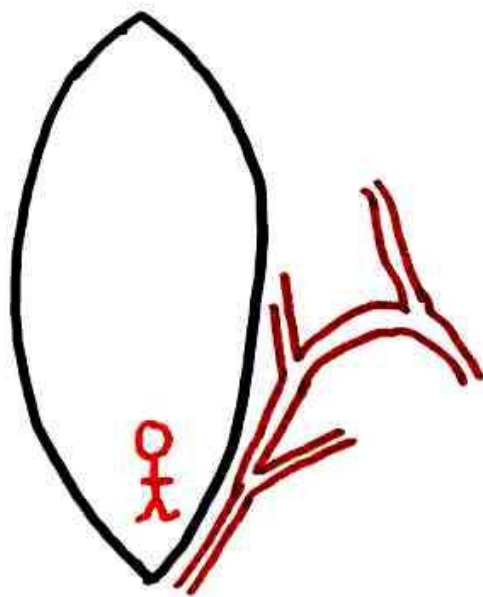
Female

Age 30-35

Living with the hepatitis C for at least 5 years

Treatment interventions:

- None

*Shona's visual text*

**John**

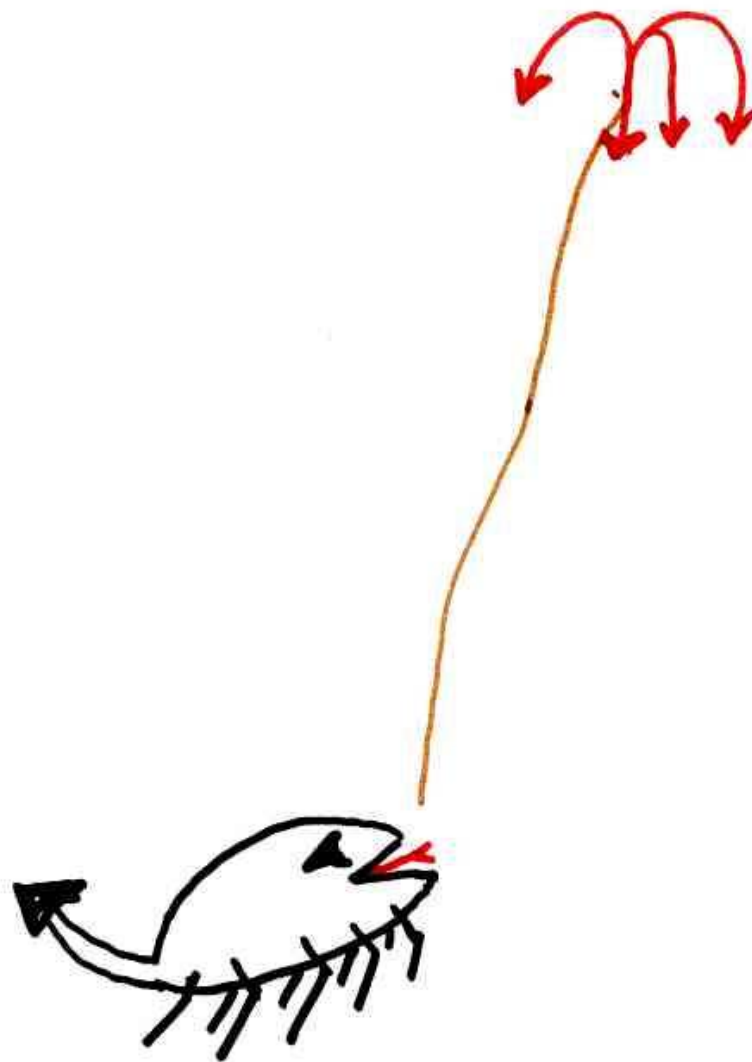
Male

Age 45-50

Living with the hepatitis C for approximately 12 years

Treatment interventions:

- Standard combination interferon therapy
- Pegulated interferon therapy
- Chinese herbs and acupuncture

