Buckle, Joseph S. (2005) *Embodied narratives of recovery: a phenomenology of cardiac rehabilitation.*

PhD thesis

Embodied Narratives of Recovery:

A Phenomenology of Cardiac Rehabilitation

By

Joseph S. Buckle

Thesis Submitted for the Degree of

Doctor of Philosophy

at the

University of Glasgow

in the

Department of Sociology, Anthropology, and Applied Social Sciences

September 2005

Acknowledgements

I acknowledge and thank my supervisor, Professor Harvie Ferguson. Always gracious and accessible, and never anything less than astonishing.

Thanks also to Dr. Trish McCafferty, a friend for life who, even by telephone, managed to administer the occasionally necessary smack round the back of the head.

My 'respects' to Dr. Lorraine 'Happy' Cook, Violet, and Biccy. We must now resume our drinking and dancing.

Finally, love and affection to Evelyn for providing a sense of stillness to calm my anxious moments.

The author acknowledges the financial and technical support of the Economic and Social Research Council.

Contents

Page number

Part One

Part Two

Three Narratives:

Abstract

Heart disease is increasingly common throughout the world today. It is the principal cause of death both in the west and, more recently, in the developing countries. The experience of heart disease can be physically and emotionally devastating, and, socially disruptive. Yet, little sociological research has been conducted in this field. Adopting a phenomenologically inflected approach, which recognizes the role of the body in the constitution of experience, this thesis examines the experience of heart disease and the process of 'narrativization' of the illness experience. The body, as the locus of intentionality, is given in experience, yet at the same time it is constructed as an object of medicine. The body of experience, it is argued, exists in tension with the textual body of medical science. This thesis traces a brief history of the medicalisation of the body, from the anatomy theatres of early modern Europe, to the clinical encounter in its various forms; from the doctor-patient relationship to the nurse-patient interaction in the cardiac rehabilitation clinics of today. It is argued that 'illness narratives' represent more than a lay response to objectifying medical discourses and practices. Such narratives are in fact constitutive of experience and, as such, are exemplifying practices. It is also argued that the body is possessed of a memory and, to illustrate this further, I present research conducted among people who have experience of heart disease, surgery, and cardiac rehabilitation. This 'memory of the body' is that which, to some extent, is lost in the dehumanising spaces of medical science, but I assert that it is by way of the body's remembered capacities that selfhood is re-established. An issue that drives this thesis is the question of whether remaking the body, during the difficult process of recovery and cardiac rehabilitation, entails a remaking of the self. Illness, as a medicalised phenomenon, disrupts the biographical trajectory of the sick person, severing affective ties to family, friends, and community. It effectively dislocates the experience of the embodied person. This thesis is concerned principally with the means by which the person relocates himself or herself.

Introduction

> [T]he life of consciousness – cognitive life, the life of desire or perceptual life – is subtended by an 'intentional arc' which projects round about us our past, our future, our human setting, our physical, ideological and moral situation, or rather which results in our being situated in all these respects. It is this intentional arc which brings about the unity of the senses, of intelligence, of sensibility and motility. And it is this which 'goes limp' in illness.
> (Merleau-Ponty, 2000: 136)

It has been noted (Claessens et al., 2005: 8) that empirical evidence regarding the experience of heart disease, particularly among adult populations, is rare. This deficiency seems rather odd, given that cardiovascular disease is the leading cause of death *in the world* (Lukkarinen and Kyngäs, 2003). This thesis addresses that deficiency by asking: what is the experience of heart disease, surgery and rehabilitation? To answer this question I assert that: 'remaking' the body, as a response to the 'unmaking' of the body by medical science, entails a remaking of the self; narrative construction (narrativization) is an important means by which experience is constituted comprehensibly; the body, as a 'walking memory', is a key element in the social activity of narrativization.

I employ a phenomenologically inflected research method because it entails an attentive awareness to the things of the world as we *live* them as well as how we conceptualise them and, thus, offers a comprehensive, context-sensitive approach to the subjects of the body, experience, and health and illness:

> Phenomenology is meant to enrich our understanding of health in adding to the disease-level analysis a level of analysis that addresses the question of how physiological states are *lived as meaningful in an environment.*
> [my emphasis]
> (Svenaeus, 2001: 87)

♥ ♥ ♥

The body possesses a certain epistemological resistance, which is to say that it eludes consciousness while, paradoxically, it is the very ground of perceptual experience. It would perhaps be more accurate to say that the fundamental experience of the body is that of proprioception; that is, the sense of being in a body that is spatially located. In our 'normal', healthy, daily activities, however, we are never *fully* aware of the functioning of our bodies. We may have a sense of where we are, yet not know what we are and what our bodies are really doing. Quite simply, the body is largely taken for granted; thematically absent from experience. Yet, it is the very stuff of our sociability. As a thing of (social) substance, as the substance of the social, the body has a representational property and, as such, is a 'readable text' (Csordas, 2000: 12). For example, the body is the most readily available indicator of gender, 'race', age, class, and health. Bodies are thus differentiated and socially 'inscribed': bodies are nameable. We can say that this body is old, that body is sick, and so on. Our bodies say something about us as persons yet, to a great extent, we remain existentially detached from them, which is in part an effect of a pervasive dualism that privileges mind over body, but which is also an essential feature of our embodied intentionality. To explain this further, in the body of the thesis, I utilise Leder's (1990) conception of the 'absent body'.

When I stated that the body might be 'read' as a social indicator of sorts I mean also that the health of the body is, in quite specific ways, readable. Indeed, it is difficult to separate the health of the body from its social status. We may read an 'old' person as such by their stooped posture, the presence of glaucoma, and/or by the inflamed and distorted fingers that are indicative of arthritis. Thus the body is already a text; a text that identifies who and what we are. My contention is that the text of the body is, to a great extent, a medical(ised) text.

The body has been taken up anew, within the human sciences and, in everyday life. Existentially, the body is that which endures through time and space and, as embodied beings, we identify ourselves with our bodies, while at the same time comprehending little, if nothing, about them. In its representational capacity, the body has increasingly come to be associated with self-identity (Giddens, 1991; Shilling, 1996). In contemporary society the body is something that we 'go to work' on. Body projects such as post-surgical rehabilitation effectively 'bring the body back in' to medicine (which would go some way to explain why cardiologists show little interest in cardiac rehabilitation). This form of 'body work' reminds us that we are bodies, or rather, that we are embodied beings. But, prior to rehabilitation, the experience of illness 'brings the body to mind' (Svenaeus, 2001) in a unique way, a point which I shall elaborate in the body of the thesis.

♥ ♥ ♥

> [T]here is no such thing as one phenomenology, and if there could be such a thing it would never become anything like a philosophical technique.
> (Heidegger, 1982: 328)

Phenomenology, particularly as it has been taken up by sociology, focuses on 'lived experience'. (Could there be any other kind of experience?) According to Van Manen (2001: 460), lived experience is 'the name for that which presents itself directly, unmediated by thought or language'. Yet, lived experience, while 'felt' pre-reflexively, is already mediated by thought and language, and accessed *largely through* thought and language. The purpose of phenomenological research is to challenge the assumptions of language, to gather vividly descriptive accounts of experience, and to uncover the (always social) strategies that people, situated within already existing social structures, employ to make their lives meaningful. By attending to the manner, or form, in which experience is described, the researcher is able to grasp how life is experienced as 'meaningful in an environment'.

As Merleau-Ponty (2000: viii) notes, phenomenological method is an attitude, 'a manner and style of thinking'. As a manner of thinking, it is 'more useful to become self-consciously aware of the differences in frames of reference between traditions so that the transformations of meaning become explicit' (Holzner, 1974: 286). To that end, I set the everyday experience and understanding of the heart and heart disease against the medical conceptualisation of the body and disease.

♥ ♥ ♥

> [S]ometimes the best way to study a pathological phenomenon is not to approach it from the point of view of its abnormality but as part of 'normal' recognizable reality.
> (Van Manen, 2001: 467)

In chapter one, 'On Experience', I explicate the phenomenological view of experience, which situates the body as the 'structuring principle' (Merleau-Ponty, 2000: 146) of the world, and I assert that the phenomenological conception of experience challenges the dualism inherent in both empiricism and idealism.

While illness is a normal experience in some respects, the experience of heart disease and the prospect and aftermath of life-saving yet physically and emotionally devastating surgery brings the body to mind in a particular way. Utilising Leder's (1990) conception of the 'absent body', I argue that illness opens up a world of experience, while at the same time the sick person falls away from the familiar things of his or her 'normal' world. Serious illness disrupts the biographical trajectory, effectively unsettling the person's relationships with family and friends, and rendering more difficult the person's 'normal' activities. The individualising effect of illness (Leder, 1990: 74) is such that it is felt as social dislocation and alienation. This I describe in terms of an 'ontological shift'. The experiential field is organized inwards and disrupts the outward intentionality or 'world-openness' that is the most distinctive characteristic of embodiment. The sick person is drawn toward his or her body while at the same time unsettled by its sudden eruption into the perceptual foreground. To be ill is to be alone with one's body. It is when the body is most keenly felt. The alienation attendant to serious illness emphasises the sense of both being and having a body and, thus, by way of a telic imperative to rectify the dis-locating experience of serious illness, offers the emancipatory prospect of re-establishing bodily coherence.

I next discuss the body image as that which establishes us *in* our social setting. The body senses its world and itself in-the-world by way of the body image, which is, as I will make clear, only in part a mental representation. Consequent to this I discuss recent debate within sociology regarding the 'importation' of phenomenological concepts such as the body image. I suggest that the body has thus far been 'taken up' by sociology largely as a figure of social action or, as a cultural, semiotic, form – that is, a bearer of signs. The body has not, within sociology at least, been addressed for what it is, in and for itself.

The development of imaging technologies permits a new experience of the body, particularly of the body interior. This is an image of the body, rather than a body image, yet by way of such imagery we experience our bodies in a new way. However, that these images are produced by medical science only serves to further objectify the body. The body that we see, reduced to a thing of parts, is not 'our' body. It is instead the body of medicine.

In chapter two, 'In Illness', I discuss the clinical encounter, from the doctor/patient to the nurse/patient relationship. The clinical encounter is significant because it is here, within this medicalised setting, that questions of health and illness are formalised. This is not to say that the sick person is not already subject to medicalising discourses. Quite the contrary, because everyday experience is, as Starobinski (1983) points out, already suffused with the language of medicine. But, the clinical encounter marks the site where the ontological shift that begins in illness is made more explicit. Medical science objectifies its subject, 'the patient', focusing on and treating the nomothetic condition – the disease – and largely ignores the experiential dimension of illness.

Sociological critiques of the clinical encounter emphasise the silencing and objectification of the patient. To support this, I outline the trajectory of medical practice, from the hermeneutic interaction of 'Bedside Medicine', to the ocularcentric practice of 'Laboratory Medicine', which analyses the body at the cellular level, effectively unmaking it, reducing it to a thing of ever smaller parts. Thus, I trace a history of the methods by which the body is both 'read' by medicine and, constructed as a medical text.

It is in the clinical setting that 'illness narratives' begin to take on a distinctive form. The objectifying practice of medicine evokes a response from the patient. The patient is compelled to tell his or her own story. I suggest that the illness narrative meets the telic demand of illness for 'interpretation and repair' (Leder, 1990). The illness narrative is thus a lay response to the experience of medicalisation.

Further to this, I discuss the 'therapeutic turn' (Armstrong, 1995) in medicine, by which the patient is produced as a 'psychosocial entity'. Western medicine is currently witness to an emergent rhetoric regarding the doctor/patient and nurse/patient relationship. The patient-centred model and 'new nursing' practices conceptualise and 'manage' the patient as a psychosocial entity, thereby neglecting the body, abandoning it to the biologistic discourses of 'Laboratory Medicine'. This new model of care is accompanied by the phenomenon of the 'informed patient', a figure that may be considered a reflexive consumer and, an active, knowledgeable, participant in self-regulating activities. Referring to phenomenological literature on the clinical encounter, it is suggested that the success of this new model is dependent upon the willingness or ability of doctors and nurses to give their charges more time and, to be open to an intersubjective engagement that emphasises listening to the patient's own interpretations of the illness experience. The chapter concludes with a discussion of the history and utility of cardiac rehabilitation.

> A drama of life and death [in] the temple of anatomy.
> (Sawday, 1996: 71)

In chapter three, 'From the Heart', I contend that the heart is possessed of a symbolic potency, so that the experience of the heart is coloured by emotionally resonant metaphorical associations. The chapter begins with a short history of anatomical dissection, in which I elaborate the argument that knowledge of the body transforms the subject of medical science into a body of knowledge. In the anatomy theatres of the Renaissance the body is perceived in terms of its metaphorical correspondence with the universe. The tropic body represents the larger world. Medical metaphors are ways of understanding the body and society and, importantly, are historically conditioned. From the organicist associations of the early modern period to the machine metaphors of the nineteenth century, the body is made to represent something other than itself. This chapter section, which offers a critique of objectivist science, illustrates the significance of historically conditioned language to the construction of meaning.

Next, I discuss the value of metaphor as a way of understanding experience. Lakoff and Johnson (2003) argue that there is no core of immediate experience that is intelligible, therefore we must employ language as a means of explication. This is achieved in part by use of the metaphors we live by. This chapter underlines the connection between body and language. Metaphors constitute experience in particular ways.

This chapter concludes by engaging with Emily Martin's (1992) discussion of 'the end of the body', in which she asserts that our bodily dispositions are 'altered' by productive forces. Developing the idea that the body is made to stand for something other than itself, Martin (1992) presents an image of the body that is a reflection of the post-Fordist mode of production. The machine-metaphor no longer applies to the post-industrial body. This move signifies a further differentiation and fragmentation of bodies and is a consequence of the technological refinement of the medical gaze.

Chapter four, 'For Narrative', examines the role of the body in the process of narrativization. The body is a 'walking memory' (Turner, 1995a: 250) and thus provides the foundation for the assertion of self-identity. Does remaking the body, in the setting of the cardiac rehabilitation unit and, in other social settings where people take their exercise, entail a remaking of the self? I suggest that illness narratives have transformative and emancipatory qualities and, as such, are characteristic of the classical narratives of modernity. Illness narratives evoke a world and exemplify a mode of being; a way of living. Illness narratives also present the possibility of mutuality, particularly if we consider that narratives are necessarily co-authored.

Regarding the question of the underlying unity of the self, it is argued that identity is forged in the process of narrativization. The 'quest' for narrative identity is a response to the fragmentation that is consequent to both illness and the process of medicalisation. If illness disrupts the biographical trajectory, effectively creating a 'hole in experience' (Sacks, 1991), does narrativization help to fill that hole? I conclude this discussion by positing the idea that narratives are actualised through the body.

In chapter five, 'Toward Interpretation', I ask why sociology is interested in 'illness narratives'. Are narratives privileged as hyperauthentic expressions of the self of the narrator? Are the (extra)ordinary stories of (extra)ordinary people suitable – that is, reliable – data sources for the social researcher? Atkinson (1997) is sceptical about the validity of illness narratives, stating that, as social constructions, they should be treated as 'social facts' and, as such, must be subjected to rigorous sociological scrutiny. Interestingly, Atkinson and Silverman (1997) suggest that the turn to narrative is a consequence of what they refer to as the 'interview society', that is, a culture that increasingly privileges the revelation of individual, interior or psychic, experience.

However, my position on this matter is that while illness narratives should not be taken at face value, they do provide a means by which people order and make sense of experience. They serve to bring some sense of coherence to the inchoate. I suggest that the fictional quality of illness narratives is not necessarily problematic inasmuch as experience is already informed by and articulated through references to the literary; that our modes of understanding draw upon the same resources as aesthetic artefacts, whether in the form of television drama or works of 'high art'. In short, reality is already 'storied'. To ignore the illness narrative is to deny the very means by which people actualise themselves in (sometimes critical) response to the larger narratives of the power structure that is medical science.

♥ ♥ ♥

Admittedly, there is a certain amount of nursing research on various aspects of heart disease, and although much of the literature is at least sociologically informed, it is more often brief and quite insubstantial. Nursing research, even when it is avowedly qualitative, inevitably tends toward the quantitative, such is the dominant paradigm in medical thought. Nursing literature also shares an interest in phenomenology; yet in general such research tends to conflate 'subjective' experience with the so-called 'essence' of the experienced phenomenon. The essence of the experience is taken to be that which each individual 'feels'. However, the very notion of subjectivity is problematic inasmuch as experience is necessarily social – there is no experience of the self without experience of and reference to another – and is thus *always* intersubjective. Intersubjectivity is an existential given or, to put it another way, subjectivity belongs to the world (Butler, 1998: x).

Aside from nursing research, sociologists have indeed provided analyses of the experience of heart disease, albeit limited to single aspects of experience: among others, for example, gendered beliefs about heart disease (Emslie et al., 2001); medical expertise and the communication of information to patients undergoing bypass surgery (Radley, 1996); and therapeutic, holistic responses to those living with heart disease (Winters, 1997). While these studies, particularly Radley's (1996), are of some interest, they do not take account of the assumptions that inform everyday and scientific knowledge and, are therefore somewhat limited in their approach to the subject, although it should be noted that they are all fairly short essays.

♥ ♥ ♥

> To acknowledge the locatedness of subjects is to reject what we might call an 'unconditioned subject', that is, a knower guided only by context-independent and value-neutral methodological rules.
> (Longino, 2002: 107)

Why the heart? The heart is a liminal thing. It is a natural and cultural object, and is therefore possessed of a symbolic potency that subtends the emotional and socio-political life of human beings. Metaphors of the heart have a considerable history, thus the heart has been made to 'stand for' many different things and, is therefore a complex object.

The symptoms associated with coronary artery and heart-valve disease are similar in many respects: breathlessness, bronchial spasm, fatigue, dizziness, pain (if angina is present), anxiety, and excitability. Furthermore, the heart tends to beat irregularly and sometimes quite violently, to the extent that it can be clearly felt as an erratic pounding in the chest. Here the body is quite clearly experienced in an unusual way. It is thus the cultural and material intensity of the experience that makes heart disease an interesting research topic.

For coronary artery bypass and for valve surgery the surgical procedure is initially identical. The patient is put on a bypass machine and the chest is opened. The surgical procedure is physically devastating (traumatic in the true sense), and yet the survival rates are very high. Heart surgery takes the patient to the brink of death and brings her back to life again. I suggest that the bodily, emotional, impact of such experience engenders a particular sensitivity to the world on the part of the patient. Quite simply, they know that they have survived a traumatic experience and, in attending to the repair of their bodies they reassert their sense of being embodied. Therefore, as informants, cardiac patients present the researcher with the means of talking about acutely felt experience.

♥ ♥ ♥

Initially I requested permission to interview cardiac outpatients, who were, or, had recently been, engaged in cardiac rehabilitation programmes at three city hospitals. I began to conduct interviews, both in rooms in the hospitals, set aside for that purpose and, if invited, at informants' homes. While the home interviews were successful – intimate and revealing – the hospital interviews were rather less so. At that point I decided to abandon hospital-based interviews altogether and concentrate on home interviews. I set about finding more informants, largely by 'snowballing', which proved a very useful method. Later, I took to walking in a local park with informants, who introduced me to friends who had undergone heart surgery and cardiac rehabilitation. In all, I successfully interviewed twenty-three people who had experience of heart disease, surgery, and rehabilitation. In addition I interviewed four cardiac rehabilitation nurses. I have only used extracts from one nurse interview in this thesis.

Interviews were recorded and fully transcribed. All recordings have since been erased, for reasons of confidentiality. Field notes were taken during and after interviews, particularly those conducted in an outdoor setting.

I began interviewing informants in Spring 2002. I continued interviewing until Autumn 2004. I conducted one interview in Summer 2005, but that is not included among the extracts presented here.

My research proposal was approved by Ethics Committees at each of the hospitals. The interviews were conducted in accordance with ethical guidelines established by the British Sociological Association. All informants are given pseudonyms. All informants signed consent forms and gave their permission to reproduce and publish interview extracts.

♥ ♥ ♥

Within this thesis I present interview extracts from seventeen informants; ten women and seven men. I believe that the number of informants in this type of study is unimportant. I could just as easily have interviewed two or one hundred people. The extracts are presented in the usual manner; that is, the informants are given pseudonyms and the extracts are indented. However, there is one addition. I have set each interview extract within quotation marks. This is to highlight the spoken quality of the extracts, and to set them apart from other indented quotes. The extracts represent the *voice* of lay experience, while other quotes generally represent that of scientifically informed opinion.

I interviewed some informants twice, largely to determine whether they felt that their state of health had improved, if they had maintained an exercise regime, and to find out how they felt about their experience, including that of talking with me, in retrospect. I wanted to determine if the informants had reflected further on the experience after the first interview. For the second interview I chose informants who had been particularly communicative during our first meeting. I shared some of my thoughts on the process of interviewing, writing, and reflecting on the research. This is in keeping with the method of 'interactive interviewing' espoused by Ellis et al. (1997: 119-149), who advocate an openly intersubjective approach to sensitive research topics.

> [A]ffective notions are part of the researcher's equipment; to discount them in the name of objectivity is to allow them to proliferate furiously but in secret, to the detriment of the 'scientific' approach...[thus]... a self-aware subjectivity is a most useful tool.
> (Pouchelle, 1999: 198)

As the research subject is socially located, so too is the researcher. I wanted to make it clear to my informants that I have a voice other than the seemingly objective voice of science. In hospital, most patients are obliged to answer questionnaires concerning health, social circumstances, mental acuity, and so on. In a sense, I wanted to give my informants the opportunity to ask questions, and to respond to mine freely. In keeping with my position that medical science objectifies the patient, I was reluctant to compound this alienating practice. Contrary to the figure of the naïve interloper of classic ethnographic texts such as that of, for example, Foot-Whyte (1943), I present(ed) myself as an informed researcher inasmuch as I have some knowledge of the effects of heart disease. I do not intend to suggest that this is the best or only way to conduct this type of research and, neither do I claim that only someone such as I can, but I believe that this knowledge facilitated an *easy intimacy* between my informants and myself.

Regarding the content of the interviews, I set my questions within general thematic frames. For example, I wanted to talk about anxiety, fatigue, social dislocation, and the work that is involved in rehabilitating the body. To this end I asked informants about: their relationships with family and friends; the emotional content of their experience; the illness 'process', from the initial awareness that 'something was wrong' to their interactions with doctors, cardiologists, technicians, and nurses; and, their more obviously embodied activities such as exercise, both in the rehabilitation unit and in other places.

♥ ♥ ♥

The narratives that are interspersed throughout this thesis are presented in a similar manner to fiction. They are italicised to distinguish them from the rest of the text, to emphasise that our everyday life is (or can be) 'storied'. The titles of the narratives are suggestive in that they allude to poetry, film, music, and drama. The purpose of this is to illustrate the narrative memory or, narrative competence of the reader. My intention in presenting these narratives is to emphasise the aesthetic quality of experience and the aestheticising nature of writing. All writing is writing from and with a history, which is to say that the writer is always historically located and possessed of a cultured memory. And that memory, which resides in the body, structures our everyday experience.

Part One

First Narrative: The Past Inside the Present

*My body is older than my oldest possession. I've had it for as long as I can remember. And prior to any recollection I know that, in a sense, it already existed: that it possessed me before I took possession of it. To say that I have a body suggests possession of some*thing *by some*one*, but this notion of possession is of a different quality to that ideology of ownership which is dominant in the current mode of production: it is rather the 'simple mineness of one's own body' (Ricoeur, 1994: 320). Perhaps I should say that I have a sense that my body is my oldest possession because it is the first thing that I remember, or more precisely, it is the thing from which I remember: it is the source of my memory, the very necessary ground upon which my memory takes shape. My first memory, if indeed it is a memory, for it might only be the memory of a dream or the dream of a memory, is of lying on my back (although I do not know that I am lying, or indeed, on my back). I am looking at something above; there is a sense of nearness and of distance, of darkness and light, and of movement on the periphery. A figure, a shape which I am able to differentiate from the general background, looms close and almost fills my field of vision, and then something is in my mouth (although of course I do not yet know it as my mouth), while other figures, much smaller, much further away, make dark flickering movements. That first memory is now vague, a slight awareness of something that might have happened, but since then I've developed a considerable stock of memories, and they are all memories of something, that is, they are memories of a sense of place and my relation to and within it. Thus memory is a spatialised awareness, a cognition of a substantive relation to something, determined by the position of my body in relation to the 'stuff'' around it. Of course, I forget my body when I remember something, some experience, unless I recall the feeling of pain or pleasure that accompanied and coloured the original experience. Experience itself is organized, given form, in memory; it is made more tangible, more definite, in* *an act of 'spectatorial decomposition' (Todes, 2001: 53) in which I learn to remember what the things of the world are. Lying there (probably in my pram), watching gulls overhead against a steel-grey sky (possibly close to water), being fed something by someone (almost certainly my mother), my being becomes aware of itself and an 'I' is formed for the purpose of understanding and knowing the living text that is the world. The world thus becomes known and presents itself to me as always and already determinate – the gulls were always gulls, the sky was always the sky. And thus I learn also to take the world for granted by way of this shift from perception to conception, from an initial undifferentiated apprehension of the world to a discriminatory and anticipatory knowledge of it. Experience, then, is the contextual interaction between embodied subjects and others (people and things). Thus, I 'come to' in the midst of things, always 'encircled by others' (Schilder, 1950: 705).*

Chapter One: On Experience.

> Our own body is in the world as the heart is in the organism: it keeps the visible spectacle constantly alive, it breathes life into it and sustains it inwardly, and with it forms a system.
> (Merleau-Ponty, 2000: 203)

> The qualities of material things as aestheta, such as they present themselves to me intuitively, prove to be dependent on my qualities, *the make-up of the experiencing subject*, and to be related to *my Body and my "normal sensibility"*. [emphasis in original]
> (Husserl, 1999: 163)

> Since something cannot be normal without being a normal something, the application of the term "normal" to people presupposes that they are normal in some respect. [...] Thus the concept "normal" becomes a metaconcept.
> (Misztal, 2001: 313)

Matters of the Heart

Any discussion of experience necessarily invokes the presence of the body, for, as Ferguson (1997a: 1) notes, there is no experience that is not bodily. And, as all experience is experience of *something*, it is vital from the outset – not least in order to avoid idealisation or abstraction, such that, for example, the body becomes merely the *idea* of a body – to address what that something is.

This chapter is guided by, and toward the phenomenological view of experience and, thereby, seeks to avoid the twin methodological failings of reductive empiricism and abstract idealism. The point is to circumvent the fallacies in which experience is conceived as either the registration of sense-data (an atomism which neglects the meaningful dialectic between the embodied subject and his/her environment), or as the product of a constituting yet detached (that is, existing independently of its world) consciousness. In both methods – empiricism and idealism (or intellectualism) – the world is essentially meaningless, comprised of barely differentiated objects, which, in the former, appear as stimuli, and in the latter, as 'aspects of the object[s] corresponding to different perspectives' (Merleau-Ponty, 2000: x). Either way, the subject, or subjectivity at work is 'impregnable...untouched by being and time' (Merleau-Ponty, 2000: x), and is thus disconnected from its world, unconditioned by history, and devoid of any sense of the social. It is therefore vital that a social theory, and methodology, of the body, while attending to the question of experience – which in this study is the experience of illness – address also the different modes of sociability that are constituted by the embodied subject.

The body, as the 'core of human existence' (Marcel, in Spiegelberg, 1976: 439), the 'lynchpin of subjectivity' (Rothfield, 1997: 33), the 'zero-point and centre of our world' (Ferguson, 1997a: 1-2), and the 'structuring principle' of that world (Merleau-Ponty, 1978: 146), is no simple possession (Mackenzie, 2001: 418-421). Nor is it, in a Cartesian sense, an extension of mind (McWhinney, 2001: 331, among others). Being is incarnated in the body and, thus, both being and having a body actualise our intimate participation in the world. Yet, despite its centrality, its essential position as the very ground of experience, the body is characterised by existential indeterminacy (Csordas, 2000: 5). The experience of illness, or being ill, as Buytendijk (in Svenaeus, 2001: 87) observes, 'is above all alienation from the world'.

As an experience illness is, initially at least, abnormal. First, serious illness brings a sense of social dislocation, psychic disturbance, and fragmentation of self-identity to the experiencing subject. Second, illness pushes the body to the perceptual foreground. Illness brings the body to mind, for if, as Gadamer has it, to be in good health is to be 'forgetful of ourselves' (in Svenaeus, 2001: 89), then to experience 'bad' health is to be mindful of ourselves by virtue of a heightened awareness of the body, particularly of its potentialities and limitations – in short, its indeterminacy.

This notion of the indeterminacy of the body is, I believe, supported by Ferguson (1997b: 7) when he observes that 'the contemporary experience of the body is a vast accumulation of body images drawn from the past'. The body is, therefore, no simple object. The experience of the body, at this or any given moment, is no less than the sum of embodied experience, and as such, the body is an historically conditioned and continuously changing source and subject of experience. It could then be said that the past (history) remains inside the present (spatially situated body) and, that the body is thus possessed of a residual memory: indeed, '[e]ach individual enters the world with the forms of movement that are constitutive of thought embodied in the environment surrounding him or her' (Bakhurst, in Burkitt, 1999: 78). Citing Ilyenkov (1977), Burkitt (1999: 78-80), observes that, as we are born into a world that history has made cognizable, thought does not emerge of its own accord; it does not spring from the mind. Thought originates some*where* in history, and is directed toward some *thing*. In short, all action and thought relies upon (but is irreducible to) a history of action and thought:

> [T]he sole thinking body with which we are acquainted, does not consist of two Cartesian halves – 'thought lacking a body' and a 'body lacking thought'. [...] [B]oth the one and the other are equally fallacious abstractions. [...] Between body and thought there is no relation of cause and effect, but the relation of an organ (i.e. of a spatially determinate body) to the mode of its own action.
> (Ilyenkov, in Burkitt: 1999: 79)

The 'sole body' may, however, lack wholeness or consistency, for as Leder (1990: 1) argues, it is during illness that the body *'dys-appears'*, which is to say that the body 'surface[s] as an absence, a being-away *within* experience' [emphasis in original]. So, while illness represents a disruption of the biographical trajectory, dissociating the subject from the familiar world of work, family and friends, and from previously held notions of self-identity, it is also when the body, or at least part of it, is most keenly felt. During illness one is, in a sense, alone with one's body, drawn to its absolute facticity as a biological, natural, and therefore troublesome entity. The opposition of culture and nature is at its most obvious in this situation: culture, as a human construction, is deemed to be malleable, whereas the natural is considered uncultured, and thus dangerous – 'at best base and unruly [and] at worst…deeply disruptive and uncontrollable' (Shildrick, 2002: 11).

In suggesting that, in illness, the body's pressing immanence impinges upon our sensibility, I do not mean to imply that the body is not otherwise strongly 'felt', as, for example, in moments of pleasure or distress. I wish to emphasise, as does Leder (1990), that the body more often, and necessarily, effaces itself, so that bodily *disappearance* seems normal. Leder (1990: 25) does not assert that the body disappears altogether. Rather, that bodily sensations are 'relegate[d] to the status of neutral background', according to the focus of perception: '[a]s such, the body itself is not a point but an organized field in which certain organs and abilities come to a prominence while others recede' (Leder, 1990: 24). Zaner (1981: 45) describes the body as a 'contexture'; that is, 'a system organized by a unifying principle or agency beyond its constituent parts, wherein each part gains its functional significance only by virtue of its place in the overall structure' (Zaner, 1981: 77). For example, at this moment of writing I am (obviously) seated at my computer, typing; my attention, or rather, my intentionality, focused upon the keyboard and the screen. I am aware of an itch on my right hand and a dull pain and sense of stiffness across my shoulders. I am not, however, aware of the other parts of my body that enable me to sit and type, although my perception is supplemented by the smell of my wooden desk and the barely discernible sounds of suburbia – birdsong, cars in the distance, children playing – all of which provide a perceptual background and thus make my experience *feel* whole. And by noticing this background and describing it I bring it more clearly into focus and begin to notice many of its previously overlooked aspects. I have just scratched the itch and it has disappeared (along with the hand that itched), and I am left only with a vague awareness of my shoulders. All other possible bodily sensations have momentarily receded into the 'corporeal background' (Leder, 1990: 25) of inattention. No. Now I have an itch on the right side of my face. This could go on forever, but I merely wish to illustrate the point that the body's awareness of itself flickers in and out of perception, surfacing to the perceptual foreground at particular times and under specific conditions. Equally, I do not imply that bodily experience in illness is constant; rather, feelings of pain, fatigue, or dysfunction may recede from the foreground of perception. For example, if the pain of angina surfaces during exertion, then it will quickly retreat once activity has ceased or if medication is taken. Nevertheless, I contend that the experience of heart disease, even when it is not strongly felt, elicits a specific response in the sick person, and as such, I assert that heart disease, for reasons which will be fully explained in due course, is felt in a particular way.

Here, I must draw a distinction between the terms 'disappearance' and 'dys-appearance' (Leder, 1990). 'Disappearance' quite simply refers to the absence of the body from the perceptual foreground, while 'dys-appearance' refers to the presence of the body 'at times of dysfunction or problematic operation' (Leder, 1990: 85).

The body, as the locus of perception, 'is the most abiding and inescapable presence in our lives', yet paradoxically, it is 'rarely the thematic object of experience' (Leder, 1990: 1). Whether immersed in thought or engaged in physical activity, the body itself is seldom the object of our attention (Leder, 1990: 1), and even when it is, attention is more likely to be directed toward specific body parts, for example, my fingers on the keyboard as I write this, or more problematically, an itching hand or a muscular pain. Disappearance thus refers to the *necessarily* self-effacing character of embodiment. To expand upon this point I must restate that all experience is experience of something. The world already exists for us – it is 'ready-made' (Merleau-Ponty, 2000: xvii) – but it does not exist as a thing apart, because, as we are already in the world we have an intimate relationship with it. The experiencing subject is thus 'bound up with and directed toward' (Leder, 1998: 123) the experienced world in projective activity; that is, he or she is possessed of intentionality, an *intending* toward the things of the world. Experience is not merely an 'incoherent bombardment of the senses' (Throop, 2003: 221), as empiricism would have it, and neither, in the manner of intellectualism, do we stand, by way of a detached, ethereal consciousness, at a remove from the world, to conceive of it as something that exists outside consciousness. Discussing intentionality, and citing Husserl's critique of Descartes, Crossley (1996: 2) asserts that 'for us, the world can never be anything other than the world of our conscious experience, [that] we can never know if there is a world beyond our conscious experience, [and] if there is, we can never know what it is like'. In short, there are not two worlds, one physical and the other 'in the mind'. There is not, somehow, beside the intentional object, a representation – an image in consciousness – 'which serves as substitute for the thing itself which is outside consciousness' (Sallis, 1995: 65), for to believe that would necessitate a return to the constitutive consciousness of intellectualism. It is precisely because we find ourselves immersed in the world, forever intending – moving out – toward the things that we are already intertwined with, that we cannot 'see' ourselves, as it were. Leder (1990: 20) puts this more succinctly when he states that the body 'is a lacuna in its actional field [and that] we ordinarily focus upon the goal of activity, not our corporeal means of accomplishment'. In grasping that which we intend toward, the 'goal of activity', the body moves away from itself, but this away-ness, or 'being away' (Leder, 1990: 22), implies a presence also – the 'from-structure' (Leder, 1990: 15 *et passim*) of the intentional body.

> The body could not be away, stand outside, unless it had a being and stance to begin with. It is never thus *fully eradicated* from the experiential world. Otherwise I would not even know I had a body. [my emphasis]
> (Leder, 1990: 22)

Thus the body is both absent and present. The term 'dys-appearance' is employed to signify the appearance, or presence of the body (or body parts), in a problematic way. Leder (1990: 84) cites the etymology of the prefix *dys*, meaning bad, hard, or ill, stating that 'dys-appearance' indicates a felt effect of vital, affective, or motor disturbance. The body normally disappears; it is necessarily self-effacing, and absent from experience. This may be described as a 'primary absence' and is that which 'allows the body to open out onto a world' (Leder, 1990: 90). But, dys-appearance is a 'secondary absence [...] born from the absence of an absence' (Leder, 1990: 90-91): it is thus the absence of a normal absence, felt, in dys-appearance, as a presence. The following interview extract illustrates a moment of bodily dys-appearance, which, according to the informant, marked the onset of his heart condition:

> "The light bulb in the garage had gone and I went to change it, something I'd done many times before. No problem! But this time, when I climbed up the stepladder, I had to stand at the top and catch my breath. I felt dizzy, and heavy...my legs were so heavy, and my arms too...I had no energy at all. I thought for a second that I was going to be stuck there. I couldn't reach up to the bulb to change it, but after a minute the feeling passed, I changed the bulb and I felt okay. I was a bit shocked at the strength of the feeling, but I thought that I was just feeling my age."
> (Robert, 59 years old)

The difficulty in accomplishing this simple, generally taken-for-granted act – "something I'd done many times before" – points to a disunity of the senses (for example, touch and spatial awareness) and a concomitant 'dis-ability' (Leder, 1990: 81) to fulfil certain 'normal' functions. The informant had to 'catch' his breath, his arms and legs dys-appeared in that they were strongly felt, and he was 'shocked at the *strength* of the feeling'. Momentarily, the feeling passed, but further experiences of similar intensity unsettled this informant enough for him to seek the advice of his doctor.

It should be stressed that bodily dys-appearance does not always prefigure serious illness, that it is possible to be uncomfortably aware of a body part – for example, a stubbed toe, a roll of flesh around the waist – without being ill, and thus it could be said that the body shifts from dys-appearance to disappearance much of the time. Equally, it is possible to be unaware of a serious condition. For example, diseases of the heart valves may go unnoticed for years because the heart can, to an extent, compensate for any 'disturbances' in its structure (Lewis, 1944: 194-200). It is the effect of dys-appearance that is significant:

> "I had this terrible, dry cough. That was the first thing, really. I thought it was a chest infection at first, but it wouldn't clear up. But it was my heart. There was fluid building up in my lungs all the time and that was what was causing the cough. Even with the pills they gave me it didn't stop. It was one of those coughs that really shakes you. I'd feel exhausted all the time with the coughing."
> (Alice, 64)

The sensations that accompany illness – for example, pain and fatigue – 'reorganize the experiential field inward' (Leder, 1990: 73), which is to say that while one remains aware of other sensations, unpleasant feelings dominate all others and engender an inwardly reflective focus of one's thoughts and attentions, just as toothache seems to blot out all other sensation and thought so that all attention is directed toward the tooth. Indeed, 'pain is the very concretisation of the unpleasant, the aversive' (Leder, 1990: 73). The body, as the point from which we attend *to* the world, is a 'from' structure – we interact with the world 'from' our body. But, the 'affective call' (Leder, 1990: 73) of illness reverses this position so that the body becomes a 'to' structure; it is that which we attend 'to':

> "My heart would beat really fast. First it was just if I climbed stairs, or walked too fast. But then it happened during the night. I couldn't get to sleep. I'd hold my hand against my chest to feel the heartbeat. It was too fast. I was doing it all the time. People started to notice. They'd ask why I was holding my chest. I'd get really worried if it was beating fast when I wasn't doing anything. I was really obsessed about it."
> (Jane, 62)

Good health is taken to be normal; the seemingly effortless workings of the body are invisible and therefore beyond immediate perception (although, referring to the idea of the body as a machine, Sawday (1996: 37) notes that the wonder of the body, in its complexity, is that it works at all). To suggest, as I have, that illness '*pushes* the body to the perceptual foreground' and '*brings* it to mind' is to imply that illness has an objective quality, that it exists somehow outwith our everyday experience of ourselves. This is not so, for this perception refers not to a quality inherent in illness, but is instead a quality of embodiment which serves to 'confirm one's identity with one's own body in a radical, inescapable way' (Leder, 1984-85: 262), which is to say that bodily malfunction is felt to a degree that normal bodily functioning is not. (That normal bodily functioning is taken to be normal may say more about the power of the metaconceptual nature of the notion of normality.) Thus, we are reminded, in illness, of our mortality and materiality: the threat to the integrity of the body and hence, the self, heralds a social dis-integration which confounds any attempt at transcendence. Much as the sick person might wish it, there is no way to rise above the body. Illness reminds us that we are embodied. To paraphrase Nietzsche (1980), our chains run with us.

> "I'd been feeling unwell for a while...oh, about two months. [...] Dizzy spells, headaches. I tired very easily, and normally I'm very active. I knew something was wrong when I found myself lying on the floor that night. I came to on the floor in the hall. We'd been at a dinner dance and C. [informant's husband] went to bed and I was tidying away in the kitchen for a little while...and then I just *came to* on the floor in the hall. I don't remember going into the hall. I must have collapsed. I lay there, looking at the ceiling. I felt fine, and I wasn't worried. No, I didn't call for C. I waited for a little while, then got myself up and went to bed. Yes, I told him [informant's husband] the next morning, and he called the doctor out. He thought it was the medication I was on for the blood pressure, but it got worse...I fainted twice more, so he sent me to the hospital for tests. I was scared to go out in case I fainted in public. I became quite ill. It got to the point where I couldn't do anything...the dizzy spells and that terrible feeling in my neck...yes, the pulsing. [...] Yes, looking back it was funny how I didn't call upstairs. I don't know why. I didn't want to worry him. I didn't want the fuss. I think it made me a bit daft at times. You know, when I had dizzy spells I'd feel awfully confused, but I didn't feel like that then. I remember lying on the floor thinking, 'this isn't right...I must be dreaming'. I was quite calm. [...] No, I didn't think it was my heart. If anything, I was worried it was the cancer coming back."
> (Kate, 75)

The world of the sick person is constricted (Leder, 1990: 80-83), and, focused inward upon herself, and faced with the prospect of leading a more limited life, the above informant may not have wished to admit her perceived weakness to her spouse. Believing that her fainting experience could be connected to a previous illness, she experienced 'dis-ease' (Leder, 1990: 81), that is, the sense of a lack of control of the inner workings of her body, a disruption of bodily intentionality, and a concomitant disturbance to her perceived 'normal' abilities. At this point it may be said that this informant is 'dis-abled' (Leder, 1990: 81).

Leder does not distinguish clearly between pain, exhaustion, disability, and the sense of approaching death, and the specific manner in which each constitute a 'phenomenological shift' (Leder, 1984-85: 262) toward psycho-social fragmentation and inevitably, a dualism which effectively separates the experiencing subject from a sense of being embodied in-the-world; a shift which ultimately stresses the objectivity of *having* a body over the subjectivity of *being* embodied. The most general form (or formlessness) of this phenomenological, or more accurately, *ontological* shift is the experience of pain. Even though, in heart disease, pain is generally only experienced if angina is present, it is appropriate to discuss the variety of its dislocating manifestations in the context of a discourse of pain. Certainly, it would be difficult to discuss heart disease without reference to exhaustion, disability and the sense of approaching death.

> "I felt let down...let down by my heart. It just wasn't working. There were so many things I couldn't do any more, and I felt very, very tired most of the time."
> (Alice, 64)

> "It took me so long to climb the stairs, and I'd have to rest on the landing before I could go on. I was so weak...not like feeling tired...much worse, as if I had absolutely no energy at all. I thought I couldn't live like this... couldn't go on."
> (Richard, 69)

> "I really thought I'd had it. That was it, you know, I'd get weaker and weaker, and then my heart would give out."
> (Robert, 59)

As an experience, illness is perhaps, for the social researcher at least, easier to grasp than good health (Svenaeus, 2001: 95), for illness represents a 'problem' – meaninglessness, helplessness, an absence (of good, normal health) – a falling away from things toward a state of isolation and alienation. Indeed, it could be said that good health cannot effectively be studied because, as a taken-for-granted, relational (to bad health) phenomenon, it is a 'non-apparent attunement…a balancing mood that supports our understanding in a homelike way without calling for our attention' (Svenaeus, 2001: 95). However, in suggesting that feelings of good health are distinct from, for example, 'other positive moods like well-being or happiness', Svenaeus (2001: 95) appears to separate the life of sickness and health from another, everyday world, particularly when he states that 'such [positive] moods colour our understanding…in a much more obvious and manifest way than health' (2001: 95). In doing so, Svenaeus (2001) apparently posits two worlds: one of sickness and health, in which the struggle to restore equilibrium characterises experience; and another, which somehow exists outside the sphere of health altogether, characterised merely by a sense of well-being. This is erroneous, for while the experience of serious illness is certainly characterised by alienation, the alienated subject yet remains firmly in the world, for to be alienated is to be in the world yet simultaneously detached (or distanced) from it. And while good health may be taken for granted, it is nevertheless possible to 'feel' healthy, as the following extract indicates:

> "It's not until you've felt that bad that you appreciate your health. Some days I get up and I just think, 'oh, I feel really good today. Tip-top.' You feel yourself again…better than that, in fact. It's just the way it is, though. You take your health for granted most of the time. You have good days and bad days, but the bad days before the operation were the worst. I didn't have any good days then."
>
> (Robert, 59)

Noting an interesting asymmetry: it is possible to feel healthy without actually being so, but *feeling ill* is to *be ill*. The sick (or formerly sick) person doubtless feels a heightened awareness of his or her bodily disposition and its relation to the world, but it is the struggle for health that is of greater significance, both to the researcher and to the experiencing subject. In the example of coronary artery or valve disease, the 'alienation' (Buytendijk, in Svenaeus, 2001: 87) that is felt often begins with a fateful moment, an incident that, in its intensity or strangeness, disturbs the equilibrium and taken-for-grantedness of everyday life:

> "We were driving to the [golf] club for dinner with friends. I'd been feeling a bit run down. I thought it was just a cold and didn't think anything of it, but the [steering] wheel felt so heavy and stiff, and then it felt like it was...the stiffness moved to my arms and then my chest. It was odd, really. I had this feeling of resistance from the car, but then it was as if I was the resistance, and I felt I couldn't control the car. For a moment the car was driving me. I had to pull over – a bit of a struggle – and sit for a while. I thought I was going to black out, but I was all right after about ten minutes and we went on to dinner. It shook me but I put it to the back of my mind. I still thought it was a cold, or maybe a virus, or maybe I was going senile [laughs] but that was the start of it for me."
> (Andrew, 66)

Put simply, the sick person feels different. From this point, this fateful moment, when disease makes itself felt, the person engages in a struggle to be normal again and, importantly, to be considered normal by others (Claessens et al., 2005: 5). Arguably, older people are less likely to take good health for granted (Lawton, 2002), but the 'radical truncat[ion] of physical capabilities' (Leder, 1990: 81) is, whatever one's age, felt as a lack, or, as Toombs (2001: 7) puts it: 'the disruption of bodily capacities inevitably disrupt the experience of surrounding space'. In the above extract it could be said that the body, in its malfunctionial relation to the car, is now experienced as beyond control, as 'other than me' (Straus, in Toombs, 2001: 7). Suddenly, it is as if there is a gap in the sick person's life and he/she is no longer in full possession of his/her body. The following extract illustrates this sense of being dispossessed, of feeling at a remove from one's own body:

> "It didn't feel right. I didn't feel like myself sometimes. It's as if I was standing outside myself, looking at this sick person who wasn't really me. I remember one night in particular, sitting on the edge of my bed. I was having difficulty breathing, just couldn't get to the bottom…to fill my lungs...I was gasping for breath, and I felt I was standing over myself…I had this picture of me sitting there, out of breath, gasping. It was terrible. I tried and tried to take a deep breath and I just couldn't. I started panicking…I was making myself worse trying to breathe deeply…you know, getting light-headed. I kept thinking I'd have to go on oxygen to breathe. That happened a lot, especially at night, so the doctor told me to use more pillows, but it didn't help much."
> (Frank, 68)

As the dramaturge, Jan Kott (1992), in his essay, 'The Heart Attack', observes, to leave childhood is to experience a shrinkage of the world, but to enter old age is to feel the world expand vertically, so that '[w]hat was level is no longer level. Flat suddenly becomes steep. Houses without elevators suddenly acquire stories they never had' (Kott, 1992: 99). Similarly, in *The Smoking Diaries*, the playwright Simon Gray (2005: 3) ruefully notes that the combination of age and cigarettes – sixty-five years old, and smoking 'something like sixty-five a day' – brings about a certain breathlessness. He describes the effort involved in wheezing up *and* down stairs, and the labour required in completing two simple acts, such as pulling on one's socks and tying one's shoelaces, which actually become 'four very distinct acts, each separated by an interval longer than the acts themselves' (Gray, 2005: 3-4).