*John's visual text*

**Ryan**

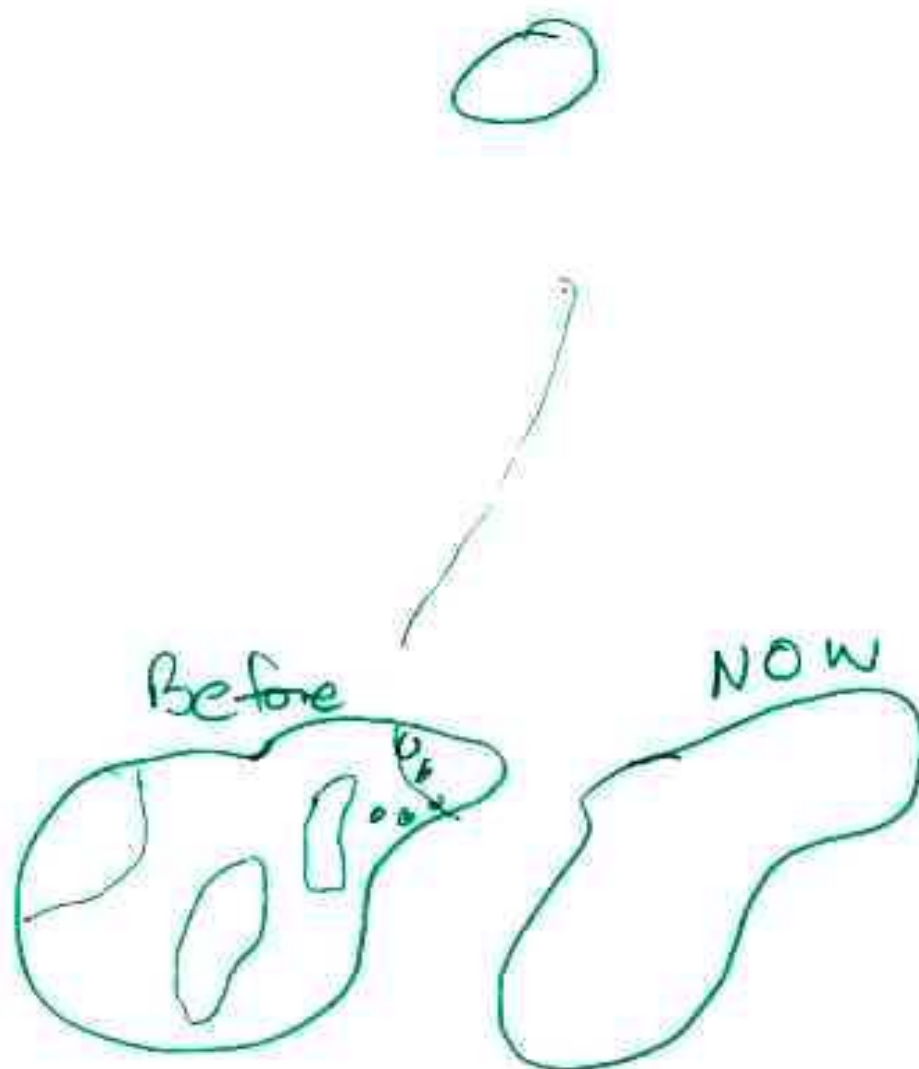
Male

Age 35-40

Living with the hepatitis C for approximately 18 years

Treatment interventions:

- Standard combination interferon therapy
- Pegulated interferon therapy
- Positive visualisation tapes

*Ryan's visual text*



**Wilma**

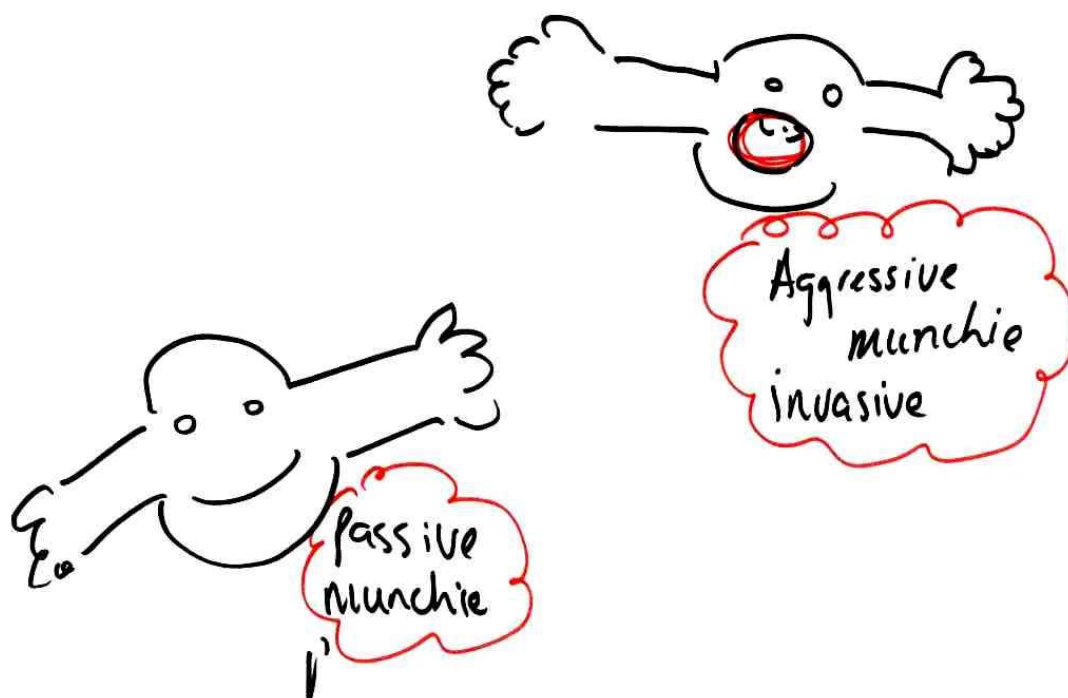
Female

Age 40-45

Living with the hepatitis C for at least 10 years

Treatment interventions:

- Herbs and supplements

*Wilma's visual text*

**Wesley**

Male

Age 50-55

Living with the hepatitis C for approximately 20 years

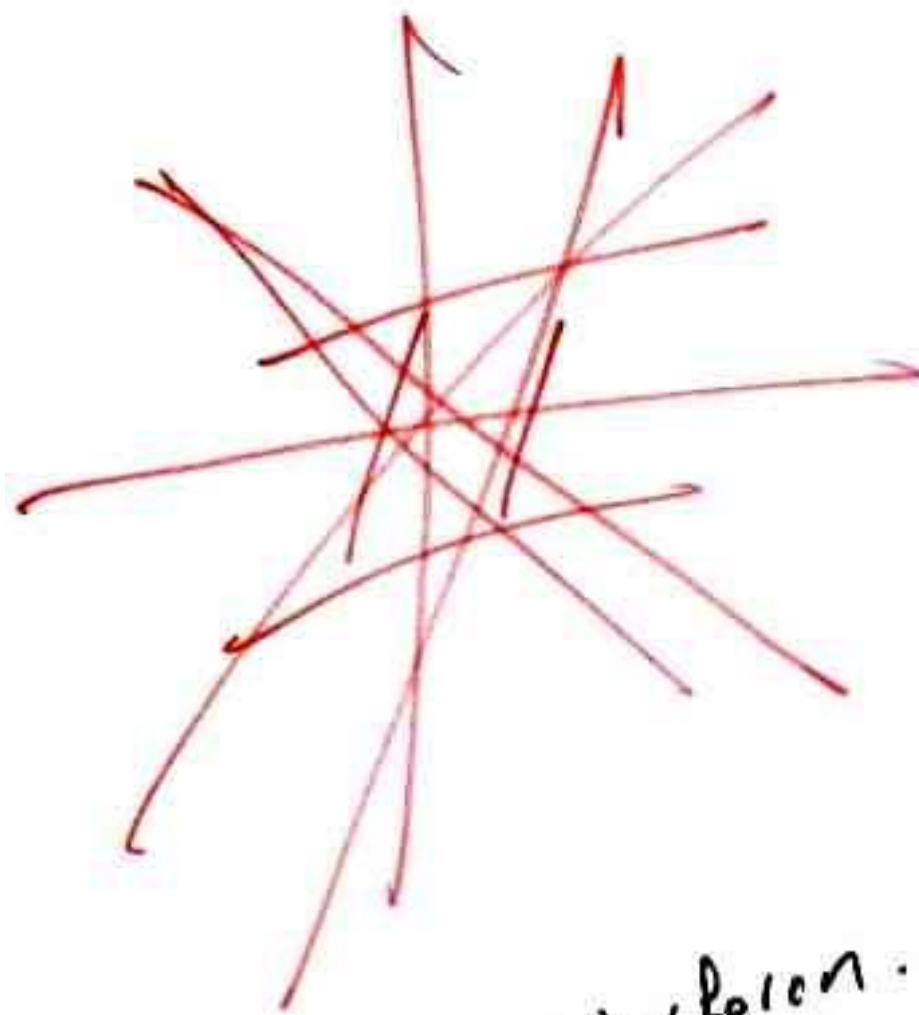
Treatment interventions:

- Standard combination interferon therapy
- Acupuncture and Chinese Herbs

*Wesley's first visual text*



*Wesley's second visual text*



interferon.

## Appendix B

### HCV Interview

#### A. Illness trajectory

- \* Can you tell me how you first found out you had hep C?
- \* What did you know about hep C before that?
- \* What was your response to being diagnosed?
- \* Have you been ill as a result of Hep C?
- \* What treatments have you tried?
- \* What led you to try these treatments?

#### B. Drawing of HCV/body

*Could you draw a picture of how you see hepatitis C in your body?*

##### 1. Identification of elements

*What parts of the body/virus are represented in the text?*

*For example:*

- a) HCV virus
- b) Liver
- c) Blood
- d) Immune system
- e) Treatment intervention

##### 2. Relationship of elements

*What is the nature of the relationship between various elements in the text?*

*Is there:*

- a) Antagonism
- b) Imbalance
- c) Harmony/disharmony
- d) Complementary
- e) Dominance and or submission

##### 3. Treatment interventions

*How do you think they work?*

- a) Interferon
- b) TCM (Qigong, herbs, acupuncture, reflexology)
- c) Before beginning treatment, did you think it might have cured you of hep C?

##### 4. Influences

Can you think of any material such as medical books, doctor's explanations, or TV programmes that may have influenced the way you visualise HCV in your body?

**\* Newsweek images: Do you think these pictures accurately represent HCV in the liver?**

**\* Do you think that ‘the sleeping dragon’ is a good description of HCV?**

**\* If you were/are cleared of the virus, do you think it would change your lifestyle?**

**\* If you had been offered TCM for free, would you have done that?**

**\* How do you think people with Hep C are viewed in community?**

**\* How did you experience the drawing process?**

### **Themes to cover**

- Self/other dichotomy
- The nature of hepatitis C virus
- The nature of relationship between hepatitis C and body
- The nature of treatment
- Credibility of treatment (how do know?)
- Disruption of biographical narrative
- Narrative reconstruction