The world of spaces and objects is thus, breathlessly, experienced anew, as distances to be crossed and obstacles to be negotiated:

> "There are so many things I did without thinking, and that changed. Okay, I was never what you could call really fit, and I am getting on I suppose, but there's this little stretch of pavement between my house and my friend's...just the tiniest slope...you'd hardly notice it, but just walking those few yards would really take it out of me. I'd feel the strain at the back of my knees, the tightness in my chest, my arms even felt heavy. And no matter how slowly I took it, that stretch always...I really laboured and felt very strange, out of kilter [...] kind of disappointed with myself. It's hard to describe, but that always upset me...no...annoyed me more than anything else. It was like a test. I'd try it to see how I felt, you know, test myself to see if I was getting worse. It's amazing how much a tiny wee slope can take so much out of you." (Helen, 72)

Kott's (1992) essay has an exhausting, dreamlike quality: he describes the sense of leaving himself, of parts of his body becoming detached, of time slowing, and of 'feeling different inside' (1992: 101). Weeks after his heart attack, in recovery, he slips into the nurses' observation room to watch the other patients' hearts beat out their rhythms in luminous signals on the monitors, and he is disturbed by the erotic quality of the experience, 'as though the heart's pulse during those hospital nights had become the pulse of sex' (Kott, 1992: 105). The urgent intensity of Kott's (1992) narrative seems to mirror the activity of the heart and, more significantly, points to its symbolic character as the seat of emotion and the centre of our being. The troughs and peaks displayed on the monitors reveal the presence of lesions, and indicate that the heart has a memory inscribed upon and within it. It might be said that Kott (1992) has 'suddenly acquired' a story he never had before.

The heart attack severs time so that the 'before' is quite distinct from the 'after'. The effortless continuity, or apparent sequentiality of existence is 'violated, if not destroyed...the diachrony of events is broken...the pre-attack is contained within synchronic memory while the entire future is a projection of the past' (Kott, 1992: 106). Kott's story echoes Merleau-Ponty's (2000: 136 *et passim*) statements on the 'intentional arc', that any deficiency in the content of experience affects the whole system – the interconnectedness of things – thus, in illness, the temporal and spatial perception of the world, and of one's own body in it, is altered. The familiar world is fragmented by that which Leder (1990: 74) describes as 'the individualising effect of suffering'. As a supplement to this point, I cite Kott's (1992) essay, 'The Memory of the Body', in which he writes that 'there are experiences where the alienation from the self is impossible. It is then that the *soma* and the *anima* are one. When you can no longer extricate yourself from yourself, the experience is no longer someone else's' (Kott, 1992: 117). This 'individualising effect' (Leder, 1990: 74) is felt as an affective disconnection from other people and objects, and characterised as a drawing inward upon oneself – an observation that is supported by much of the cardiovascular nursing literature, albeit generally addressed in terms of depression (for example, Goodman et al., 2003; Lukkarinen and Kyngäs, 2003). Quoting from Updike's poem, 'Pain', in which the comforting human world recedes such that 'these kind things slide away', Leder (1990: 74) states that while the 'individual' does indeed feel alone, spatially constricted and focused inwardly upon specific, though mysterious body parts, there is yet a felt need to re-establish the 'intentional arc' (Merleau-Ponty, 2000: 136 *et passim*), and with it, the intimate relations that are essential to being human:

> "I became quite depressed. Everyone said I was different, and I felt it sometimes. The angina gave me a real fright. I kept worrying about it, even when I had the pills for it. Every pain...no matter where it was, I'd think, 'this is it, I'm having a heart attack'. I felt so bad-tempered all the time, moping around the house. I drove the wife crazy, complaining about everything. She

> said I was really cynical about everything...couldn't see the good side. She was right. After a while I tried to make an effort. I still felt bad, but I tried not to show it. I kept my mouth shut...[laughs]...tried to smile more often."
> (David, 63)

To be ill, then, is to fall way from the 'normal' world, while simultaneously to be drawn to one's body, to be alone with one's body, and alone in oneself. This change of direction, felt as an inner-directedness, suggests that to be alone is to visit oneself in memory. Kott (1985: 80) writes: [d]uring our healthy life we move through time like passengers on an escalator. While we remain stationary, everything around us imperceptibly shifts into what has been. [...] During healthy life, time is continuous'. The body, as a repository of past experience, is a 'walking memory' (Turner, 1995a: 250). As our experience of the world is at first, and in its immediacy, intangible, it is left to memory to render life meaningful. Visiting the past in memory, thinking of the future, the constant in this is the heart, always present, inside and yet 'a thing apart' (Kott, 1992: 111), seemingly belonging to someone else, yet very much 'my heart', a suddenly treacherous possession, now fetishised so that it takes on a new significance. For my informants, their future development is now clearly tied to an attempt to retrieve and understand their past.

> "You know, I thought I had a healthy lifestyle before. Plenty of exercise, good food, and I gave up smoking a long time ago. I just couldn't understand why I should have blocked arteries. I kept thinking about what I might have done to deserve this...no, what I could have done to avoid this."
> (Anne, 65)

> "I realised that I had a very bad lifestyle previously, although I'd never been seriously ill. I ate huge meals, very fatty, and usually with wine. I didn't exercise, apart from playing golf every now and then. I wasn't what you'd call an active person. I suppose it had to happen, but I never thought it would."
> (Richard, 69)

Body Image and Body Images

> The physical thread of the body through time provides an important sense of continuity for self-conceptions and externally imputed identities.
> (Kelly and Field, 1997: 364)

The biological body has proved to be something of a *bête noire* for sociology which has, more traditionally, devoted its efforts to studies of the cultural, political, and economic spheres of human activity. Although bodies are often implied – for example, in Marx, as a productive force, and as the material foundation of consciousness – the various divisions of sociology have, in the past, and in general, avoided the body because the 'biological conditions of action were [considered] relatively unimportant in the construction of a science of action' (Turner, 1996a: 7).

The body entered the orbit of sociological investigation only 'once it had been translated into an *organic system*' [my emphasis] (Turner, 1996a: 9) that could then be analogised with other, more obviously social systems in the manner of, for example, Spencerian functionalism. Subsequently, theories of homeostasis adhered to the body, identifying it as determinate and therefore inconsequential to theoretical considerations of the social agent in society (Turner, 1996b: 62). Indeed, feminism, for example, long resisted the 'turn to the body' in the social sciences, precisely because of reductionist associations of the feminine with the biological/natural (see, for example, Birke, 1999; Connell, 2002; Wijngaard, 1991). More recently, however, interest in gendered bodies, sexualities, environmental issues, and health and illness has 'impel[led] and facilitate[d] new ways of thinking about the relationship between biology and the human sciences' (Williams, 1996: 701). These 'new ways' present a challenge to established binary classifications such as mind/body, society/nature, and reason/emotion, and critically question 'assumptions about what, precisely, biology is' (Williams, 1996: 700-701). This is not to imply that the body is now immune to reductive association – far from it, as I will show in the following chapter – but for the remainder of this chapter I turn my attention to the phenomenologically inflected conception of the body image, and discuss its utility and value for sociological studies of health and illness.

I must begin, however, on a note of caution, by acknowledging that, subsumed under 'sociological orthodoxies [the body is] assimilated to a tradition of describing and analysing aspects of social differentiation [and as such], as an extension of the critique of the Enlightenment, [the body] is not...simply... reclaim[ed] for itself' (Ferguson, 1997a: 2-3). A sociology of the body is thus, in its infancy, already a sociology of signs attached to (or circulating around) the body, for example, those of 'race', gender, and disability, and more superficially – that is, in an inscriptive sense – concerned with issues such as body adornment, body modification, and fashion. This semiotic approach to the body is, in itself, not without merit in that it *redresses* any purely biologistic accounts of the experienced body by affirming the power of social forces in the shaping (or fabrication) of bodies and identities. But, as Ferguson (1997a: 4) notes, the question of the body-for-itself remains, in sociology at least, as yet unanswered. It could be ventured that this sociology of signs is more concerned with images of the body – or with the body as a 'billboard' (Ferguson, 1997a: 3) – than it is with the living body image.

It is an interesting and much-noted point (Foucault, 1980a, 2003; Gallagher, 2001; Toombs, 2001; Turner, 1996b) that 'the emergence of social science was closely connected with the growth of rationalised medicine' (Turner, 1996b: 60), for example, in the collection of health statistics relating to the 'demographic upswing' (Foucault, 1980a: 171) of industrial populations of the eighteenth and (more significantly) nineteenth centuries, yet sociology has consistently and vigorously set itself in opposition to medicine. This is precisely because the limitations of the 'clinical gaze' are such that the person is effectively abstracted from illness and is thus 'disembodied and dehumanised' (Toombs, 2001: 8), treated as 'a disease entity, or a piece of meat' (Leder, 1998: 122). In a statement so transparent, so banal that it borders on profundity, Gallagher (2001: 147) notes that 'the most general and most obvious fact about medicine is that it concerns the body. If one eliminates the body one eliminates the subject and object of medical science and practice'. That the sociology of the body is still largely associated with medicine is quite apparent. Indeed, at the beginning of interviews I used to tell my informants that I was interested in the sociology of the body. As the mists of incomprehension descended upon them they would say, for example, "oh, is that about medical stuff?", and I would reply, "um, not necessarily...sometimes", and then proceed to ask them about 'medical stuff'. It would appear, then, that the body, at this moment in history, is so intimately associated with medicine, so thoroughly *medicalised*, that it is virtually impossible to think of our bodies without considering them in (quasi-) medical terms, so it could be said that the image we have of our own bodies is, to some degree, informed by the imagery of medical science. As Armstrong (1983: 2), referring to the medical-scientific 'mapping' of the body, observes, '[t]he reality of the body is only established by the observing eye that reads it'. By this, Armstrong (1983) means that the medical 'atlas' is not a representation of the body, but rather, the body is a representation of the 'atlas'. I will address this point in greater detail in chapter three, where I outline a brief history of the development of anatomical knowledge, but for the moment I turn to a different but not unrelated image of the body.

As the body is central to a discussion of experience, so the body image is indispensable to an understanding of the body in its social being. The body is a liminal being, occupying both a personal and a social space. It might be argued that the idea of a 'personal' or individualised body – a body belonging to oneself, 'a carrier of values and legally enforceable rights' (Ferguson, 1997b: 1)

– is but a recent development that owes much to a persistent dualism that can be traced back to Descartes, and which, in addition, is supported by the current mode of production (the latter being a point to which I will return in chapter three).

Merleau-Ponty's (2000: 203) statement, that the body 'forms a system' with the world, and Husserl's (1999: 163), that the qualities of the world are dependent upon the 'normal sensibility' of the body, imply the rather obvious point that the body is *actively* 'in-the-world'. As such, the *embodied* subject (as if there could be any other kind of subject) organizes his or her world in an act of self-recognition – that is, a recognition of situatedness, of spatio-temporal location and attitude, directed toward 'certain or existing possible task[s]' (Merleau-Ponty, 2000: 100) – by way of the body image. The body image is not only a mental representation of what the body looks like and how it is constituted, but is also a *sense* of being embodied, of being and having a body, *in a situation.* The body image is, thus, the mysteriously localised sense of being oneself; self-presence. There is, therefore, a recursive interplay between body and world, through the medium of the body image.

Gallagher (2001: 150) offers a rather simplified definition of the body image as 'the subject's *perceptual* experience of his or her own body; the subject's *conceptual* understanding (including folk and/or scientific knowledge) of the body in general; and the subject's *emotional* attitude toward his/her own body' [emphasis in original]. This combination, or, more accurately, the *gestalt* of the perceptual, the conceptual and the emotional is that which gives the body image its sociological value in that it provides a link between body, mind and social space (Williams, 1996: 706). Summarising Schilder (1950), Breakey (1997: 108-109) states that the body image is 'the picture of our body we form in our minds as tridimensional units, including interpersonal, environmental and temporal factors'. While it is a picture, a mental representation of sorts, the body image is also more than that inasmuch as it is a 'feeling' *of and for* the body as it extends itself into its environment. More precisely, the body image is:

> [T]he picture of our own body which we form in our mind, that is to say, the way in which the body appears to ourselves. These sensations are given to us. We see parts of the body-surface. We have tactile, thermal, pain impressions. There are sensations which come from the muscles...and sensations coming from the viscera. Beyond that there is the immediate experience that there is a unity of the body. This unity is perceived, yet it is more than a perception. We call it a schema of our body or bodily schema... [...] We may call it 'body image'. The term indicates that we are not dealing with a mere sensation or imagination. There is a self-appearance of the body. It indicates also that, although it has come through the senses, it is not mere perception. There are mental pictures and representations involved in it but it is not mere representation.
> (Schilder, 1950: 11)

Citing Hughlings Jackson (1931), that the body image is not an idea of the body, that in fact we have no *ideas* of any parts of our bodies, Ferguson (1997b: 20) notes that the body image is 'but a *living* form through which the self, organic processes, sensations, emotional life and the world are experienced in their *immediacy and continuous transformation*' [my emphasis]. The description of the body image as a *'living* form' is of significance, for, as Merleau-Ponty (2000: 100) notes, '[i]t is inadequate to say that [the] body is a form, [a] phenomenon in which the totality takes precedence over the parts'. Better then to consider the body image as an experience in itself, as a dynamic and 'complex interrelation of the body sensing the world, and the body sensing itself through sensing the world' (Ferguson, 1997b: 21).

Recent debate (Kelly and Field, 1996, 1997; Williams, 1996) concerning the lineage of the body image and its value to sociological theory and investigation has focused largely upon the term's origin and usage in psychoanalysis and philosophy. Critical of Williams' (1996) assertions that the concept of the body image provides 'a way out of the problem of the understatement of the body in sociology', Kelly and Field (1997: 359) contend that, as a non-sociological idea, the concept of the body image adds nothing to analyses of fundamental sociological issues regarding the body in illness, and that 'theoretical mechanism[s]' (Kelly and Field, 1997: 360) such as self and identity are already adequate to the task of analysing and explaining the problems inherent to the illness experience – problems such as the 'pragmatic and practical difficulties [faced by] sufferers and significant others, as well as [their] links to social structure' (Kelly and Field, 1997: 364).

Kelly and Field's (1997) statements are similar in tenor to that of Howson and Inglis (2001: 298), who argue against: the 'importation of philosophical solutions to the 'problem' of the body in sociology' and, the use of conceptual tools that are distinctly non-sociological. While sympathetic to Kelly and Field's (1997: 360) interactionist position, specifically when they speak out against the biological imperialism of medical science, I believe that theirs is a misreading of Williams (1996), particularly as they state that he has conflated 'pop-psychology', or common-sense notions of 'body image', and the psychoanalytic concept of the body image (Kelly and Field, 1997: 360). In addition, I believe that Kelly and Field's (1996) position is supplemented by Williams' (1996) reading of the body image by virtue of his situating of the body at the centre of his analysis, and thus their positions, while different in parts, are not mutually exclusive.

In summary, Kelly and Field (1996; 1997) argue that the interaction between self and identity provides a theoretical connection to manage the relations between biological and social facts. In this view, the self is not a 'biologistic thing having a real substance underlying or based on the physiology of the person' (Kelly and Field, 1997: 364). Furthermore, identity, as the link to social structure, exists in tension with notions of self, which is to say that the body/self is subject to external 'labelling'. And finally, the body, in its obduracy, provides a sense of continuity, (despite bodily changes resulting from illness); the body is the point where 'the self is in touch with itself' (Kelly and Field, 1996: 251).

Williams (1996) points out that Kelly and Field (1996) devote 'greater attention to the social construction of the self than to the body itself' (Williams, 1996: 702). Indeed, by situating matters of self and identity within a 'general linguistic process', Kelly and Field (1997: 364) appear, initially, to subsume bodily experience under language, but they maintain that 'feelings of self and identity are founded upon our ideas about the body [and] of how others see us'.

Arguing that the body image concept 'readily lends itself to socio-historical and cultural analysis of the body', Williams (1996: 705) observes that the body image always 'involves relations between the body and its surrounding spaces, including other objects and other bodies, organized according to such fundamental bodily co-ordinates as "vertical" and "horizontal"'. I would add that this suggests that we not only make the world, in our image, as it were, but also that certain postural models are privileged over others: for example, 'up' is more while 'down' is less (Leder, 1990). 'Up' is good while 'down' is bad. (Although, how would we evaluate someone who has her head in the clouds or her feet firmly on the ground?) Consider the informant lying on the floor in her hallway while her husband lies in bed upstairs. The body abed is coherent while the body on the floor is disturbing, out of place. Or, the patient in a hospital bed, or on the operating table, while apparently healthy, *intentional* people scurry around. The first indicator of recovery is the ability to get up out of bed. Vigarello (1989: 149) writes that '[f]rom the Middle Ages on, every failure of physical uprightness has been attributed to two main categories: the stigma of deformity, sanctioned by the attention given to strength and aesthetic qualities, and the lack of the proper deportment prescribed mainly by socialised ethics'. In a more complex manner Elias (1996) also has described a history of the differentiation and sequestration of bodily activities. The informant who fainted stated that she worried about doing so in public. Perhaps fainting is best 'experienced' in the safety of one's own home.

Williams (1996: 706) states that the body image is not a map of the body, or rather, that it is not mapped *onto* the body, but that body and body image are 'interconsistent', and that the relationship between both attests to:

> [T]he radical inseparability of [the] biological and psychical elements of social being, [and that] not only is the body image...of fundamental importance to our sense of bodily integration, co-ordination and being-in-the-world [but] as a mediatory term between the biological, psychological and sociological levels of analysis, [it is] crucial to our understanding of the processes involved in chronic illness as a biographically disruptive experience.
>
> (Williams, 1996: 707)

I will take up this issue up again, albeit briefly, in chapter four, in a discussion of the ageing body, but I conclude here with the observation that, as an historically contingent and socially conditioned phenomenon, the content and integrity of the body image is subject to revision. For example, the heart may now be seen (and heard) in many different ways – by x-ray, nuclear angiography, electrocardiography, echocardiography, and magnetic resonance imaging – which, altering the conception of the heart as a medical object, affects the quality of the subject's perception of his or her own heart. The heart is already possessed of a symbolic potency, as the source of feeling, the seat of emotion and, more recently, the very engine of our vital forces, but seeing and hearing a faulty valve regurgitate blood in an echocardiograph could perhaps undermine any taken-for-granted notions regarding the heart's integrity and durability. Oddly, ultrasound technicians often apologise to patients when they adjust the volume to better hear the heart valves (mal)functioning. My informants had mixed feelings about this experience:

> "The girl [the ultrasound technician] said she was going to turn the sound on and it would be loud, and she said she was sorry but it had to be done and it wouldn't last long. Well, it didn't bother me, but it *was really loud*...like a machine, but muffled too. You know what it reminded me of? A wobble-board. I just thought of that. We used to play with them when we were children, you know, a bit of board and you just kind of flex it. But this was more regular. Actually, there were quite a few different sounds there, but I didn't like to ask the girl because she was talking to the young doctor. I couldn't see what was on the screen all the time because she'd have me turned away, on my side, but when I was lying flat I could see the screen. It's hard to tell what you're looking at. It looks almost like flesh, it's kind of...[laughs] ...wobbly-looking, but there's this mechanical sound and when you see the valves they're like machines too."
> (Alice, 64)

> "The technician turned the screen away so I couldn't see the picture of my heart, but I asked to see it and it was vague at first, but then I saw what she was looking at. It wasn't the sight of it that bothered me, though. It was the noise...that gurgling, wet, whooshing sound. It wasn't what I expected. And then the doctor pointed to the jet of blood gushing back into the heart...I couldn't make it out at all, but I must say, it upset me. I knew it was my heart they were looking at, but it didn't feel like mine."
> (Eleanor, 67)

Thus, the 'anonymous visceral domain' (Leder, 1990: 150) in which the heart resides is exposed, and to some extent, demystified. Or perhaps made more mysterious, for just as the prospect of heart disease and surgery is difficult to countenance, so it is unsettling to see the living heart perform its mundane functions (particularly, in this instance, badly). This suggests that the image of the body informs the body image and is indeed central to the formation of self-identity. It might also be ventured that this new experience – which is a new perspective – of the heart, with its 'gurgling, wet, whooshing' quality, forces one to admit, like Nietzsche, that 'body I am entirely, and nothing else' (in Diprose, 2002: 21). The dys-appearance of the body, the absence felt as presence within experience (Leder, 1990: 91), demands attention if a state of personal and social equilibrium is to be achieved. This breach of bodily integrity is addressed, so I shall argue, by way of a narrative construction of experience, and central to this narrative is the establishment of a coherent sense of body and self.

Second Narrative: The Boy with Blue Lips.

If, as Parsons (1952) states, illness is a socially legitimate form of withdrawal from the expectations and obligations of the larger social system, then it is unsurprising that the sick person withdraws from many 'normal' forms of interaction; for example, conversation. Eavesdropping (perhaps the oldest social research method of all) in the waiting rooms of cardiology clinics, I notice that new patients (whose first lesson is to learn to wait) rarely discuss their medical condition with others. I am at first surprised, but that is the way of it, for illness is, initially at least, and despite its public aspects, a very private matter that is difficult to articulate. Radley (1996) notes that, faced with the barely conceivable prospect of heart surgery, patients rarely wish to discuss what is yet to come. Confronted by the 'double prospect' (Radley, 1996: 124) that surgery will either kill or (partially) cure them, patients may choose to wait in silence; although waiting is hardly a matter of choice.

In a waiting room I sit opposite a young man. We are the only people in the room – as if in a drama, wherein all the supernumeraries have been written out in order to enhance the effect of isolation – but we do not speak, this young man and I. He is possibly no older than nineteen. His lips are blue. His skin is bluish and almost transparent, and his fingers are extremely long and clubbed (that is, enlarged, shiny and darker than is normal – often an indication of congenital lesions in the heart). His fingernails are blue also and marked with splinter haemorrhages, indicative perhaps of a bacterial infection of the heart. We are both there to see our respective consultants, waiting together in silence to find out if we are 'good' candidates for surgery. He looks worse than I feel, and I wonder what words might issue from his blue lips; and what words in response could comfort him, could possibly make him less blue. Transfixed by his blue lips, I imagine that his mouth speaks without moving, and in a sense it does, because his lips can be 'read'. I wonder if the consultant *will give more attention to the appearance of his lips than to that which issues from them. This boy seems too young to have yet seriously abused his own body to the extent that his heart is failing. I suspect that, like mine, his condition was visited upon him by the sheer 'tyranny of chance' (Zaner, 2001: 132). I wonder if, again like me, his doctor had asked him if he did not curse God or cruel fate for giving him a life-threatening disease. I am reminded of the story of the great-great-great nephew of Gregor Mendel, Benedict Lambert, a dwarf, who insisted that he did not 'have' a medical condition – achondoplasia – preferring instead to state that 'it is me...there is no other' (Zaner, 2001: 132). It is this difference that intrigues me. For the consultant, I have a heart disease, but for myself I am a person with a heart disease, which is to say that my 'condition' is an integral part of my being. My heart, which is in me and very much part of me, is diseased. Thus, no matter which self, or sense of self that realises itself in the world, I am always, inescapably, someone whose heart is flawed. While my condition is not as visible as the blue boy's – my red cheeks are rarely commented upon, and the slight ('early') clubbing of my fingers is noticeable only to my cardiologist and myself – and while I am not as obvious as, for example, a dwarf, nevertheless, my disease is not something that is felt as external to me. My body is given; it is always 'here' for me, thus the problems of the body are always present also.*

Years later, a rehabilitation nurse tells me that cardiologists often assure patients that surgery is a cure, but she insists that it is not, and that although one's quality of life may be greatly improved by surgery and attention to the details of lifestyle, there is really no 'cure', no treatment that will fully restore normality. Indeed, normality in the medical example is always someone else's idea of what is normal.

Chapter Two: In Illness

> [T]here is no health as such. Deciding what is health even for your *body* depends on your goal, your horizon, your powers, your impulses, your mistakes and above all the ideals and phantasms of your soul. Thus there are innumerable healths of the body; and the more one allows the particular and incomparable to rear its head again, the more one unlearns the dogma of the 'equality of men', the more the concept of a normal health, along with those of a normal diet and normal course of an illness, must be abandoned by our medical men. [emphasis in original]
> (Nietzsche, 2001: 116-117)

> [T]he sick man must follow his illness to the place where it is treated, in the specialised enterprises where it is immediately transformed into a scientific and linguistic object foreign to everyday life and language. [...] Captured at that point, he becomes unknown to his own people. He no longer lives in their homes or in their speech. Perhaps the exile will return from the foreign land whose language his people do not know, a land which can only be forgotten.
> (De Certeau, 1988: 191)

The patient, whose burden it is to wait in this 'foreign land', has, so it is claimed (Armstrong, 1993: *passim*), crossed from one space to another; from the healthful, communicative space of everyday, ordinary existence, to the silent space of disease and sickness, wherein the only voices heard are those of specialists. It is perhaps unhelpful to think of illness as a foreign land (although 'foreign bodies' may cause disease): rather, it should be considered as somewhere we claim (or reclaim) as native. Illness is an experience which others translate for us, by which I mean to suggest that we are not properly ill until someone, preferably a doctor, says we are (Mackenzie, 2001: 419). '[T]o have any illness is the effect of diagnostic processes and professional judgements, which are in turn the outcome of historical and social determinations' (Turner, 1996b: 179). Thus, while illness *may* be experienced directly, it is a socially mediated phenomenon. It is, in the correct use of the term, a 'medicalised' condition, that is, an aspect of everyday life that 'come[s] under medical dominion, influence and supervision' (Conrad, 1992: 210).

Health/Unhealth

In this chapter I selectively examine the literature on the clinical encounter – from the doctor-patient, to the nurse-patient relationship – the purpose of which review is to provide a general description of the arena in which questions of health and illness are formalised. Examination of clinical interaction is necessary because the ontological shift (and the attendant alienation and objectification) that begins in illness, is 'consummated in the modern medical encounter' (Leder 1984-85: 262-263).

In chapter one I stated that illness is experienced, at first, as abnormal. This is an over-simplification, for as Herzlich (1973: 53) observes, neither health nor illness are 'unitary and clearly defined entities'. Rather, there are degrees of health and illness. One can feel ill, yet be in good health, and the opposite is true also, therefore health and illness, as both experience and concept, are complex, multi-layered, and 'not simple unities' (Herzlich, 1973: 53). Herzlich (1973: 55-58) identifies three 'healths', or rather, a 'hierarchy of types of health': 'health-in-a-vacuum', the 'reserve of health', and 'equilibrium'.

First, 'health-in-a-vacuum' refers to the 'absence of illness', which is to say that health is not something positive, but rather, that it is 'simply not being ill' (Herzlich, 1973: 56). Similar to Leder's (1990) concept of bodily disappearance, 'health-in-a-vacuum' is the lack of awareness of one's body, which is 'correlated with the absence of illness' (Herzlich, 1973: 56).

Second, the 'reserve of health' is quite simply a capacity, a form of bodily capital, a sense of physical robustness and resistance to illness. 'Health-in-a-vacuum' is deemed to be something that is 'independent of the person', but the 'reserve of health' is considered to be an 'organic-biological characteristic of the individual', a congenital constitution and temperament (Herzlich, 1973: 56-57), and, as such, it is a capacity that remains with the person until death.

Third, 'equilibrium' is an idealised state of health conceived as 'an abundance of energy and bodily potential' (Herzlich, 1973: 60).

> Just by reference to equilibrium, personal aspirations and the specific and as it were indescribable quality of experience are relatively clearly communicated. Beyond merely indicating a state or symptoms, equilibrium is the key which opens the world of health, the symbol which transports us there.
> (Herzlich, 1973: 60)

'Health-in-a-vacuum' is a fact, the 'reserve of health' is a value (implied by the term 'reserve'), and 'equilibrium' is a value also; it is a state that people wish to attain – 'when the body functions like a well-oiled machine' (Herzlich, 1973: 58) – yet which is most elusive. Thus it can be said that if there is a norm of health, it is the desired norm of equilibrium that is in actuality quite unattainable, or at least unsustainable. Herzlich (1973: 59-60) admits that 'equilibrium' is the most difficult to define 'health'. It is characterised by the absence of fatigue, evenness of temper, and the felt presence of the body as a physical well-being.

Herzlich (1973: 60) cites Canguilhem when she states that 'equilibrium carries the possibility of excess and abuse', and that 'it is the possible abuse of health which lies behind the value which is accorded to health'. 'Equilibrium' is thus the actualisation of the 'reserve of health'. One must have a reserve in order to draw upon it, and the drawing upon depletes the reserve, therefore equilibrium is, for the existentially indeterminate body, unsustainable. While 'health-in-a-vacuum' is a form of being, and the 'reserve of health' is a form of having, 'equilibrium' is a form of doing, that is, a movement toward a desired state of healthfulness. It is, in short, a dream of full health, a fantasy of effortless control, and speaks of a longing to be free. As such, equilibrium is normative, rather than the norm (Canguilhem, in Herzlich, 1973: 62). It is worth noting that the 'energetic' experience of health, where health is considered an energy, is specifically modern and related to the development of industrial machinery (Asendorf, 1993; Rabinbach, 1992). Rabinbach (1992: 38) points out that fatigue, if it existed in the pre-modern era, did not emerge as a subject of medical discourse until the 1870's. In the medical literature of the period 'fatigue appears – much like idleness – as an obstacle to work, as the horizon of forces or energies within the body [...] the head is weighty, the spirit becomes lazy, memory and the will all languish' (Rabinbach, 1992: 39-40).

I should add that the experience of illness is partial because none ever experience all illnesses: to have a cold is different to having a heart disease, which, in turn, is different to cancer. However, this is not to suggest that each form of illness is unique, and that there is no underlying identity of illness experience. Rather, illness can be conceived as a patterned behaviour: in a Schützian sense, there exists a 'social recipe' by way of which illness is interpreted and at least partially comprehended. To employ a more familiar sociological – that is, Parsonian – terminology, there are socially prescribed techniques for coping with illness. But, such 'coping' is not a simple matter. The 'telic demand' of serious illness is both an 'attentional [and] existential demand', a response to bodily dys-appearance that is at once an 'affective and metaphysical wrestling with embodiment' (Leder, 1990: 92). In chapter one I stated that bodily dys-appearance is not always problematic. For example, a muscular pain that demands some attention, but which subsides either seemingly of its own accord or because of minor adjustments to posture, is an example of dys-appearance, yet it could hardly be described as an illness, let alone serious. For bodily dys-appearance to be regarded as serious it must provoke a powerful, and to some extent debilitating, affective response: it must, initially at least, be regarded as abnormal.

Significantly, Herzlich (1973: 54) notes that in reality the norm – of 'normal' everyday experience – is actually an 'intermediate state', somewhere between health and illness. The everyday experience of headaches, fatigue, hangover and such like are not exactly manifestations of illness, but neither are they representative of full health, thus it can be argued that there are only degrees of health and illness. Perhaps it is more productive to consider the sick *not* in the Parsonian sense, as an ideal type, abstracted in terms of their (dys)functionality within a larger social system: better to think of illness in terms of an 'impaired role' (Gordon, 1966, cited in Gerhardt, 1987: 112-113). This notion of impairment suggests that everyday experience is informed by a certain tolerance of difference, or as Zola (1991: 8) puts it, 'differentness'. Furthermore, a distinction may be drawn between being ill and having an illness (Turner, 1995b: 247): it is the 'having' that is more problematic in that illness appears as something that is external to a sense of self and, as such, a burden. However, the distinction, between being and having may not be easy to discern for the person caught up in the initially mysterious and sometimes frightening sensations attendant to heart disease:

> "When I found out it was my heart it was a shock...and a relief in a way, I suppose. At least they knew what was wrong with me. As I said, the symptoms got much worse, with the [dizzy] turns, and being confused a lot of the time. I had to sleep with lots of pillows, but I didn't get much sleep really, except dozing off during the day. They [cardiologists] knew it was my heart, but they didn't seem to know what they wanted to do. At first they gave me tablets to slow my heart down...digitalis, but that made me feel worse, and I read about it and it's really dangerous, so my G.P. took me off it. I was taking

> water pills [diuretics] too...I lost so much weight on them, but I think they helped. Then when I got the letter to see the consultant, and he suggested surgery, a new valve...well, to be honest, that terrified me, but by that time I was so ill I thought it'd be for the best. But I think they still weren't sure about it, about what to do. They mentioned an artificial valve at first, then a pig's valve, and then they talked about keeping me going on pills. I asked the consultant if I should go for a second opinion. I thought of going private. You know, we could just about afford a private consultation, but not surgery or anything like that. But the consultant said he didn't think that was necessary, and he said he thought surgery was probably the best way for me, and because of my condition I probably wouldn't have to wait too long."
> (Kate, 75)

Regarding the 'normality' of health and the 'differentness' of illness, most of my informants are over sixty years old, and as such, expressed a certain resignation when discussing the everyday experience of the bodily sensations of, for example, fatigue and pain:

> "You get used to aches and pains, and feeling tired. Although some days you feel something new – a new pain, a dizzy turn, something you don't remember having before – and you just think, 'what next?' but you get used to that too, really."
> (Eleanor, 67)

Yet, the same informants would go on to say, for example:

> "...but I generally felt quite good...no real problems other than the angina."
> (Margaret, 65)

Aside from the differences in experience of heart disease, which for some is quite debilitating, the tolerance or acceptance of the feeling of 'differentness' *in illness* is an 'acceptance of an inevitable part of oneself' (Zola, 1991: 8). This resignation to illness suggests that, for some at least, *being* ill is not necessarily as problematic as *having* an illness. Health, or the lack of it, is experienced anew each day; it is renewed daily. This act of renewal is rather unimaginatively expressed in the cliché, 'one day at a time,' a phrase which was employed *many* times during interviews, describing the attitude of informants to their daily struggle for 'normal' (un)healthiness. So, daily experience, particularly for the elderly, involves the acceptance of a degree of discomfort, their current position marked on a continuum of health. In short, people 'get by' on a daily basis according to their needs, thus to function normally is not necessarily to be in perfect health; rather, it is to be *able* to do what one wants and needs to do:

> "I had to watch what I did. I couldn't do that much housework, and I didn't go out much…just short walks. The doctor told me I'd be better after the operation, so I just had to wait, and be careful. […] It annoyed me, yes, especially letting the housework go, but if I forgot and ended up doing too much I'd feel terrible or I'd just have to stop because I didn't have the energy. I'd get out of breath and dizzy, and I'd have to go for a lie-down. I slept quite a lot during the day, but not much at night, though. It turned my life upside-down, but I got by. It's amazing how you always do."
> (Anne, 65)

In the previous chapter I cited Jan Kott's (1992) essay, in which he expressed 'feeling different inside' (1992: 101). Unless the 'fateful moment' that heralds the visible surfacing of heart disease is also a potentially fatal moment – for example, a heart attack – it is more often an awareness of 'feeling different' that drives people to visit their doctor:

> "It was the fact that I couldn't climb the stairs without coughing and stopping every few steps."
> (Marie, 64)

> "Oh, it was the pain. I'd be walking and I'd get this terrible tightness, like a strap tied round my chest, and then it would spread to my arms and up my neck. I'd feel it in my teeth. It was really powerful and it got worse, so that's what made me go to the doctor."
> (Dave, 63)

The Clinical Encounter: Taking Your Illness for a Walk, from Confession to Consultation

> The clinical encounter is a curious event. Through it our body and our life, that which is most intimate and private, is given to a stranger. It involves an offering that we would more usually reserve for a lover, a mother, or a friend. And through this encounter, a corporeal itinerary that is specific to us becomes generalised, subsumed under a medical discourse known better for its promotion of a universal objective body than for its sensitivity to different ways of being.
> (Diprose, 2002: 107)

The clinical encounter is described variously as 'highly volatile and ambivalent' (Komesaroff, 2001), 'disinterested' and 'objectively judgmental' (Gothill and Armstrong, 1999; Rudebeck, 2001), and, 'a one-sided matter' (Diprose, 2002). In general, the sociological literature tends to be critical of the doctor-patient relationship, more often stressing the silencing and objectification of the patient (Connolly, 2001) at the hands of a disinterested clinician who is but a mere representative of a humane yet dehumanising science.

But why does the clinical encounter further alienate and objectify the patient? Just as Herzlich (1973) claims that illness is not a unitary experience, so Mol and Berg (1998: 3) note that 'medicine is not a coherent whole...not a unity...rather an amalgam of thoughts, a mixture of habits, an assemblage of techniques...a heterogeneous coalition of ways of handling bodies, studying pictures, making numbers, conducting conversations'. Yet medicine remains a powerful, determining force: 'people's bodies and lives are shaped by the activities of doctors, nurses, technicians, and technologies, [all of which are constituents of] the work involved in making textbooks come true' (Mol and Berg: 1998: 3):

> The clinical method practiced by physicians is always the *practical expression* of a theory of medicine – a theory which embraces such concepts as the nature of health and disease, the relation of mind and body, the meaning of diagnosis, the role of the physician, and the conduct of the patient-physician relationship. [my emphasis].
> (McWhinney, 2001: 331)

Synott (1993: 28) provides a clue to the question of objectification when he notes that medicine turned from an art into a science in the eighteenth century. Medicine, at this point, became more certain of itself and of its relationship to its subject. Amundsen and Ferngren (1983) provide an outline of the gradual formalisation of clinical relationships, although they identify the Middle Ages as the point at which medical practice was accorded the status of a regulated profession. However, this transformation that Synott (1993) refers to has been discussed by, among others, Foucault (1980a; 2003), Jewson (1976), McWhinney (2001), and Porter (1985, 1997). McWhinney (2001: 331) observes that '[i]n recent times, medicine has not paid much attention to philosophy', largely because it has been so successful that there is no need to question the assumptions of medical knowledge. Philosophy in medicine has in fact been taken up again, this time in nursing theory, although, as I will argue later in this chapter, largely uncritically. Western medicine of course has its roots in philosophy; roots that can be traced back to the fifth century B.C., to the Cnoan (natural) and Cnidian (academic) schools, but for the purposes of this study I provide a brief outline of the development of modern clinical medicine, which has its foundations in eighteenth century Europe.

Jewson (1976) describes the trajectory of medical practice in European society – from a person-orientated to an object-orientated discipline – in terms of transformations in the modes of production of medical knowledge. Three distinct modes of production are identified: first, 'Bedside Medicine'; second, 'Hospital Medicine', and third, 'Laboratory Medicine', each mode 'associated with a characteristic...cosmology' (Jewson, 1976: 227), that is, 'ways of seeing [and] of not seeing [...] ways of knowing (and ignoring)' (Jewson, 1973: 226). At each stage in the construction of medical knowledge, the person, or more accurately, the embodied person, is further removed as the subject of medicine, until eventually he or she disappears altogether.

'Bedside Medicine' was a holistic and individualising approach in which sickness was conceptualised as 'a total psycho-somatic disturbance' (Jewson, 1976: 228). The patient, who was also, significantly, a patron, and therefore the social equal (or superior) of the attending physician, described his or her subjective feelings and was thus able to 'dictate and define the nature of illness' (Armstrong, 1999: 19). The patient was thus effectively 'read' by the doctor in a hermeneutic context that attended to the 'external and subjective manifestations' (Jewson, 1976: 228) of sickness. This view of the sick patient, as a whole person, 'transcends the distinctions of psyche and soma' (Jewson, 1996: 227) that are characteristic of medicine today, yet at that time medicine was an unruly art, its 'disciplinary boundaries weak and amorphous' (Jewson, 1976: 227). The problem was that 'Bedside Medicine' treated the patient as an individual, with his or her 'own unique pattern of bodily events' (Jewson, 1976: 229), and thus illness was regarded as particular to each person. Consequently, each physician held to and sometimes ruthlessly promoted his own set of beliefs to the 'affluent sick' (Jewson, 1976: 234). Physical, emotional and spiritual aspects were taken into consideration because they were 'deemed relevant to the understanding of the functions of the constitution' (Jewson, 1976: 229). Diagnosis was therefore a highly interpretive, speculative matter, and treatment was 'heroic and extensive' (Jewson, 1976: 228).

Certainly it is easy to understand why, given the system of patronage, medical treatment was extensive (we only have to substitute the word 'expensive'); and the heroic nature of the 'cure' would surely speak of the distinctiveness of both physician and patient. In such a competitive climate, physicians vied for epistemological distinction, thus theories of sickness and cures became ever more diverse. More sympathetically, Porter (1985: 193) states that this form of practice went beyond drug interventions, and involved 'complex rituals of comfort and condolence, the consolations of philosophy and grit, acted out by the suffering, with the physician sometimes sharing in the psycho-dynamics of the bedside encounter'.

> In the absence of decisive anatomical or physiological expertise, and without a powerful arsenal of cures and surgical skills, the ability to diagnose and make prognoses was highly valued, and an intimate physician-patient relationship was fostered.
> (Porter, 1997: 9-10)

While Jewson's (1976) account lacks historical detail – for example, in the seventeenth century, Thomas Sydenham (1624-1689), although necessarily a practitioner of 'Bedside Medicine', was the first modern physician to use systematic, non-speculative observation (Cunningham, 1989; McWhinney, 2001) – it nevertheless provides a convincing social history of the separation of psyche and soma and the eventual objectification of the body in medical cosmology. The next step toward this objectification was taken at the beginning of the nineteenth century, in the new teaching hospitals of Paris.

The bodies of the poor, accumulating in the growing cities of a soon to be industrialised Europe, witnessed at first hand the emergence of 'Hospital

Medicine', and were, under the 'clinical gaze' (Jewson, 1976: 229), subject to its classificatory systems. 'Hospital Medicine' was informed by its precursor because, despite serious discrepancies in theories of disease, nosologies were constructed to account for the subjective and external manifestations of sickness, and thus general principles (in the form of a symptomatology) were established. As a mode of production, 'Hospital Medicine' is, arguably, linked to the maintenance of social order in that the poor – 'the accumulation of men' (Foucault, 1980a: 171) – represented the problem of the containment of disease. As such, the superficial appearance of disease was of less import than its internal, underlying causes. The verbal analyses and interpretations that were typical of 'person-orientated' medicine were superseded by physical examination, and observation and classification of organic structures (Jewson, 1976: 229), and by autopsy and statistical analysis (Armstrong, 1999: 18). Importantly, as the patients were of a lower economic status, the social relationship was reversed so that the physician held dominion over the patient, 'a configuration which has remained in place for the last two centuries' (Armstrong, 1999: 19). Thus, medicine took on the status of a science and a profession was born. Listening gave way to seeing as the dominant form of investigation, and as medical science gazed ever deeper into the interior of the sick person, searching for underlying pathologies of illness, the next mode of production, 'Laboratory Medicine', appeared.

The development of imaging devices (Foucault, 1991; Stafford, 1997) doubtless contributed to the success of 'Laboratory Medicine', which sought to 'discover' the 'fundamental particles' (Jewson, 1976: 231) of life. Once the basic units of life were 'discovered' the sick person was 'lost in a network of anatomical structures [and] particles of organic matter' (Jewson, 1976: 238). In a sense, the physician disappears at this point also, for 'Laboratory Medicine' reveals disease entities in a transparent manner: they speak for themselves, and as such require little or no further interpretation. This particular view of disease – the view through the microscope – obscures the human presence, which is dissolved in a process of reduction, so that 'illness is increasingly removed, first by dualism, and then specialization, from the individuals who are ill, and from the physical, psychological, and social environmental contexts in which they became ill' (Synott, 1993: 39):

> Knowledge that matters is impersonal, public, productive, and empirically verifiable. Knowledge that is personal, experiential, or tacit is much less trusted and valued.
> (McWhinney, 2001: 338)

Proper scientific knowledge is, then, that which is apparently decontextualised. Jewson's (1976) essay marks an important contribution to the study of medical practice in that it illustrates the significance of the relationship between the doctor and his or her object of study – from the intimacy of 'Bedside Medicine' to the remoteness of 'Laboratory Medicine' – and that this relationship, however constituted, is instrumental in establishing the form(s) of medical knowledge. In short, Jewson (1976) 'undermines the assumption that medical knowledge was *discovered*' [emphasis in original] (Armstrong, 1999: 19). Aronowitz (1998) supports the argument that medical knowledge is the outcome of a negotiation between different perspectives, and that it is not, as such, 'discovered'. Indeed, the notion of 'discovery' implies that the 'truth' of the body (or of nature) rests within it (Armstrong, 1999; Geyer-Kordesch, 1989).

Medical technologies that 'visualise and measure' symptoms – for example, coronary artery lesions – effectively objectify the condition so that, for example, 'chest pain is more important for the pathological process it might signify than for how it is experienced by the patient' (Aronowitz, 1998: 106). Consequently, the objective visibility (and quantifiability) of disease, 'defined as an everyday reality [makes it] more difficult for physicians to empathise with their patients' pain' (Aronowitz, 1998: 106). To suffer chest pain, to be told by a general practitioner that it is probably angina, and then to be informed that, although tests reveal coronary heart disease, angina, as defined at this particular moment, is not present, undermines the patient's ability to comprehend and articulate his or her experience:

> Modern classificatory practices thus run the risk of constructing diseases that may have little or no clinical significance yet carry costs to individuals and society, such as iatrogenic harm, worry, [and] stigma.
> (Aronowitz, 1998: 107)

Tellingly, if pain is present yet angina is not diagnosed, the source of the pain is often attributed to confusion of the cerebral cortex (Aronowitz, 1998: 107). Thus laboratory medicine finds a way to explain experience while at the same time redefining it, according to the prevailing cosmology, as an objective fact. Certainly, disease is subject to clinical redefinition, but this medicalisation does not occur in a vacuum. The apparent objectivity of medical science is itself an aspect of social and cultural transformations in which its meaningfulness is rooted. That is to say, medicine is delimited by what can and cannot be said at any given time, which is to underline the obvious point that medicine is a socially constructed practice.

In spite of the understanding that symptoms are representations of bodily experience they are nevertheless privileged to the extent that experience itself is given little attention (Rudebeck, 2001). On the one hand the physician's apprehension of the patient's experience of illness is primarily restricted to symptom categorization, and as such, interpretation is, historically conditioned, possibly 'shallow' (Rudebeck, 2001: 297). On the other hand the patient may *feel* that the physician does not fully comprehend the whole experience of illness, and therefore, unable to describe the experience, withdraw from the interaction:

> "I felt awkward about it. I didn't know what was wrong - that's why I was at the doctor's – but I wasn't getting through to him. He kept asking me about smoking. I stopped smoking years ago, but he kept going on about it and I became quite annoyed with him...his attitude. All he did was listen to my chest and then he said it was probably just a virus or something. [...] He was quite different the next time I saw him...he referred me to a cardiologist right away. [...] I don't know *what* was different. Perhaps he realised that he'd missed something the first time round, or maybe I was more...determined to get my case across...or just more ill.
> (Andrew, 66)

Medical science demands a high degree of objectivity on the part of the physician. Effectively, the physician must enter the private sphere of the patient in order to determine what is wrong, yet at the same time must maintain a position of 'affective neutrality' (Parsons, 1952: *passim*), 'which is the necessary corollary of the fact that medical practice is applied science' (Gerhardt, 1987: 117), or more specifically, 'applied biology' (Seldin, in Pellegrino, 1983: 154). Affective neutrality is the very mark of scientific objectivity, yet despite the disappearance of the sick *person* from medical discourse, the patient is nevertheless present *in practice*:

> "It's as if you're not important at all. Like you don't really need to be there. I went for these tests. They lasted nearly the full day. The last test was when they attached these things to my head, like the pads they use in ECG's [electrocardiographs]. They didn't even tell me what it was for. I had to ask. It turned out they were testing for brain damage, you know, a stroke. The doctor, a young lady, a junior doctor I think, didn't even talk to me. It was her assistant who told me what was going on, eventually. It was like *I had brain damage* and they were just ignoring me. You'd think if they were testing for a stroke they'd have asked me a few questions first."
> (Frank, 68)

It is apparent that medical science objectifies illness, treating the disease and not the patient. Indeed, it is argued that the physician abstracts and focuses upon the nomothetic condition – the disease – and, as such, ignores the actual experiencing subject: in short, the physician focuses upon the indications of disease rather than the phenomenon of illness (McWhinney, 2001: 340; Zola, 1991: 9):

> "I didn't like it, but you've got to give them their due. They run you through the tests one after the other, and they try to tell you what's wrong, but it's a bit half-hearted. The cardiologist showed me this slip of paper, my ECG, and he points out this line at the bottom. He said it wasn't right, it was spiky in all the wrong places. It meant nothing to me, but I just nodded and he kept talking. To tell you the truth, I didn't have a clue what he was going on about. He was talking about my heart, but it was just a piece of paper. I felt he was talking down to me a wee bit, but maybe he was just trying to impress me. He was quite a young bloke, nice enough, I suppose."
> (Dave, 63)

As the above interview extract suggests, patients allow themselves, or at least their illness, to be objectified, to be understood as something that exists independently of themselves. In the highly technologised space of the modern clinic it is difficult to retain a sense of one's humanity:

> "You go from one machine to another. You wait for ages, then you're called into a room and they wire you up to a machine, and then you sit outside and wait again until the doctor calls you to give you the test result. Then you get to go home, if you're lucky, or you're sent for more tests. It's just one machine after another, and they don't usually tell you what they are. And after the operation I was surrounded by machines. Tubes and wires sticking out of me. Even the painkillers were from a machine. It's like the nurses and all the rest are just there to look after the machines."
> (Margaret, 65)

Radley (1996: 128-132) claims that, after heart surgery, patients become emotionally attached to the hospital, stating that the mystique which surrounds hospital equipment becomes attached to the staff. I did not find this to be true of my informants, but it could be said that, because the hospital invests so much in the care of the patient, a little part of it remains in the patient's heart. Radley's (1996) statement is not surprising, however, particularly if we consider Parsons' account of the relationship between doctor and patient:

> [T]he element of dependency, through 'transference', is a basis of a strong attachment to therapeutic personnel, which can then be used as a basis of leverage to motivate the therapeutic 'work' which eventually should result in overcoming the dependency itself.
> (Parsons, in Gerhardt, 1987: 126)

And if we ever thought that medicine was other than paternalistic, and does not infantilise us, then consider the following.

> Ideally speaking, the patient gradually gives up his deviant orientation and comes to embrace maturity in its stead.
> (Parsons, in Gerhardt, 1987: 126)

The clinical encounter is the site where narratives begin to take a distinctive shape, that is, in the conflict between the language of science and the language of everyday experience; which is to say that the originating narrative of the sick person is subsumed under the more specific form of the medical narrative:

> "I definitely felt the doctors ignored me most of the time. They don't really listen. It's as if you're on a conveyor belt and they just go through the motions with you. It was like that with my own doctor, and it was worse in hospital. I never really felt they were listening."
> (Helen, 72)

As Komesaroff (2001: 317) points out, medicine has, for the past two hundred years, considered a 'singular discursive system', built upon an epistemology that serves to unify the disparate elements that constitute the body. Medicine, as 'applied biology', makes the body into a differentiated object. The facticity of the body, in this limited view of science as a unitary entity, provides the foundation for the truth that medicine speaks:

> [R]emembrance [is] guided by a language wherein the categories of medicine play a greater role than it presumes or recognizes. In order to speak the body better than medicine does, it is necessary to find a language that is both intelligible and suited to the purpose; everyday language is willing to offer its services - yet it is entirely wrought with medical reminiscences, wherein lies the difficulty of abandoning medical language in order to, in this case, speak against medicine.
> (Starobinski, 1983: 279)

Lay experience provides the grounds for a form of resistance to medical discourse (Radley, 1996), although our language is already deeply coloured by that of medicine. Indeed, Gioia (2000: 209) asserts that the very language we employ to talk about our bodies is impoverished by reference to 'mostly clinical terms'. This is perhaps overstating matters for, as Komesaroff (2001: 318) observes, the language employed in the clinical encounter is 'stratified and heteroglot...[incorporating] a diversity of speech types and voices...[from] specific jargon to colloquial language'. Komesaroff (2001), however, justifiably refuses to reduce the clinical encounter to the collision of two grammars, the scientific and the everyday, in which the latter is subsumed under the former; rather, he suggests that the encounter is the site of a dialectical manufacture of narrative. Importantly, the patient is as multi-faceted as the types of speech used in this encounter (Komesaroff, 2001: 321).

> Illness involves a process of dissecting and reintegrating meanings of bodily experience. An important moment of the dynamic of the clinic is this process of revision and critique.
> (Komesaroff, 2001: 321)

This point 'fleshes out' Leder's (1990) – that the telic demand of illness calls for interpretation and repair – by stressing that interpretation is an intersubjective, *intercorporeal* process. Komesaroff (2001: 322) suggests that dialogue, between doctor and patient, is part of the constituting process of selfhood, 'through the operation of a dense and conflicting network of discourses and signifying practices that are bound up with the intricate phenomenology of the self-other relation'.

Illness compels the patient to seek out a human response to the distress that it engenders, but Komesaroff (2001) seems to invest the doctor with a basic humanity that borders on the naïve. Patient and doctor are re-humanised in their face-to-face encounter (Komesaroff, 2001: 322), and the doctor responds not with empathy, but with the basic human quality of 'caring'. This is just too simple, for aside from the assumption that caring is a basic human quality, it does not take into account the larger structure of medical science, which demands objectivity and an affective neutrality that essentially negates the doctor's own sense of humanity. Additionally, this position does not account for the economic constraints that determine medical practice: it may be difficult to 'constitute one's selfhood' within the eight minutes of a standard consultation, although Stewart et al., (in McWhinney, 2001: 346), report that 'nine minutes is the critical duration for patient-centred consultations'. The matter of that extra minute notwithstanding, Komesaroff (2001) implicitly constructs an emergent model of practice that has become increasingly familiar; that of the patient-centred approach to clinical interaction.

While the general practitioner is expected (or trained) to engage intersubjectively with the patient, and must therefore by definition be a subject him or herself, or at least have a firm purchase on subjectivity, he or she is somewhat constrained by the over-arching authority of medicine (Gothill and Armstrong, 1999). The individual practitioner's view is considered to be 'indistinguishable from that of the collective 'body' of [his or her] professional peers' (Gothill and Armstrong, 1999: 10). Despite assertions that the new, patient-centred medicine represents a 'paradigmatic departure' from the biomedical model, this emergent form 'shares[s] the basic medical premise that there [is] an objective reality called *the patient*, which should be examined objectively in order to devise and apply rational methods of treatment' [my emphasis] (Gothill and Armstrong, 1999: 6). The principal difference in patient-centred medicine is that the language of anatomy and physiology has been replaced by that of biography and psychology (Gothill and Armstrong, 1999: 6).

The importation of psychoanalysis into general practice 'permit[s] doctors to make interpretations which define a psychological reality lying beneath the patient's presentation of their problems' (Gothill and Armstrong, 1999: 3). It is argued that the patient was previously, to some extent, able to 'control the penetration of the clinical gaze' by detaching him/herself from his/her body during examination (Gothill and Armstrong, 1999: 3). But, in an examination that includes psychological evaluation this is much more difficult, as all behaviour is deemed 'legitimate material suitable for decoding by the doctor' (Gothill and Armstrong, 1999: 3).

As a newly psychologised entity, the patient requires a new type of doctor, a sensitive, 'perceptive, personal doctor' with carefully constructed social skills (Gothill and Armstrong, 1999: 7). The doctor's self therein becomes an instrument of communication and elicitation: a therapeutic tool. 'The message carried by the new methods of training in consultation skills was not so much 'know thyself' as 'invent thyself'' (Gothill and Armstrong, 1999: 8). The doctor is thus constructed as a subject who mirrors the patient's own subjecthood, eliciting information in a manner which is similar to that of 'Bedside Medicine', now relocated to the setting of the doctor's surgery. That doctors are themselves monitored (by, for example, Balint groups, established to psychoanalyse and review doctor-patient interactions), indicates the enduring presence of a larger body of medicine that enjoys an anonymous, epistemic privilege over its subject, which is now expanded to include the general practitioner.

The patient-centred model represents a further refinement of techniques of surveillance and interrogation that 'produce' the subject as an objectified patient. Medicine has found a way to introduce the 'sensitivity of subjectivity into the clinical gaze without sacrificing the power associated with its reputed objectivity' (Gothill and Armstrong, 1999: 3). It has effectively produced an intimate space in the form of the doctor-patient relationship, yet has rendered this space subject to surveillance.

In support, I cite Zola (1991: 3), who argues that the process of medicalisation – that is, the means by which the person becomes a patient, and in so doing, becomes an object of medical inquiry – contains within it the potential to invalidate the individual as a person, or otherwise, the potential to render the sick person *invalid*:

> Medicalisation consists of defining a problem in medical terms, using medical language to describe a problem, adopting a medical framework to understand a problem, or using a medical intervention to "treat" it.
> (Conrad, 1992: 211)

The Informed Patient

> [T]here is no reason why the history of the sick should prove any more intractable than the history of the labouring classes, of women, criminals, the illiterate...or any other sort of history 'from below'. In fact, it should be easier. [...] Pain has been evenhanded enough to visit the rich, educated, and visible...and so the annals of sufferers are neither short nor simple.
> (Porter, 1985: 183)

The informed patient, a close relative of the 'reflexive consumer' of Giddens (1991), has emerged as a significant figure in sociological literature (Atkinson, 1981; Davin, 2003; Frank, 1999; Fullagar, 2002; Henwood et al., 2003), and is ideal typical of current rhetoric concerning patients' charters, doctor-patient partnerships, and holistic care. Henwood et al. (2003: 596 *et passim*), in their discussion of 'information landscapes' (the various settings in which medical information is found), challenge the notion of the patient as a reflexive, literate, information-seeker by arguing that patients may not wish to take the responsibility to seek out health-related information for themselves, that they may lack the literacy skills to identify, retrieve, and interpret relevant information, and that, even if they are able to comprehend health information and apply it to themselves, they may not be capable of communicating such interpretations to their doctors. In addition, the ability of the 'informed patient' to assert himself or herself successfully is dependent upon the willingness or capacity of the general practitioner to accommodate or *enable* the patient as a *self-disclosing* phenomenon. In this respect, Henwood et al. (2003), argue against the anti-paternalistic model espoused by, for example, Eysenbach (2000) and Ferguson (1997), which describes the patient as a newly empowered reflexive consumer:

> What is clear is that the informed patient will not emerge naturally or easily within existing structures and relationships [particularly] where 'lay'

> knowledge does not coincide with expert/medical knowledge and where a certain level of compliance with medical opinion is required.
> (Henwood et al, 2003: 605)

Both positions in the clinical encounter are in fact social roles and thus, just as the patient may be reluctant to challenge the superior knowledge and authority of the general practitioner, so too the doctor may be unwilling to take on the role of equal partner in a relationship of care (Henwood et al., 2003: 602-604). In such a structurally asymmetric relationship it is arguably easier for the patient to remain passive in relation to the doctor's authoritative objectivity:

> "I like to think I'm quite assertive, but you've got to be careful with doctors. They don't like it if you're too smart, and yet there's all this information now – not like when I was young – about how to look out for your health, what to eat, what not to do, etcetera. But when I go to my doctor I think that sometimes it's best just to sit quiet and make my own mind up later."
> (Elizabeth, 68)

> "You tend to believe what doctors tell you. But now there's so much...so many people telling you about health. When I was a girl we had a big medical encyclopaedia at home, but nobody ever really read it. We were scared to. Now it's different. You can find out anything about anything now. My grandson looks things up on the computer for me...the Internet. Right enough, I forget most of it by the time I go to the doctor."
> (Helen, 72)

With such diversity of 'information landscapes' (Henwood et al., 2003: 596 *et passim*) – the Internet, television, public health announcements, information packs – it is difficult to imagine a consumer who is not now reasonably well informed about health matters:

> "I used to like all the documentaries, and I watched *Casualty*, then *Holby City*, but mostly *ER*. And I'm old enough to remember *Doctor Kildare* and *Emergency Ward 10*. I like *ER* especially though. I know it's a bit... overdone, but some of it seems quite realistic. It's just a bit exaggerated. You can make a connection with some of the characters, and the things that happen seem real enough, most of the time. But I don't watch them now, not at all. I can't stand to see them now. Especially anything to do with the heart. It's just too...upsetting. Like those scenes when someone's heart stops and the doctor shocks them...I can't stand that now...it happened to me, so they [nurses] told me. They said I was out for a little while and they had to...shock me. Yes, I suppose they seem *too real* now. I'm probably just a bit sensitive just now, but I'll maybe watch them again in the future."
> (Richard, 69)

Davin (2003) points out that viewers attribute informative properties to television dramas such as *ER*, that such dramas have educational and familiarising qualities which help to raise awareness of health risks by providing information on 'physiology, symptoms, diseases, treatments [and] the practice of medicine' (Davin, 2003: 664), and, that they 'help to prepare viewers for the experience of...going into hospital' (Buckingham, in Davin, 2003: 665). Thus, fiction, more compelling than 'fact', has a 'pedagogic potential' (Davin, 2003: 665). As Birke (1999: 114) notes, 'such stories remind us how used we have become to the drama of heart failure'. Rather surprisingly perhaps, Davin (2003: 668-669) suggests that while viewers expect more in the way of 'facts' from documentaries, in reality they believe that they are more likely to glean useful information from dramas, holding the view that drama is better researched and less subject to bias. For example, some of Davin's (2003: 669) informants believed that the pharmaceutical industry is implicated in the discourses of medicine, so that when medicine speaks, on television, it does not especially do so with its own voice. Thus viewers' expectations, based on the form in which information is presented, may affect the perception of content (Davin, 2003: 669). Dramas such as *ER* foster emotional identification between viewers and (the plight of) characters, thus it is argued that:

> [C]ontrary to the long-held belief that new knowledge directly leads to behaviour modification (i.e. once informed that their conduct may be dangerous, rational listeners [*sic*] will stop/alter it), responses to health messages may have more to do with emotions than cognition.
> (Davin, 2003: 671)

This suggests that 'reasonably well informed consumers' are not necessarily *rationally* responsive to their situation, or perhaps it is that fiction (in this instance, in the form of television drama) provides a richer and more persuasive description of the experience of hospitalisation than do other informative media. As Lupton (in Henwood et al., 2003: 592) observes, the concept of rational reflexivity underestimates the complexity of emotions that characterise the experience of illness and the clinical encounter. Quite simply, a rational response may not be possible. Emotional engagement with fictional lives, with the intertwining and continuous narratives of a variety of characters, seems, in Davin's (2003) argument, to be perceived as more real than, for example, documentaries, and more informative than public health announcements. Interesting as her argument is, Davin (2003) does not discuss whether patients' actual experience of illness and hospitalisation corresponds with dramatic representations. If fiction is more credible than fact, then perhaps this explains why my informants are now reluctant to watch hospital dramas:

> "I watched an episode just a week before I was due to have the operation, and that was it, never again. There was this character in for heart surgery, and everything that could go wrong did. It really gave me the willies. I had to stop watching there and then. I felt like asking the surgeon about it, about the

> programme, but I knew he'd just say it wasn't like that in real life. But you see much more on telly than you do when you're in that situation yourself."
> (Robert, 59)

Information about health also comes in other forms:

> "I read a lot of health magazines, and I take leaflets from my G.P.'s [waiting room]. I bought one of those little books that tell you about the pills, about side effects and that kind of thing. Doctors don't always tell you about side effects."
> (Jane, 62)

This notion of the patient's 'informedness' is taken up by Atkinson (1981), who addresses the social organisation of knowledge within the clinical setting in terms of the problematic nature of its (knowledge) management and distribution. Too much openness on the part of the clinician may result in, at best, the patient's withdrawal from the relationship while, at worst, it may lead to genuine distress for the patient. Doctors must remain sensitive to the effects of knowledge, particularly when the patient is in a state of 'closed awareness' (Glaser and Strauss, in Atkinson, 1981: 61); that is, when the patient is uncertain as to the doctor's perception of him or her and of the degree of knowledge that the doctor has regarding his or her medical condition. The well-informed patient may 'threaten' the doctor's display of medical competence, which may result in a 'loss of face' on the part of the doctor (Atkinson, 1981: 67-68), a point illustrated in guidelines issued to junior doctors, which state that 'especially in front of intelligent patients some obliquity of expression is to be commended' (Atkinson, 1981: 62). The clinical encounter thus oscillates between guarded transparency and complete obfuscation.

The enabling myth of the informed patient is that he or she is deemed knowledgeable and, consequently, a willing participant in the medical encounter. The patient, as a 'client', agrees to participate in therapeutic activities and exercise a degree of self-regulation.

The Therapeutic Turn

> [I]f it ever becomes possible to remove the hyphen from the term "psycho-somatic", and subsume all of "medical science" under a single conceptual scheme, it can be regarded as certain that it will not be the conceptual scheme of the biological science of the late nineteenth and early twentieth centuries. It is also certain that this conceptual scheme will prove applicable to a great deal of the range of social action in areas which extend well beyond what has conventionally been defined as the sphere of medical interests.
> (Parsons, 1952: 431)

Western medicine, in principle at least, now treats the patient more holistically than previously, in recent history (Rombalski, 2003). The therapeutic turn in medicine, and particularly in nursing, has effected the partial transformation of the medicalized *habitus* – that is, the embodied disposition – of the patient, from the more traditional, 'passive and analysable' (Armstrong, 1993: 402) patient, who is expected only to comply with the advice of physicians, to the active, corrigible patient, who is 'invited' to work with the physician or nurse in order to reach a mutually agreed, desired outcome.

Medical literature on the rehabilitation of patients with heart disease now clearly stresses the efficacy of an assisted transition from dependence to independence, so that the patient may soon return to a state of health that is 'as near as possible to normal' (Jones and West, 1995: 2). Addressing the political underpinnings of therapeutic medicine, May (1992: 599) suggests that such practice effectively redefines the patient as '*more* than the object of clinical procedure and attention' [emphasis ion original]. Armstrong (1993: 402) adds to this by stating that the therapeutic subject is constructed as self-aware and willing to participate in 'temporal spaces of possibility', by which he means, presumably, that the patient will engage in projects directed toward some form of rehabilitative self-help. Although the patient is, seemingly, a willing participant in, for example, rehabilitation, it can be argued that he or she remains over-socialised, a mere functional requirement of a social system which now demands *willingly* 'docile bodies' (Foucault, 1980; 1991).

May (1992: 599-601) argues that the subjectification of the person *as a patient* imbues him or her with a new found ability to resist the intrusions of the clinical gaze. Quite how this works is another matter, for May (1992: 600) only states that the patient, in interaction with medical staff, has the power either to lie or to say no. The strength of this argument rests upon the notion that the patient is no longer a mere object of medical science, but rather is accorded a greater degree of subjecthood, and as such, possesses a greater degree of autonomy. Yet, as this subjecthood is conferred from above, as it were, the problem of the over-socialised patient remains, for the subjectivity of the patient is only instantiated in relation to the structure of medicine, *in the moment of play*. In short, the over-socialised patient is compelled to adopt roles within this therapeutic encounter, responding 'eagerly or anxiously to the expectations of other role-players in the settings in which he finds himself' (Wrong, 1961: 190).

So the question remains: is rehabilitation, in practice, a different approach to the disciplining of bodies? If it is, we return to Parsons (1951: 616), who states that the physician always, knowingly or not, exerts a psychotherapeutic effect on his or her patients. If modern medicine is a disciplinary force, and if it functions by means of surveillance, first of populations, and then of individualised subjects, can we say, as Turner (1995b: 14) does, that *every* 'aspect of modern medicine is a contribution to surveillance'?

Nursing Theory and Practice: Sometimes a Bedpan is just a Bedpan

> 'New nursing' represents itself as a site of resistance to the medicalisation of illness, and as a form of practice whose field is the embodied person rather than the body of the patient. [...] '[O]ld' nursing accepted medicine's construction of the patient as a psychologically inert body, whose hypothetical status as a person was irrelevant to care and treatment.
> (Paley, 2000: 106-107)

Contrary to the notion that nurses deal only with bodies, that they do all the dirty work, 'new nursing' theory (Mulholland, 1997; Paley, 2000) focuses on 'nursing's rediscovery of the mind' (Paley, 2000: 103). It is argued (Paley, 2000: 106) that 'new nursing', in adopting a holistic paradigm, which 'fastens on the psycho-social dimensions of the patient's illness and claims them for its own...elides the body'. This form of nursing represents a new division of labour in which 'medicine gets the body and nursing gets the mind' (Paley, 2000: 106). Certainly, interviews with cardiac rehabilitation nurses (as part of this study), revealed that their express intention was to 'change the patient's mind' regarding his or her attitude to the care of the self, for example, by way of dietary and general health advice, and in the provision of specifically tailored exercise regimes. This advisory role marks an obvious elevation of status, and is indicative of a general trend toward professionalisation within nursing (Pendleton, 1991; Witz, 1992). 'New nursing' is in part regarded as overly ambitious and potentially invasive in that it reconstructs the patient as yet another subject of discourse, and 'far from providing a genuine alternative to the 'medical model', and the mind/body dualism with which that model is identified, the holistic paradigm merely serves to confirm and reinforce [the dualism]' (Paley, 2000: 104-105).

Nursing theory has recently taken up philosophical, phenomenological, and sociological concepts such as the 'lived body' (McDonald and McIntyre, 2001), 'lived experience' (Claessens et al., 2005; Miklaucich, 1998), 'intersubjectivity' (Pierson, 1999), 'hermeneutics' (van der Zalm and Bergum, 2000; Wiklund et al., 2002), and 'narrativization' (May and Fleming, 1997; Sakalys, 2000), as methods of addressing patients' experience, as well as more traditional, 'old nursing' issues such as 'care'. In this, many of the nurse-researchers turn to Husserl, Heidegger, Merleau-Ponty, and Polanyi, albeit in a highly selective manner (Paley, 1998).

'New nursing' adopted sociology first, bringing it into the educational curriculum in order to stress the humanization and communicative aspect of nursing care (Mulholland, 1997: 845). Willingness to include sociology in the nursing curriculum resonates with a dominant managerialism, in that 'sociology is seen as a valuable tool for nursing because in certain forms it empowers nurses to exercise particular modes of power over clients' (Mulholland, 1997: 845). The communicative model of nursing, that is to say, should not be taken as a 'discarding of power [but] rather it ought to be seen as the adoption of an alternative mode of power vis-à-vis clients and other professionals' (Mulholland, 1997: 845). This instrumental approach serves to determine just what kind of sociology is taught in nursing colleges, the criteria for which 'owe much to largely unacknowledged political and ideological assumptions' (Mulholland, 1997: 845) about what constitutes a relevant topic of study for nurses. Sociology in nursing is thus largely individualistic, micro-oriented, and uncritical of professional practice. As such, 'sociology is more likely to be used to examine 'them' (patients) than 'us' (medical professionals)' (Mulholland, 1997: 845). Misappropriated as a theory of patient control, sociology in nursing cannot take on a transformative or emancipatory role unless nursing is prepared to challenge its own taken-for-granted assumptions (Mulholland, 1997: 847).

Equally, in adopting phenomenology as a method of investigation, nurse researchers frequently mistake subjective experience for the 'essence' of phenomena, making no distinction between phenomena and the way(s) in which they are experienced (Paley, 1997: 189). While Paley (1997: 192) states that accounts of lived experience are valuable, they are not to be mistaken for universal truths.

Pierson (1999: 297) suggests that for nurses to be more effective they must not rigidly adhere to a single scientific perspective, and that they must find a way to reconcile 'instrumental skill and objective knowledge [with an] *aesthetic,* intuitive, emotional, imaginative, spiritual and experiential approach' to their interactions with patients. Emphasising the point that health is a 'practice', Pierson (1999: 301) states that the 'single scientific perspective' is overly determinative and as such impedes the development of the intersubjective process necessary to the optimisation of effective health care. However, we must ask: is this not, to some extent, what nurses already do? Similarly, Bolton (2001: 91) describes 'new nursing' as patient-centred rather than task-oriented, and states that 'nurses…work to achieve a fine balance between showing concern and care for the patient whilst also maintaining a professional demeanour'.

Mulhall (1997: 969) is critical of 'new nursing' theory because it is founded upon research or theoretical discussion that is removed from nursing 'in practice', and is in reality too obscure and unfocused to implement. It would appear that nursing theory is at the moment subject to much discussion regarding its implementation, but whatever it is, it is evident that nurses are choosing to take the more difficult option of caring about, rather than only caring for their patients. Perhaps Gothill and Armstrong's (1999) assertions that the general practitioner has been reconstructed as a subject can be applied to the 'new nurse', who is now imbued with subjectivity in his or her position in relation to the patient.

It is beyond the scope of this study to provide a detailed review or analysis of the theoretical content of 'new nursing' literature, but it is significant that, despite claims to the contrary, nursing seems to have somehow misplaced the body (Paley, 2000: 105-108). Paley (2000) should add that this is largely a theoretical loss, because nurses, in practice, can hardly escape their own embodiment or that of their patients.

Cardiac Rehabilitation: Gym'll Fix It!

The feeling of 'differentness' (Zola, 1991), to which I referred earlier, is addressed by Moons et al., (2002), who recognize that it is not only that the patient feels different about him or herself, but indeed also feels so about the surrounding environment and other people. Configuring this as a 'psycho-social-problem', Moons et al., (2002: 26-27), suggest that patients require education regarding 'behaviours', screening for psycho-social symptoms, and counselling to address any problems that may arise from such problems.
It was a common complaint among the nurses I interviewed that they did not have the tools at their disposal for the screening of psycho-social problems, and that they had to deal with patients' problems on an ad hoc basis.

In the field of cardiology, rehabilitation is one example of increased roles in nursing (Smith, 2002: 19-21), and, as a practical response to the problem of heart disease, it marks the transition to a model of care 'encompassing health promotion, disease prevention and management' (Smith, 2002: 19).

Formally, the goals of cardiac rehabilitation may be outlined thus:

Medical goals

- Prevention of sudden death
- Decrease in cardiac morbidity, infarction, and graft closure
- Relief of symptoms: angina, breathlessness
- Increase in work capacity

Psychological goals

- Restoration of self-confidence
- Relief of anxiety and depression
- Improved adaptation to stress
- Restoration of enjoyable sexual activity
- Relief of anxiety and depression in partners or carers

Social goals

- Return to work, if appropriate
- Independence in the activities of daily living in the elderly

Health service goals

- Reduction in direct medical costs
- Early discharge and early rehabilitation
- Fewer drugs
- Fewer readmissions

(Source: Cay, 1995: 35)

Less formally, the purpose of cardiac rehabilitation is quite clear:

> "We want to get them back on their feet and feeling better about themselves. We don't ram it down their throats, but it's there if they want it. We know it's too easy just to sink back into old habits. They don't always realise that their arteries could get blocked again, or that they'll need another angioplasty. It's convincing them that it works that's the main problem. We need to convince cardiologists too.
>
> (Rehabilitation nurse)

In terms of post-surgical treatment, cardiac rehabilitation has some history. From the efforts of the eighteenth century English physician, William Heberden, to the publication of William Stokes' (1854) *The Diseases of the Heart and Aorta*, the 'pedestrian cure' of mild exercise and strictly regulated gymnastics was strongly advocated. However, after Stokes' death in 1878 his regimens were forgotten, superseded by the 'bed rest' method. As recently as the 1940's and 50's, extended bed rest was deemed necessary for patients with heart conditions. During the Second World War the American Medical Association held a symposium on 'the abuse of rest in the treatment of disease' (Dock, 1944: 1083-1085). Physicians such as Levine and Lown (1952) then recommended 'armchair treatment', which required that the patient not lie in bed too long, but instead sit by the bed as soon as possible after surgery. This heralded a move [*sic*] toward early ambulation and a regime of progressive, graded activity. Without citing numerous studies on the subject, over the next five years a marked decrease in mortality rates of patients who suffered myocardial infarction (heart attack) was observed.

Heart disease is, as already stated, the main cause of death in western society, and it is now on the increase in developing countries (Cay, 1995: 35). Heart disease is therefore a costly business: loss of working hours, cost of treatment, and sickness benefits are all economic factors that must be taken into consideration by governments. Illness cannot be separated from the socio-economic conditions in which it occurs. An example of this is found in Howell (1994: 94). During the First World War, British soldiers affected by Da Costa's syndrome, also known as 'athlete's heart', or 'soldier's heart', were initially treated with extended hospital bed rest. However, economic and political exigencies – the strain on military hospitals, and the institution of a military draft to replace convalescing soldiers – led the Medical Research Council to reconceptualise 'soldier's heart' as 'effort syndrome', to prescribe a series of graded exercise rather than bed rest, and to reclassify soldiers as fit for service (Howell, 1994: 94). This example could be said to represent a paradigm shift in medical science, brought about by economic demands. In this, Foucault's (1980b: 58) question – 'what type of body does society need?' – has a particular relevance in that the larger social requirements determine the form of the socially desirable body. As such, it might be said that society, at this moment, needs healthy, productive, consuming bodies (Sawchuck, 1995). As recently as the 1960's, many cardiac patients 'led miserable unproductive lives', frightened to engage in normal activities and, as such, 'became cardiac invalids' (Cay, 1995: 31). In the early 1970's cardiac rehabilitation, initially in the form of exercise only, was developed strictly for patients who had suffered myocardial infarction. Exercise training was directed at selected groups, largely male, and consisting of those whose infarcts were deemed 'uncomplicated' (Cay, 1995: 32). It was not until the 1980's that rehabilitation was further developed to encompass other heart conditions and post-surgical patients, and to include stress management and lifestyle advice, and then only in a limited number of hospitals.

> "Money's always been the problem. That, and being taken seriously. There's a lot more money available for English hospitals, yet we've got more patients, more people in need of help. There's been studies, not like a few years ago when we didn't have a clue what the long-term benefits were, or how successful we were, but it's getting the information to the right people that matters, and then getting the funding. [We] spend a lot of money on health education, and that's fine, but that won't reduce the numbers much. We'll still have plenty coming in for bypass. The numbers don't seem to go down at all. The wards are as busy as ever, and we're moving them through the system faster and faster all the time. [...] The problem is...rehabilitation is regarded as an extra...not part of the whole treatment. We talk about 'total patient care' and 'holistic care', but it comes down to money in the end. That and the fact you can't force people to change their lives."
> (Rehabilitation nurse)

In the cardiology literature it is generally held that 'lifelong exercise protects against coronary events, independently of [other factors such as] smoking, obesity, and hypertension' (Julian, 1995: 6):

> "I'm not so worried about them smoking a bit, or drinking, as long as it's not excessive. Diet's important, but you've got to be practical about it. They can't always just change their diet. They can't always afford to. I think stress is an important factor...a lot of the literature supports that. If we can help them with stress that'll go a long way to helping. Exercise definitely reduces stress, and we show them relaxation techniques as well. I think it helps build their confidence back up...it helps them stop dwelling on morbid thoughts." (Rehabilitation nurse)

While previously it was believed that exercise had to be taken vigorously in order to be effective, it is now thought that mild exercise – 'sufficient to cause slight breathlessness' – taken three times a week, is adequate for most needs, healthy or otherwise (Harris *et al.*, in Julian, 1995: 6). Strenuous or vigorous exercise may indeed bring about a heart attack, but only in those who take no exercise at all (Julian, 1995: 6). Thus, 'progressive mobilisation', 'early ambulation', and 'graded exercise regimes' (Julian, 1995), are all terms familiar to cardiac rehabilitation staff:

> "Yes, graded exercise is what we try to do. We tailor it to meet the needs of individual patient as much as we can, and we monitor them very carefully, but for the average patient in the fifty to sixty-five [year-old] range, we try to push them a bit, if we think they're up to it. This notion of causing mild breathlessness is really relative. At the beginning of the programme we'd expect to see a lot of breathless people, but twelve weeks later, if they keep at it, they should be able to push themselves a bit harder but still be a little breathless, so it's a progressive thing. They're still out of puff but they're more capable, more flexible and fit. There are degrees of breathlessness. What we do is show them how to take their pulse, and they monitor themselves...see how quickly their pulse-rate drops back to normal. That's the test of fitness.

> [...] The problem is, there's new people coming in all the time, so you'll have someone who's been there for six weeks, say, working out beside someone who's only just started, so we really have to keep an eye on them all. Of course, some of them don't put much effort into it. They're here for the tea and biscuits...and the company."
> (Rehabilitation nurse)

Progressive mobilisation, graded exercise programmes, and stress management techniques may even reduce the need for medication (Julian, 1995: 12), thus cardiac rehabilitation has the potential to reduce the costs of long-term health care (Cay, 1995: 35-36).

Rehabilitation nurses realise that they are dealing with people who have been through an emotionally and physically devastating experience, but their principal concern is with the body of the patient:

> "We're not psychologists, but we have to deal with different problems. We can refer patients if they need it, or if they ask, but the patients who talk to us about their emotional problems – you know, intimate problems, or family matters – they'd rather talk to us than go for counselling. I mean, they're depressed enough, some of them, and it's hard getting them to come here in the first place, so we don't want to scare them away. We can't go poking about in their lives. I doubt the older ones would go to a psychologist anyway, because of the stigma. They'd rather talk to us, but we don't push them into it. At the end of the day we're here to help them get into better shape. There's patients who don't do much exercise, but they still come, so there's definitely a social aspect to it, and that helps. And there's some who are really frail, the older ones. They're basically disabled. But if we help them to think about themselves...take care of their bodies a bit better, get their confidence back...you've got to remember they were mostly out of condition for ages before the surgery. But if they look after their bodies, you know a healthy body and a healthy mind...they go together."
> (Rehabilitation nurse)

Cardiac rehabilitation is yet in its infancy. The increasingly diverse nature of the cardiac population (Horgan and McGhee, 1995: 244) demands a sophisticated response to the problems attendant to heart disease. The rehabilitation nurse is quite clearly an example of the increased specialisation and professionalisation of nursing. He, but more often she must be a counsellor, a coach, and an educator (Fridlund, 2002: 15), capable of adopting different perspectives according to the needs of individual patients; for example, if the patient is obese the nurse will design an exercise programme that is suitable and which will not discourage him or her from returning to the clinic. The nurse's response is therefore both 'medico-physical and psychosocial' (Fridlund, 2002: 15), and as such, is in keeping with the recommendations of the 1993 World Health Organization Report on Cardiac Rehabilitation.

> The rehabilitation of cardiac patients is the sum of activities required to influence favourably the underlying cause of the disease, as well as to ensure the patients the best possible physical, social and mental conditions so that they may, *by their own efforts*, preserve, or resume when lost, as normal a place as possible in the life of the community. Rehabilitation cannot be regarded as an isolated form of therapy, but must be integrated with the whole treatment, of which it forms only one facet. [my emphasis]
> (Extract from WHO Report, 1993, in Fridlund, 2002: 17)

Cardiac rehabilitation provides a means of 'empowering' both patient and nurse (Fridlund, 2002; Smith, 2002). First, rehabilitation contributes to the patient's well-being and improves quality of life. Second, nurses take on a greater advisory role in the care of patients, and in some cases, become more involved in their daily lives. Cardiac nurses also visit patients at home, to assess mobility, psychological well-being, and to address any needs arising from post-surgical disability or depression. It is important to note that cardiac rehabilitation is relatively inexpensive.

> "We believe that exercise and careful lifestyle management might save the patient from coming back for more surgery later. It's not definite. There are too many variables you just can't control to take into account. But, if we can keep them off the operating table then we've helped them and we've helped ourselves. It beats sitting around waiting for your arteries to clog up."
> (Rehabilitation nurse)

Responsibility for the maintenance of health ultimately rests with the patient. Risk management is thus passed on to the patient, but this is shared, for a while at least, with the rehabilitation nurse who, according to Smith (2002: 21), is best positioned to 'drive forward initiatives to promote improved health care'. May's (1992) position, that the patient may resist the intrusion of the therapeutic gaze is borne out by the fact that attendance at rehabilitation clinics is not compulsory. But, it would seem that cardiac rehabilitation, as yet far from being unduly intrusive, is a valuable addition to the field of coronary care.

> "I didn't want to go to rehabilitation at first. The idea of exercising in a gym didn't appeal at all. The last time was in the gym at school...that was a long time ago. I'm not one for joining clubs, but I changed my attitude after the first session. I was doing things I'd forgotten about, or thought I couldn't do any more. Really, it was like being back in school again, exercising – ten steps this way, ten steps that way – and I felt so good afterwards. Tired, but good."
> (Marie, 64)

> "No, I didn't like the idea at all. I was quite depressed, now I look back on it. But I felt obliged to go. The [rehabilitation] nurse was so nice I couldn't refuse her. It was hard work at first, but I got used to it and I really enjoyed it. I looked forward to my sessions. It really helped me to get my confidence back. It's such a simple thing too. It's just like dancing. And I made new friends there. We keep in touch now, go out for walks and visit each other. It's like our wee gang."
> (Kate, 75)

Concluding Remarks

It would appear that in developing a programme of holistic care, and the patient-centred model of clinical interaction, the body has once more disappeared, and that the Cartesian dualism which lies at the heart of modern medicine has been reasserted.

Yet it is not that simple in practice, for on the one hand medical science apparently objectifies its subject and, seemingly, constrains the self-revelation of the patient; but, on the other hand, the therapeutic turn in medicine, which effectively produces the self of the patient (and doctor), is deemed to amount to an invasion of the private sphere of subjectivity. Is the therapeutic turn representative of the further objectification of populations, or is it a genuinely more holistic treatment of the patient? Can we have it both ways? We expect doctors to be omniscient but we do not want them to know *too much* about us. As for 'new nursing', despite the turn to sociology and phenomenology in nursing theory (and practice, perhaps), nursing remains what it has been since its inception, that is, 'communicative and reflexive' (Mulholland, 1997: 847) and, an embodied activity that is directed toward the embodied patient (Fridlund, 2002: 16).

Porter (1985: 194) states that we should stop seeing the doctor as the agent of primary care, for 'people took care before they took physick'. Medicalisation theses such as Foucault's over-determine the patient, and thus neglect the contribution that the sick make to medical knowledge. We should thus be wary of rigid, mechanistic views of doctor-patient relationships. History is in eternal flux, as are the people who make it. Relationships may seem fixed, and indeed some doctors and patients may wish to step into an already established role, but if, as stated, social relationships determine the form of medical knowledge, then the dynamics of those relationships need not be eternally fixed.

Some literature (for example, Van Manen, 2001) already acknowledges the intersubjective nature of the clinical encounter, and suggests that greater attention be given to the dynamics of speaking and listening in the doctor-patient relationship. Therefore, research that focuses upon the general practitioner's experience of the patient may yield some insights into the practice of medicine. As ordinary language is suffused with that of medicine, so medical language is informed by the everyday usage of its practitioners. It is not as if doctors live in another world, detached from the everyday life of their patient.

McWhinney (2001) suggests that time is of vital importance, that for the clinical relationship to develop beyond the current patient-centred model, the doctor must learn to wait, to wait for the patient to describe experience in his or her own terms, without prompting, without pre-judgement, and most importantly, without recourse to orders of abstraction.

Third Narrative: Going to the Theatre

I am sitting up in a hospital bed, waiting to be taken to the operating theatre, waiting also for the sedative to take its effect. I know that, soon, my chest will be opened and that a surgeon will cut into my heart, remove two diseased valves, and replace them with carbon-titanium prostheses. Prior to this, my heart and lungs will be taken 'offline', their normal actions performed instead by a bypass machine. To initiate heart-lung bypass, the surgeon must first impair my body's own clotting system, otherwise my blood will immediately clot upon exposure to the plastic tubing and artificial surfaces inside the heart-lung machine. Thinning of the blood (anticoagulation) is achieved by administering a powerful anticoagulant called heparin. Once clotting is impaired, a large drainage tube will be placed in the right atrium, one of the upper chambers of the heart. This tube drains the blue (oxygen poor) blood from my right atrium into the heart-lung machine. Then a smaller tube leading from the machine will be inserted into the arterial system – most likely, into my aorta – so that red (oxygen rich) blood can be returned to my body. Thus, artificial oxygenation and circulation is established and maintained (by a technician called a perfusionist) and my heart can be stopped for anything from a few minutes to a few hours. I know that, according to the surgeon, I have a ninety-two percent chance of survival; a seemingly precise calculation – four percent per valve. I know this, and I want the sedative to take its effect so that I will not need to think about it, that other eight percent. I am surprised to see two nurses and a porter arrive with a trolley. They tell me that it is time to go. I begin to fret, feeling indignant at the same time because I am not ready. I am not yet unconscious. Like the character in Catch *22, Major Major, who is only available for appointment when he is not in his office – who can only be seen when he is not there – I cannot possibly make myself available while I am still here. I want to be 'not here'. The last time this happened I was out before I left the ward, a slight stinging in the back of my* *right hand the last thing I remember before waking after the operation. But this time I am fully awake. Nothing happens. Then I am in an elevator, a nurse at my side, holding my hand, squeezing gently while she talks with the porter, exchanging words about people I don't know. Life goes on, apparently. Meanwhile, the elevator descends slowly, noisily, deep into the heart of the building, to the surgical suite. The nurse says something to me, a question I think, but I am staring at the fluorescent ceiling of the elevator. I turn to say something but nothing happens and then the elevator doors open and we are in a tropical jungle by Henri Rousseau. Gigantic spiked plants, smiling lions, exotic birds, and, rather oddly, a desk. Other people are there too, but I cannot see them. They must be hiding. Then, nothing happens...[...]...and I hear someone say "swallow". A bird? But no, someone is telling me to swallow. I cannot see anyone. They must still be hiding. All I can see is that I am in a cathedral, where splashes of stained glass and white light melt and run into each other. Wet colour, like the feeling of wetness in my throat as I feel something move. Ah yes, I must swallow something, but as I swallow (although I have no sense of actually making any effort), I feel something come out of my mouth. Surely this is wrong. Somehow I extract a memory from the few thoughts that flutter around me, the memory that when you swallow, things don't come out of your mouth. But now I feel a tube slithering in my throat – an air hose, like a deep sea diver's (yes, I have been under) – and then it is out, and a voice says "good". I am free to return to forgetfulness. The colours of the cathedral, its enormous vaulted ceiling, the sense of people nearby, all merge, subside, are washed away, and then... nothing happens again. David Mamet (1998: 53) writes that the gambler does not play for riches, but plays instead for time, more time at the table. The patient gambles on just the right amount of time at the table.*

Chapter Three: From the Heart

For here the lover and killer are mingled
who had one body and one heart.
(Douglas, 'Vergissmeinnicht, 1943')

Special days are made of special moments that live forever
in the memory of the heart.
(Hallmark Greetings Card)

The Heart – 'that shiftless emblem' (Atwood, in Birke, 1999: 112)

From poetry to philosophy, from the sublime to the less so, it is apparent that the human heart is imbued with powerfully evocative tropological qualities. Any English language dictionary of quotations will contain multiple entries for 'heart', and of those entries few invoke a medical frame of reference (although, as an organ a biological status is generally implied). In the most recent edition of *The Penguin Dictionary of Quotations*, 'heart' occupies one-and-a-half pages of the index, whereas its figural opposite, 'head', occupies only half a page, which suggests that, as a signifier, the former has a greater symbolic potency than the latter. The head and heart couplet has endured, from Graeco-Roman Antiquity to the modern epoch, but as Le Goff (1989) notes, the 'metaphorical strengthening' of the heart (over the head, liver, and other organs and limbs) was more firmly established by mediaeval Christianity. Largely, metaphors of the heart, 'designat[ing] the affective life and interiority' (Le Goff, 1989: 16), refer to the passions: love and hate, anger and remorse, joy, longing, desire and loss.

Admittedly, many of the metaphors of the heart are very old, but despite the development of anatomical knowledge, which has thus far produced a mechanistic model of the human body, the heart yet 'signifies on many levels'

(Stevens, in Emslie *et al.*, 2001: 207). Indeed, it is in part this 'rich history of metaphoric associations' (Birke, 1999: 112) that makes the heart such a productive topic for study. The heart, as something that occupies biological and imaginative space, seems at once familiar yet strange, both reliable and treacherous. As such, the human heart is far from 'shiftless', that is, 'lacking resourcefulness; lazy; inefficient' (*OED*, 1990). Rather, the heart is a 'versatile organ' (Birke, 1999: 125) in that it supports so many metaphors.

> "It *is* a pump, isn't it? I mean people say that, they talk about the heart *pumping* blood. It's electrical as well. I didn't know that before, how your heart needs the right amount of salt to make the electrics work. That's why I was on potassium tablets. It's for the salt. They [cardiologists] told me that I had fibrillation. That's like the heart getting jittery because the electrical parts aren't working properly. A young doctor said it was like a bag of worms, that's what they call it when it's fibrillating. Apparently it's quite common when you get older. You don't even need to have something wrong with your heart to get fibrillation. I never thought of the heart as electrical, so I suppose it's an electric pump."
> (Kate, 75)

> "It's not until it goes that you realise just how hard your heart works, how important it is. That's not right, I mean I know it's important...*it's the heart*...but, although I know about...heart disease...you can't avoid knowing about it nowadays, and I've relatives and friends who've died from heart attacks, but you still take it for granted. You think that one day it'll give out, but until then, you don't tend to give much thought to it, pumping away all the time. I mean, if it was a washing machine *you'd expect it to break down*, wouldn't you?"
> (Tom, 67)

The heart may be regarded as a 'pump', whose 'work consists in the propulsion of blood through the circle of vessels in adequate quantity to meet the needs of the body' (Lewis, 1944: 1). This metaphor apparently originates in William Harvey's (1578-1657) *prelectiones* – notes to be read aloud by the author during public dissections (Wilson, 1987: 62). It should be noted, however, that although Harvey observed and conceptualised the action of the heart in mechanical, or more accurately, in hydraulic terms, in his view the heart only 'accidentally' resembled a pump (Plochmann, 1963: 209). Developing an Aristotelian methodology, Harvey drew his premises from 'one subject matter at a time…[and thus]…would not prove conclusions about hearts from premises about pumps, or conclusions about blood from premises about divine spirits' (Plochmann, 1963: 209). However, Sawday (1996: 23) argues that Harvey's, like Aristotle's, was a theory of correspondence, and as such, 'features observed within the body were held to replicate features to be seen in the world at large'. It seems unreasonable to suggest then, as Plochmann (1963) does, that Harvey's conceptualisation of the action of the heart was not at least partially informed by an already established knowledge, or at least awareness, of hydraulics. As Harvey was primarily concerned with establishing a theory of the movement of blood, it can be argued that he was actively seeking an explanatory mechanism that would account adequately for this; therefore a pump seems a likely metaphor to choose. Indeed, Pouchelle (1999: 103-104) notes that, prior to Harvey, mediaeval surgeons commonly drew upon the 'mechanical arts' – for example, architecture – to explain the inner workings of the human body in terms of 'engines', that is, 'cunning techniques' (Pouchelle, 1999: 104-106). It is important to note that while the heart is metaphorised in mechanical terms, this is not to say that the heart is, at this point in history, considered machine-like. Harvey's was a hydraulic economy and, as such, is distinct from later, industrial economies; for example, that of the nineteenth century (Asendorf, 1993; Rabinbach, 1992).

Harvey's epistemological position was already established within a specific (Christian) tradition of thought and practice, a tradition which had at its centre an 'organicist conception of society based on bodily metaphors' (Le Goff, 1989: 13). As such, the body represented the larger social system, and objects within that system were in turn taken to represent parts of the body. Further to this, Pouchelle (1999: 195-197) asks how metaphorical representations could coexist with anatomical knowledge, and why the progress of the latter did not effect the death of the former. Her answer is that to see is immediately to interpret, and that to interpret is to draw upon a stock of socially prescribed, deeply embedded images.

> Thus dissection, far from dealing the deathblow to metaphor, used it as a jumping-off point, and afterwards, for anatomical knowledge progressed via a complex and *almost incomprehensible* dialectic of visual perception and mental images deeply rooted in language. [my emphasis]
> (Pouchelle, 1999: 196)

The early anatomists, struggling to make sense of 'the chaos of the human interior, [the] mad confusion of unidentified tissues' (Pouchelle, 1999: 196), saw what they wanted or expected to see. If what the early anatomists saw when they *opened up a few corpses* (Foucault, 2003) was 'almost incomprehensible', it was not only because the interior of the body was a muddle of barely distinguishable parts, but also that their thoughts were not immediately able to organize what they saw.

The Anatomy Theatre: From Corpse to Corpus

Boyd Hill (1965) writes that, according to at least one mediaeval school of thought, the heart was perceived as the seat of vital forces – it is where the spirit resides, and is thus conceived as a house (Hill, 1965: 73). Blood flows from this house, through the conduits of the arterial system, filling the body with spirit, and thus the heart is the animating 'matter' of the body. Noting that the word 'record' derives from '*cor*', the Latin for heart, Jager (1996: 2-3) identifies the mediaeval heart as the literal site of memory, and as such is equated with interiority, or the innermost self. To speak from the heart is to speak the truth of oneself. The heart is then a book of the self. Text and heart are intertwined, and it is therefore impossible to think of the heart without recourse to a long history of association that can be traced far back in history; 'and today if we still refer to learning texts by heart, to writing down records [it is] because we speak a language inherited from the Middle Ages' (Jager, 1996: 26).

Aside from being 'resolutely bound to ancient [medical] texts' (Siraisi, 1997: 1), the study of human anatomy in the Middle Ages was subordinated to a religious (Christian) text, which prohibited experimental research. Thus, 'perception [of the body] was submitted to a textual meaning that controlled the gaze' (Gil, 1998: 220). While discussion of mediaeval conceptions of the body is beyond the scope of this thesis, it is enough to say that although anatomical investigation was constrained by religious ideology, the body was nevertheless positioned centre-stage for what was to become the spectacle of its anatomisation:

> [T]hey undertake with their own hands to probe and examine more profoundly in man and the rest of the animals those things that were handed down to them.
> (Vesalius, in Siraisi, 1997: 32)

Despite anatomical dissection's association with the illicit – 'an association resulting from the use of executed criminals as subjects [and] the low esteem in which surgeons, who touched the body, were held' (Wilson, 1987: 68) – the practice of dissection became increasingly ritualised and spectacular, often accompanied by banquets, theatrical performances and concerts. Anatomical dissection as spectacle reached its peak in the public demonstrations of Andreas Vesalius (1514-1564), who was arguably as much a showman as he was a remarkable anatomist, and one whose 'touch' animated the corpse and made of it a body of knowledge. Dispensing with the services of the usual assistants, Vesalius dissected and lectured simultaneously, cutting into, pointing at and discoursing on what he revealed of the body.

The title page to *De Humanis Corporis Fabrica* (1543) [see following page] presents the viewer with a representation of early medicinal secularisation. Indeed, it has been suggested that the publication of the *Fabrica* 'mark[ed] the beginning of modern science' (Saunders and O'Malley, 1973: 19). The illustration, a woodcut, is an outstanding example of sixteenth-century engraving, 'executed with a skill and craftsmanship of the highest order' (Saunders and O'Malley, 1973: 42).

The illustration, which could just as easily be of a theatrical scene, presents Vesalius, slightly to the left of centre-stage, in the process of revealing a womb. Interestingly, in the history of western theatre, stage-left, the sinister side, is traditionally reserved for the entry of devils and villains (Nagler, 1952). This is perhaps a minor point, but given that the artist is believed to have 'deliberately diminished Vesalius' actual stature' in order to create the effect of the anatomist being engulfed by the crowd (Wilson 1987: 71), one may wonder if his contemporaries did not hold Vesalius in similarly low esteem to that of the mediaeval anatomists.

The illustration depicts an outdoor scene, evident in the plants clinging to the arch on the left. Perhaps this refers to the public nature of the spectacle, or it may suggest that anatomical dissection, not at this point fully respectable, yet awaits entry to the academy. Vesalius, surrounded by his students and fellow physicians, and representatives of the nobility and church, is half-turned toward the viewer while his hands are engaged in demonstration. (I will return to the issue of the gaze of Vesalius momentarily, for it is a matter of some

Title page woodcut for the *Fabrica* of Vesalius, 1543.

ANDREAE VESALII
BRVXELLENSIS, SCHOLAE
medicorum Patauinæ profeſſoris, ſuorum de
Humani corporis fabrica librorum
EPITOME.

CVM CAESAREAE
Maieſt. Gallorum Regis, ac Senatus Veneti gra-
tia & priuilegio, ut in diplomatis eorundem continetur.

Title page woodcut for the *Fabrica* of Vesalius, 1543.

significance.) Unusually, he is discoursing, not, as is traditional, *ex cathedra*, but instead *from* the cadaver, thus indicating a break with authority. He has dispensed with the services of the dissector and the ostensor, relegating them to a position beneath the table where they are seen, apparently quarrelling. In the foreword to the *Fabrica*, Vesalius comments on the decline of medicine, observing that physicians lost their 'practical acquaintance' with anatomy because they left the manual work to others (Saunders and O'Malley, 1973: 42). The robed figures in the foreground represent the 'golden age' of antiquity. That they stand on the same level as Vesalius indicates the anatomist's aspirations to respectability: 'there is ground for hope that anatomy will ere long be cultivated in all of our academies as it was of old in Alexandria' (Vesalius, in Saunders and O'Malley, 1973: 42). This 'dynamic confrontation between living and dead authority' (Sawday, 1996: 66) is illustrated also by the presence of the monkey and the dog (foreground, left and right), which are symbolic of the older, Galenic tradition – Galen (129-199 AD) drew inferences about humans from his study of animal anatomy. Sawday (1996), and Wilson (1987) point out that Vesalius would probably have vivisected the animals at the end of the lesson for purposes of comparison. Wilson (1987: 71) comments that, 'still living, they are members of the audience', the monkey seemingly watching the dissection, the dog possibly looking for scraps to eat, and thus, 'both in different senses behaving like men', are superior to the men quarrelling beneath the table. The suggestion that an animal is like a human, merely because it is looking for food, is, I believe, an unsupportable reading of the illustration.

The nude figure clinging to the column on the left represents the importance of surface anatomy, while the skeleton at the centre is of course the very foundation upon which the human body is formed, and quite properly occupies a position of authority, suspended above the dissection, for Vesalius insisted that the study of anatomy must begin with the bones (Saunders and O'Malley, 1973: 42). The scene is comprised of little spectacles that constitute 'rival visual centres of anatomical information' (Wilson 1987: 71). For example, the slashed hose of the man standing on the extreme right could be taken for the muscles of the leg, as could the brocaded arm of the man three figures to his left, all of which 'give[s] the peculiar sense that [the] body is permeable to vision' (Wilson, 1987: 71). All bodies, live and dead, clothed and naked, man and animal, are 'potential subjects of dissection, and all share with the cadaver the anatomising gaze of the onlookers' (Wilson, 1987: 71).

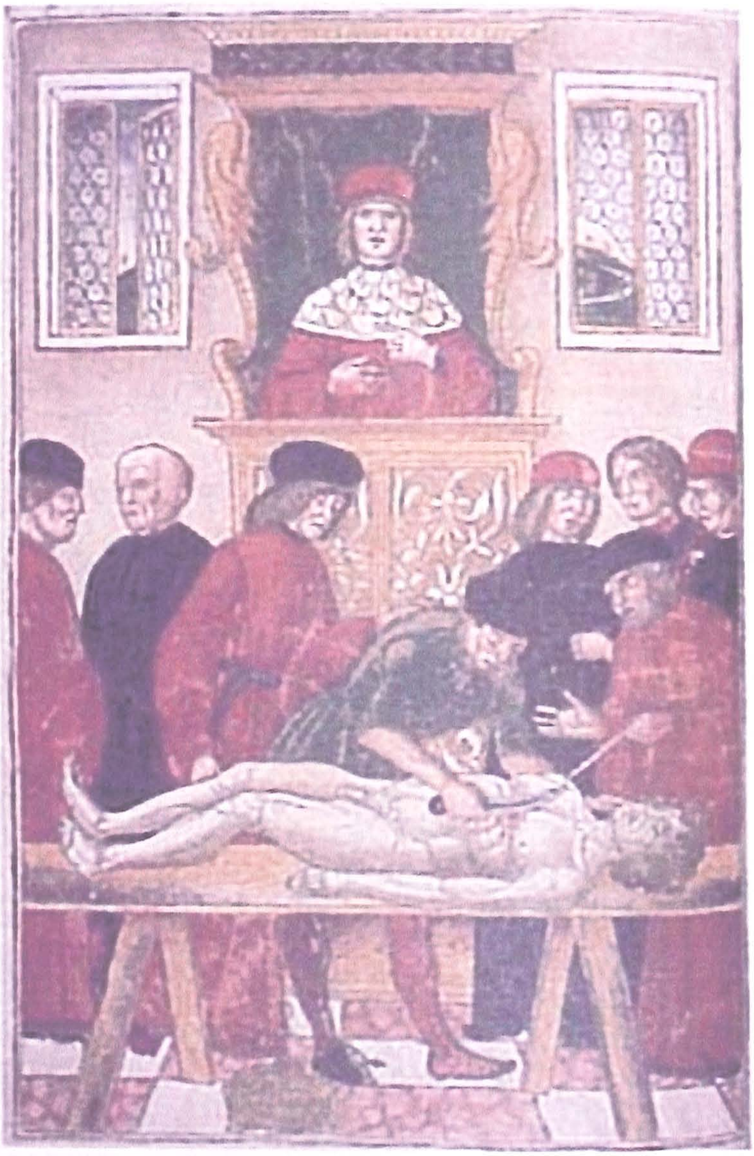
The illustration perfectly exemplifies the new Renaissance principle of aesthetics, which was that art should faithfully represent its subject matter. This principle 'required that the artist acquaint himself with the structure and physical properties of natural phenomena in order to insure objectivity and with the rules of perspective and mathematics in order to obtain representational correctness' (Saunders and O'Malley, 1973: 22). Mathematics, a system of 'anonymous signs, by rights useable and comprehensible for everyone' (Gil, 1998: 218), challenges the hermeticism of arcane knowledge, which can only be read by initiates. Additionally, as Sawday (1996: 73) notes, the structural elements of architecture are founded upon the dimensions of the human body, thus the illustration provides an example of correspondence between art and reality, or between the human-made and the natural world. Despite the apparent chaos of the scene, it is unified by the vertical axis, which draws the eye from cadaver to Vesalius, and to the skeleton, all enclosed within the precisely rendered Corinthian columns. In this aesthetic correspondence between the body and science we find the origins of 'modern' rationalism.

> The path that leads to the new scientific gaze had been traversed for a long time by the representational technique that painters discovered: perspective. In overturning mediaeval iconography, it introduced precise tools; perspective analysed space, separated bodies, de-sacralised nature. The exactitude of the plates in the *Fabrica* are instances of the powers of the new gaze. [They] are

> not just illustrations, additions to the text; rather they bring an irreplaceable dimension to scientific work – more than a 'reminder', as Vesalius says, they are an instrument of analysis, and, as such, they contribute to the installation of a knowledge.
> (Gil, 1998: 221)

Returning to the illustration, this complex scene, in keeping with the time, 'a brassily strident age' (Saunders and O'Malley, 1973: 42), is worthy of lengthier discussion, but I must restrict myself to the exploration of two points: the public nature of the anatomy lesson and the focusing of the 'anatomical gaze', by which the flesh is opened 'to the experience of the eyes' (Turner, 1990: 8); and the animation of the cadaver – the bringing to life of death – and the consequent re-textualisation of the body.

Earlier depictions of anatomical dissection (see following page) were static in comparison to that of the Vesalian scene. Usually, as in the image reproduced here, the physician is observed, elevated, lecturing from an ancient, authoritative text, while the dissector and the ostensor work on the cadaver below, all arranged in 'a hierarchical presentation of knowledge' (Sawday, 1996: 65). Generally, few others are depicted. The anatomising gaze is thus restricted to a few, and originates in the book, the authoritative text. But, in the Vesalian scene, we are witness to what seems like 'the sudden eruption of a crowd into the anatomy theatre' (Sawday, 1996: 66). The formerly private, esoteric gaze of medicine is herein made public. Both Sawday (1996) and Wilson (1997) concur that the Vesalian scene is an 'idealisation', but Gil (1998: 223) states that the subject of the demonstration, the womb, would have attracted an interested crowd, and therefore the illustration is a realistic depiction of an actual event. That the womb should attract so much attention is significant in that 'the question "where do children come from?" is the foundation of the desire for knowledge' (Gil, 1998: 224).



Fasciulo de Medicina, 1493

> Yet this belly only shows organs, and the open womb will only bring out...the *Fabrica* itself, that is, medical knowledge. [...] It has given birth, by Caesarean section, to a science.
> (Gil, 1998: 224)

The central positioning of the skeleton immediately above (perhaps touching) the womb is of great significance. The body, from birth to death, is situated within a mathematical, 'uterocentric' (Sawday, 1996: 71) universe, its entrance and exit from the world metaphorically contained within the conjunctional image of the womb and the tomb:

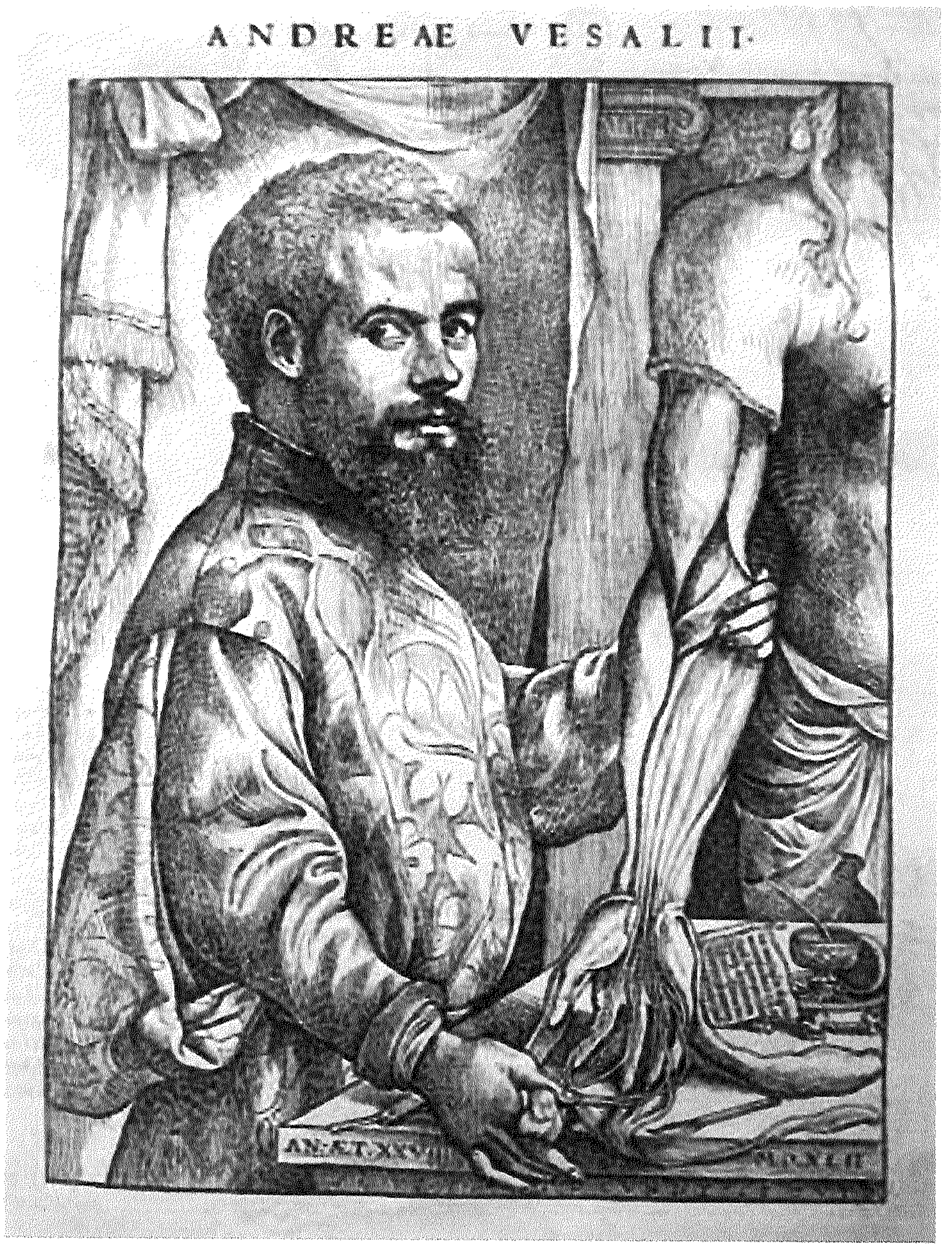
> What is represented is no less than a demonstration of the structured coherence of the universe itself, whose central component – the principle of life concealed within the womb – Vesalius is about to open to our gaze.
> (Sawday, 1996: 70)

Sawday (1996: 215) comments that the identity of woman, in anatomical investigation, is defined entirely by her uterus. As Laqueur (1992), among others, (Petersen, 1998; Shildrick and Price, 1994), has noted, within the binary categorisation of the two-sex model, the male body is affirmed as the standard, and thus the female is implicitly inferior. Sex was not simply an ontological category, but was in fact distinctly sociological (Laqueur, 1992: 8). However, it could be said that while the cadaver of the woman in the *Fabrica* is the 'unquestioned font of authority, enforced by the lordly skeleton that presides over the scene' (Laqueur, 1992: 72), her sex is immaterial: it is only the body that matters. Laqueur (1992: 74) states that the availability of bodies, and not sexual politics, determined the sex of the generic cadaver. Yet, almost two hundred years after Vesalius, in 1734, Bernhard Albinus, who produced the definitive illustration of the human skeleton, lamented that 'we lack a female skeleton' (Schiebinger, 1986). Additionally, in later editions of the *Fabrica*, the woman's body is further eroticised, posed suggestively at the feet of a clearly male skeleton (cloaked and holding a scythe – the grim reaper, no less). As Birke (1999: 115-116) notes, by the nineteenth century, a recurrent theme of medical illustration was the 'beautiful but dead young woman lying draped suggestively on a mortuary table'.

What Vesalius brings to the practice of anatomical dissection is the 'performative" (Wilson, 1987: *passim*): that is, he animates the body with his touch so that his and the dead body are almost indistinguishable. Thus, a drama of life and death is played out in the anatomy theatre, and 'the gaze no longer has to bend itself to the meaning dictated by the written work' (Gil, 1998: 220). No longer ostensive, the anatomist's role is now presentative: 'the 'body' the anatomist shows is both his own and that of the cadaver' (Wilson, 1981987: 69). It is as if Vesalius says to us: "Look, here it is", rather than the anatomists who read the body from a book and declared, "There it is". Life and death are intertwined in the presentation and representation of the body. Anatomising the dead body, Vesalius presents the viewer with an understanding of life. The frontispiece to the *Fabrica* (see following page) illustrates this point more effectively.

Here, Vesalius is seen holding, not pointing at, the flayed arm of a corpse. The upright posture of the corpse – for the purpose of more effective display – suggests an equality or lack of distinction between anatomist and his subject. That the corpse seems taller than Vesalius could imply that it is possessed of a greater authority than he (Wilson, 1987: 69), and therefore it could be said that it gives – or hands – its secrets to Vesalius. In this sense the body is implicated in its own anatomisation.

In bringing the body to life, Vesalius establishes the 'life of science' (Gil, 1998: 222), which is to say that death is exorcised from the body, and thus the proper subject of medicine becomes life instead; 'a life detached from the forces of



Portrait of Vesalius, 1543

nature, whose bodily functions will be progressively assimilated to physiochemical processes' (Gil, 1998: 222). It is not, then, the corpse that is the object of medicine, as Foucault (2003: 124) asserts when he states that the dead body is the 'first principle of positivity'. Death is effectively separated from the body by the gaze of medicine, reconstituting its forces in the text of scientific knowledge (Gil, 1998: 222).

The opening up of bodies in theatres of anatomy is an attempt to understand not only the body, but also the larger structure to which it corresponds, for 'the human body [is] seen metaphorically as the microcosm of the macrocosm' (Turner, 1995b: 27). As the foundation of life itself, the body is more than metaphor. The body, opened by medical science as a subject of investigation and knowledge, later becomes closed to the experiencing subject, which is to say that the body is appropriated, and made a thing of parts, by medical science, which, as an agent of social forces, determines or at least constrains embodied modalities, that is, ways of being and having bodies. Additionally, medical science determines the language of embodiment, through which is expressed the being and having of a body. Such language therefore diminishes our capacity to understand our bodies (and embodiment) in anything other than medicalised terms.

Sawday (1996) and Turner (1990; 1995) describe a political economy of anatomical dissection in which the body, laid open in order to reveal its secrets, is circumscribed by a moral discourse that supports an ethic of world-mastery (Turner, 1990: 4). As the production of a 'masculine discourse of science and reason' (Sawday, 1996: 230), anatomical dissection is not only concerned with mapping the body's interior; it is also an attempt to consolidate and exercise authority over irrational, feminine, nature (Sawday, 1996: 245; Turner, 1990: 13). Laqueur (1995) and Sawday (1996) trace a detailed genealogy, which situates the creation of this new type of body firmly in the seventeenth century.

It is at this point, they argue, that the language of science becomes less veiled, less metaphorical, in the attempt, by scientists, to get at the thing itself, that is, the body, and by extension, society. Yet, the body, in the seventeenth century, is increasingly analogised in terms of the mode of production (for example, see Hobbes' comments on the circulation – again a hydraulic metaphor – of money). The anatomist Walter Charleton, in furthering William Harvey's efforts, conceived of the heart in terms of it having an 'office with work to perform within the larger structure of a mechanical process' (Sawday, 1996: 243). The circulation of blood, in this analogy, represents the circulation of money, the lifeblood of a newly emergent system of commerce – capitalism. The body thus remains machine-like in that it mirrors the machinery of state bureaucracy.

> The heart of animals is the foundation of their life, the sovereign of everything within them, the sun of their microcosm, that upon which all growth depends, from which all power proceeds. The King, in like manner, is the foundation of his kingdom, the sun of the world around him, the heart of the republic, the fountain whence all power, all grace doth flow.
> (Harvey, in Rothman et al., 1995: 68-69)

According to Sawday (1996: 245) science developed, at this point, a 'stridently aggressive language from which it has never recovered'. Further to this point, Emily Martin (1991) discusses how culture shapes scientific description, that metaphors of aggression (male) and passivity (female) are embedded in the language of medicine, and as such, serve to naturalise social practices. It is not then the body of which science speaks; rather, it is the socio-economic inequalities of the larger social system that are projected onto the body. The anatomist is then the guardian not only of knowledge, but also of power (Turner, 1990: 13). Despite certain philosophers' disdain for metaphors – for example, Hobbes, who thought that metaphors 'openly profess deceit', and must therefore not be admitted to reason (Hobbes, in Sawday, 1996: 235) – the body, as a medical object, held to be 'the paradigmatic figure of truth' (Leder, 1990: 45), retained its capacity for macrocosmic correspondence.

The body, its contents 'secret...hidden and dangerous' (Donne, in Sawday, 1999: 159) is, in illness, a 'place of treachery' (Sawday, 1996: 159). Conceived as an architectural trope, the body is, in its familiar immediacy, home-like (or homely), and simultaneously its opposite, *unheimlich* (Sawday, 1999: 159-162). But, in order to construct this metaphor, the body must first be deconstructed and 'imagined as a scattering of parts' (Sawday, 1999: 160), before it can be considered a composite entity. Quite simply, this means that in order to consider the integrity of the body as a whole one must be able to think of it also in terms of its integral parts. A specific awareness of the heart as lacking in integrity will then undermine the feeling of wholeness, and the body will thus be considered incomplete, strange and uncanny. The following interview extracts illustrate this sense of the uncanny, of the moment when body and machine, or body and other become indistinguishable, and raises the question: '[w]here, now, are the bounds of body-property which the anatomists struggled so hard to establish?' (Sawday, 1996: 267).

> "The surgeon said I'd probably tick afterwards, but he said it quite jokily and I didn't think much of it. But the first week after surgery my heart was ticking so noisily, and it seemed so erratic that I kept thinking there was something wrong. By the time they sent me home it had quietened down a little, and the ticking became very regular, like a clock. That disturbed me even more. It's funny how we sometimes call it a ticker, you know, and now it really is a ticker...it's like a constant reminder of the time...of time running out."
> (Frank, 68)
>
> "I have a pig's valve now, and when I tell people they ask if I 'oink'. It's funny, I keep wondering how long pigs live."
> (Kate, 75)

Far from quieting our anxieties, medical science has 'succeeded only in introducing new manifestations of the fear of interiority' (Sawday, 1996: 267). While medical conceptions of the body could be said to determine, if not dominate everyday understanding, medical science operates within a larger, cultural framework – as we have seen, in the correspondence theories of the surgeons and anatomists of the Renaissance – and therefore further examination of cultural association is required.

By way of an aside, it should be noted that Hobbes's hostility to the abuse and misuse of language (catachresis) is characteristic of seventeenth century philosophy in its concern with transparency, with representing social reality in *realistic* – that is, objective – terms (Stillman, 1995: 791-792).

> [Metaphors] are capable of inventing the most fantastic entities by dint of the positional power inherent in language. They can dismember the texture of reality and reassemble it in the most capricious of ways [and] in the most unnatural shapes.
> (De Man, in Stillman, 1995: 792)

Metaphor then, in the seventeenth century, is a potential source of embarrassment, because of its association with subjective fancy and passion. Yet metaphor, this 'monstrous rebel to linguistic law' (Stillman, 1995: 792), has a constitutive role in Hobbes's (and others') philosophy: what else is his 'artificial man' if not a metaphor? *Leviathan* is a monster created to do battle with the monstrous abuse of thought, yet a 'discursive victory over metaphor [can] only occur outside of language altogether' (Stillman, 1995: 793), that is, either within the positivist *dream* of an uncontaminated objectivity (affective neutrality), or 'in the *design* of a pious magic to create a discourse in which words have the power to become incarnate as things, as the very fulfilment of desire' [emphasis in original] (Stillman, 1995: 793). I will return to the question of the objectivity of language in chapter four, but in concluding this discussion of anatomical dissection, I turn to another image that represents the emergent spirit of modern capitalism.

The Anatomy Lesson of Dr Tulp, 1632

The anatomy lesson portrayed here could hardly be more different to the unruly Vesalian scene. Here we see a return to the reading of the body from a text. The anatomist is restored to the chair of authority, and the spectators appear as the bourgeoisie of a mercantile, Protestant society, 'wealthy surgeons… representatives of an intellectual elite' (Sawday, 1996: 150). The cadaver, this time male – Adriaen Adriaenszoon, convicted of stealing a coat – 'is the matrix of a demonstration of civic and corporate power' (Sawday, 1996: 150). Equally the painting represents 'a discourse about medical and bourgeois authority over the disruptive forces of human disease, frailty and error' (Turner, 1990: 11), in which the social, or civic, body triumphs over death (Sawday, 1996: 150).

The scene is an idealisation, for the hand would not have been the first part to be anatomised. The hand is that which differentiates the human (from the animal) as a creative, productive being. As such, it represents a corporeal reality, reminding us of life rather than death. It was a hand that stole the coat, therefore its dissection – an extreme and rational violence (Sawday, 1996: 153) – may be considered a further punishment. Anatomical dissection, in this example, is a distinctively Protestant response to deviance, to the recalcitrant will of the criminal, who reminds us that the rational, *Cartesian* mind is susceptible to potentially disruptive desires. The anatomist probes Adriaenszoon's flexor muscles, his dead fingers made to curl, an action indicated by the anatomist's left hand, and thus the 'Cartesian truth of...order and rationality' (Sawday, 1996: 153) is re-established in this demonstration of the *mechanics* of the body. The anatomy lesson is a punishment. What is punishment if not a lesson? It is the application of scientific reason to the unruly, frighteningly natural body. But, at the same time, it is more than that, for opening up the body is an attempt to know oneself, and in so doing, to know God – *cognito sui, cognito dei.* Dr Tulp's anatomy lesson is, above all, a metaphor of Calvinist self-examination.

While the history of science and the rational-scientific 'discovery' of the body – which was part of a larger discovery of the laws of nature (Geyer-Kordesch, 1989) – is a fascinating and very important topic, it is beyond the scope of this thesis to further investigate this history.

Medical science focuses on the unpredictability, or irrationality of the body, yet 'at the core of modern medical practice is the Cartesian revelation: *the living body can be treated as essentially no different from a machine*' [emphasis in original] (Leder, 1998: 121). The informants in this study have certainly experienced the 'irrationality of a heart gone crazy' (Birke, 1999: 115). The 'bag of worms' effect of ventricular fibrillation, the wild contractions of the heart's 'walls' during infarction, the 'furring' of occluded arteries, speak of an organ that has yet to be tamed by rational science. The metaphor of the heart as a pump sustains the image of a fairly simple organ, one that is both industrial and domestic. Yet, the heart is perceived as so much more than that. It is the very ambiguity of the metaphorical heart that connects the emotional and the rational.

Myth and metaphor

> The signifier of myth presents itself in an ambiguous way: it is at the same time meaning and form, full on one side and empty on the other. As meaning, the signifier already postulates a reading...
> (Barthes, 2000: 117)

The body, ultimately, cannot be grasped through its metaphorical extensions, but the value of metaphor in understanding experience is made clear by Johnson (1987), Kirmayer (1992), Lakoff and Johnson (2003), and Stelter (2000). Metaphorical conceptualisation plays an important role in defining reality, for as Lakoff and Johnson (2003: 77) explain, 'metaphorical concepts [are] ways of partially structuring one experience in terms of another'. But, such concepts 'have little to do with objective reality, *if there is such a thing*' [my emphasis] (Lakoff and Johnson, 2003: 184). This is to say that metaphors are devices for understanding, and are not *identical* with the reality they are employed to explain.

> The fact that our conceptual system is inherently metaphorical, the fact that we understand the world, think, and function in metaphorical terms, and the fact that metaphors can not be merely understood but can be meaningful as well – these facts all suggest that an adequate account of meaning and truth can only be based on understanding.
> (Lakoff and Johnson, 2003: 184)

'Fact', 'world', 'truth': clearly, Lakoff and Johnson (2003) do not deny the existence of an objective world. Rather, metaphor is the principal interpretive device mediating between the experiencing person and the experienced world. That is to say, metaphor is constitutive of ordinary experience. To state that metaphors have little to do with 'objective reality' is similar to Butler's (1998: 279) observation that 'the linguistic effect is not the same as the referent it fails to capture'. This raises the issue of the value of using metaphor as an explanatory tool in that disparities between the phenomenon (the topic) and its metaphorical referent (the vehicle) may be discounted purely in order to make the metaphor work. For example, in chapter two I cited an informant who stated that being in hospital was, at times, just like *ER*. The significant question then is: how much like *ER*? What I am suggesting is that, because it is not identical with its object, there is inevitably a gap between the experience of the world and its description.

Metaphors are one-sided analogies in which salient features of the vehicle are applied to the topic in order to make its latent features conspicuous. This asymmetry is made clear if I say that a heart is a pump, but a pump is not a heart. Perhaps in establishing what something is like, and therefore by determining what it is not like, it may eventually be possible to get to the heart of the matter. However, the purely linguistic approach to the comprehension of bodily experience is inevitably confounded by the privileging of textuality, which is to say that language describes words more effectively than it does things (Barthes, 2000). Therefore, metaphor never quite manages to capture the sensuous vitality of the body.

Stelter (2000: 64) advocates a distinctly non-objectivist approach to the description of bodily experience wherein the experiencing subject and the environment 'are understood as interrelated, or better, *co-dependent*' [emphasis in original]. He suggests that bodily experience does not easily find its correlate in an objectively verifiable reality. The 'tacit dimension' (Polanyi, in Stelter, 2000: 68) of experiential and bodily-based knowledge is inaccessible and therefore cannot be communicated in the usual manner, through the use of language. In normal communication, Stelter (2000: 69) argues, the unique aspect of the individual's meaning system, the 'personal content', is a 'felt meaning', which cannot realistically be communicated. But, in stating that this personal content 'evolves from the subject's own history and experience, and as such, is influenced by the social, cultural and economic basis of society', Stelter (2000: 69) appears to contradict himself when he admits that all communication is a matter of negotiation *between* perspectives, and *within* a context. Communication is a drawing upon of shared resources, and as such it is a reciprocated negotiation, which is only to say that meaning cannot be determined in isolation.

Although he does not distinguish between 'personal content' and 'personal narrative', Stelter (2000: 69) admits that the process of negotiation effects the creation of a 'more broadly accepted narrative', which is influenced, if not determined by the 'power structure of the social context'. This last statement is useful if it can be applied to descriptions of bodily experience, or 'felt meaning', because it permits an understanding of the ways in which power 'goes to work' on the body, a detail which Howson and Inglis (2001: 312) argue is missing from a phenomenologically inflected sociology of the body. In order to obviate the problem of incommunicability, Stelter (2000: 70) applies Gendlin's (1981) method of bridging the gap between 'empirically based knowledge and discursive knowledge by the use of imagination', which transforms 'felt meaning' (implicit and pre-reflexive) into a specifically structured language by way of images and metaphors (explicit analogues). For example, if a patient is asked by her doctor, 'what's the pain like?', she might respond thus:

> "It was a metallic pain, like chewing silver paper, like my teeth were being pushed out. Then it was a jaggy feeling down my neck, like wee pins jagging me."
> (Elizabeth, 68)
>
> "Did the doctor understand you?"
>
> "Yes, he took notes, and he said it could be angina."
>
> "But he already knew you had heart trouble?"
>
> "Yes, he suspected as much."

Couched in such imaginative terms, the pain of angina is *imaginable*, and communicable: indeed, we can feel it, or something like it, with her. Yet angina could just as easily present itself differently, and be described otherwise. The informant draws upon the experience of something else – chewing silver paper, the sharpness of pins – to convey her pain experience, which is identified with that of angina. The question of whether or not she felt the pain differently *as she experienced it* is answered by Lakoff and Johnson (2003: 57), who state that 'it can be misleading to…speak of direct physical experience as though there were some core of immediate experience which we then 'interpret' in terms of our conceptual system'. Pain can therefore be experienced differently. There is no pain that exists objectively, no pain of angina. Only the pain of the experience of angina. This is what Lakoff and Johnson (2003) mean when they say that metaphorical concepts have little to do with an 'objective reality'. The sense and communicability of the informant's description is dependent upon the doctor's experience or knowledge of what it is like to chew silver paper. As such, perhaps the term 'objective reality' should be placed within inverted commas. Or perhaps it should be replaced by the term 'shared reality'.

In the following extract, responding to the question of how fatigue was felt, an informant is describing his experience of a weekly round of golf with friends.

> "It got to the point I was so out of breath I couldn't keep up with the rest. I'd tell them to walk on while I caught my breath, and I'd stop for a bit, but I couldn't really catch my breath at all. I'd calm down a bit and then I'd catch up with them. Then I'd go through the whole thing again, stopping and starting. I felt I was really letting them down, but I just couldn't keep up. [...] We kept it up for a few weeks, but I had to give it a miss eventually. I had to stop playing."
> (Andrew, 66)
>
> "Was this always a problem? Was it only on the golf course that you experienced this type of breathlessness?"
>
> "No, no. I was breathless a lot of the time. It was worse there, though. [...] Well, maybe not. But it felt worse there. We were always a four for golf, every Saturday for a long time. I think that's when I felt it most. That's when it really bothered me. Falling behind like that...always feeling I had to catch up."

Here, the problem of fatigue is described in terms of shortness of breath. The informant's feeling of inadequacy is expressed by the word, 'catching' – 'catching breath' and 'catching up'. His subjective, bodily feeling (catching his breath) correlates with the objective reality of not being able to keep up with his companions. Thus, the 'tacit dimension' of experience is rendered more explicit by the metaphorical 'bridging' (Stelter, 2000) of the gap between a seemingly private feeling, of inadequacy or incompetence, and a more obviously social problem, that is, of letting his friends down. 'Felt meaning' and the social context are therefore quite clearly interrelated.

When Lakoff and Johnson (2003: 185-194) state that 'truth is always relative to a conceptual system, that any human conceptual system is *mostly* metaphorical in nature, and that, therefore, there is no fully objective, unconditional, or absolute truth' [my emphasis], they do not subscribe to a radical subjectivist epistemology. Rather, treating both subjectivism and objectivism as 'myths', which effectively oppose and negate each other, they espouse that which they refer to as an experiential alternative, founded upon the 'experientialist myth' (Lakoff and Johnson, 2003: 186). The term 'myth' is not applied derogatorily, but in a loosely Durkheimian sense, in that myths provide 'ways of comprehending experience; they give order to our lives' (Lakoff and Johnson, 2003: 185). Myth, according to Lakoff and Johnson (2003: 185-186), is the overarching system of thought, while metaphor is the tool employed to bring thought to bear upon its objects, although at times it seems as if myth and metaphor are conflated, or at least reduced to simile.

Metaphors are realistic in that they must refer to something that is relevant to the topic, so, for example, to think of the heart as a pump, the heart must have features that are *similar* to a pump. It would be of no use to think of the heart as having features similar to, for example, an umbrella, for this just would not work. Therefore, a metaphor must find its correlate in experientially real and relevant objects. But, what is it about the heart that leads Harvey to the analogy of a pump? What I am trying to suggest is that the motion of the heart is inexplicable until a referent, a metaphorical association, can be found. Therefore, metaphors are actively sought as a means of understanding the world. What if there were no pumps in existence and Harvey had said that the heart is like an umbrella? Would that metaphor have endured because he had the power, the scientific authority, to make his meaning prevail? Would he have looked at hearts until he found a resemblance to an umbrella?

Lakoff and Johnson's (2003) theory of myth and metaphor points to the ways in which linguistic communities – for example, medical practitioners – and individuals (such as patients) employ language that is drawn from the wider social system. Thus, metanarratives and individual narratives draw from each other and from external sources. The metaphorical description of the pain of angina as something like 'chewing silver paper' was readily interpreted by the doctor, although, suspecting an underlying heart problem, he brought his own cultural presuppositions to bear upon the topic. He was therefore able to match one set of metaphors with another to arrive at a conclusion, which, in the end, was correct.

What Lakoff and Johnson's (2003) work reveals, more than anything else, is that objectivism remains the dominant paradigm, and as such, their (objectivist's) metaphors can be presented as objective reality. Finding correlation between the patient's description of pain, and his understanding of pains, the doctor was able to arrive at the 'objective reality' of angina.

Laurence Kirmayer's (1992) essay on metaphor as presentation and representation in illness experience begins with the rather odd statement that the turn to the body, in reality (that is, outside the rarefied sphere of academic abstraction), 'represents a longing for community' (Kirmayer, 1992: 324). The reason for this longing is that the world of 'substance and feeling' is 'unmade' by a hyper-rationalism that ignores the significance of 'felt meaning' and, as such, divorces ideas from agents, or thoughts from bodies. In addition, the postmodern decontextualization of knowledge and value neglects the historical trajectory of human expressivity, and as such, divorces communication from its textual and 'communal ground' (Kirmayer, 1992: 323-324). Humans are then isolated between two extremes, of objectivist abstraction and of subjectivist relativism, both of which 'negate the [felt] meaning of the individual' (Kirmayer, 1992: 324). Again the problem of language is raised when

Kirmayer (1992: 324) asks: 'how can we say the body is "so-and-so", when that knowledge is worked out through language that imposes its own structure on experience and thought?'. This effectively reduces the ability of the 'sufferer' to express and understand the meaning of illness: body and text co-exist in a relationship of 'epistemological circularity' (Kirmayer, 1992: 324) in which language closes off the self-understanding of the body and, in return, the body eludes textual explanation. (In short, there is no language without the body, and no body without language.) Developing this point, and as a corrective to the structuralist privileging of text over experience, Kirmayer (1992: 324-325) notes that body and text exist in a dialectical relationship, that 'text[s] stand for a hard-won rational order, imposed on thought through the careful composition of writing, [but] the body provides a structure to thought that is, in part, extra-rational and disorderly'. Meaning resides not only in relationships between concepts, but is grounded in bodily experience and practice (Kirmayer, 1992: 334-335). Bodies, as Mauss (1979) notes, are skilled in practice, and it is this skilfulness, in the form of 'body techniques', that structures our apprehension and understanding of the world. For example, the person who walks the same streets every day knows their every (relevant) feature, but when one day a slight incline causes the feeling of breathlessness, then the practised walker knows that something is wrong. A new technique is thus required in order to circumvent this problem. The development of this technique does not require a linguistic intervention, although it may be thought in terms such as, 'I'll walk more slowly', or, 'I'll find another route'.

Imag[in]ing the heart

> [I]n the domain of perceptual apprehension, images belong so fundamentally to the structure of the phenomenon that to attend to the phenomena (as the things themselves) requires a correlative attending to the relevant imaging. (Sallis, 1995: 64)

Returning to the matter of the heart, Guillemin (2004) provides some insight into the ways in which patients represent their hearts (and disease) pictorially, and in so doing more effectively communicate the different modes of being that are experienced in illness. Like Herzlich (1973), Guillemin (2004: 224) notes that illness (in this instance, heart disease) is not a single entity, but is characteristically diverse, and thus not experienced in the same way by everyone. Guillemin (2004) is specifically concerned with drawing as a process of telling the story of illness, a process which is comprised of an 'assemblage of cultural metaphors, biomedical knowledge and lived experience' (Guillemin, 2004: 224). Drawings are not then merely depictions of disease; they are neither 'stable products [nor] coherent representations' (Guillemin, 2004: 224), but instead they offer insight into lay understanding and the *practice* of illness.

When Guillemin (2004) states that she is more interested in the process of drawing – wherein 'drawing' is a verb – than with the product of drawing – in which 'drawing' is a noun – she is concerned with the ways that patients situate themselves in relation to the lived experience of illness, to the immediate, interactive environment of friends and family, and to the larger social system (including the institution of medical science).

Similarly, Scheper-Hughes and Lock (1985: 7-8) identify three realms of the body: the individual body-self of lived experience, the social body of everyday representation and interaction, and the body politic of power, domination and regulation, this latter type exemplified in Foucault (1980b; 1991; 2003). Kirmayer (1992) points out that these distinctions indicate not three types of body, but rather, three ways of conceptualising bodies; in short, three types of text (Kirmayer, 1992: 324).

This criticism, however, does not apply here, as the utility of Guillemin's (2004) study lies not in its textuality, but in the power of images to convey complex meanings that cannot be reduced to words but can yet be communicated. In other words, images have a capacity to express and invoke the feeling, or 'felt meaning' of experiential phenomena that texts do not, which is to say that images are possessed of a 'sensual capability' (Sontag, in Shusterman, 1991: 106) which eludes interpretation. Images have a presentational quality as well as a representational quality. In addition, and despite Guillemin's (2004) necessary translation of the images into sociological text, drawing is, for her informants at least, a less rigidly structured mode of communication, particularly as none of her informants are artists. The drawings in themselves, other than representing the heart in a different way to that of medical science, do not necessarily provide a richer account of the experience of heart disease, but attention to the process of drawing, the 'drawing upon' of diverse sources to explicate the experience of illness, expands more traditional ethnographic approaches and permits 'a different kind of insight into illness experience and knowledge production' (Guillemin, 2004: 236). The most striking conclusion to be drawn from this work is that drawing, a different form of expression from that normally employed in daily life, evokes quite vividly the 'different kind of social reality' (Guillemin, 2004: 235) that patients experience. Their experience of heart disease is situated in different locations – personal, social, familial. It may be problematic in one setting but not in another. For example, one informant drew her 'personal' heart in the form of the traditional love-heart, whereas her 'social' heart was misshapen and seemingly 'threatened' by arrows. The very fact that I can describe this suggests that, as the viewer, my apprehension of the image is informed by cultural presuppositions, and as such, I cannot help but 'read' the image.

That the heart, or rather, heart disease, is felt in different ways in different settings, goes some way to explaining the comments of my informants, previously cited in chapter two, that the pain of angina may be experienced, yet, in certain circumstances, not present a problem.

In discussing the use of metaphor as a way of exemplifying bodily experience the problem arises: does this transform the body into a text? Am I, as Barthes (2000) describes, just writing words about word, and not in fact discussing the body and embodiment?

For Butler (1993) the body, or rather, its materiality, cannot be understood outwith its materialisation in language. 'The body posited as prior to the sign, is always *posited* or *signified* as *prior*' [emphasis in original] (Butler, 1993: 30). If this is the case, then what is actually doing the positing, and why? Language as a constituting force (or form) cannot conceive of a body without reference to itself (language) as that which constitutes the body in the first place.

Johnson (1987), and, to a lesser extent, Sheets-Johnstone (1990; 1994), provide a corrective to the post-structuralist privileging of language, by stating that it is the form, or *eidos*, of the body that establishes the grounds upon and from which we make the world meaningful *for us*. It is our immediate bodily intentionality that provides the structure(s) of consciousness. Language is merely the expression of that intentionality (Sheets-Johnstone, 1994: 265).

> The body...abides over time and is part of an unbroken, continuous historical process. Constructionist theories that fail to take the evolutionary body into account not only ignore the relational ties that the historical process describes and that bind us to certain corporeal acts, dispositions, and possibilities, and to a certain related intercorporeal semantics; they also put us on the edge of an unnatural history. It is as if we humans descended *deus ex machina* not just

> into the world but into a ready-made culture, a culture that, whatever its nature, can only be the product of an immaculate linguistic conception.
> (Sheets-Johnstone, 1994: 69)

The Body is the Spanner in the Works of the Project of Modernity

> [T]here are changes afoot in our embodied dispositions.
> (Martin, 1992: 134)

> The migration of the body's perceived centre, from the heart to the head, is a consequence of the privileging of and trust in reason.
> (Jager, 1996: 3).

From the body with manners (Elias, 1994), to the upwardly trained body (Vigarello, 1990), to the accumulation of men (Foucault: 1980a; 1991) – wherein bodies were disciplined and machine-like (Asendorf, 1993), subject to a strict clock-time both in production and in consumption – to the present, and the flexible bodies of the post- or late-modern epoch, there is reason to consider that the body, or perhaps more accurately, the image of the body, is a direct correlate of the mode of production.

Citing as support Lévi-Strauss's contention that phenomena become of scientific interest at precisely the moment when they are coming to an end, Emily Martin (1992) proclaims the end of the body. However, as she goes on to suggest, the body has not reached its end; rather, it is only that bodies are undergoing fundamental changes in the ways that they are organized and experienced (Martin, 1992: *passim*). A supplementary argument is that the body has come to prominence at the time when the intellect, as the seat of subjectivity, has been decentred by the postmodern turn (Csordas, 1994). Perhaps it is simpler just to say that bodies last longer now, there are more of them than ever before, and because of this they have become increasingly problematic, as medical, economic, political, moral, and social entities. Because of this, the salience of 'the body' to social theory is beyond question. What is questionable is the manner in which the body should be theorised. When we discuss it, what is it that we are talking about?

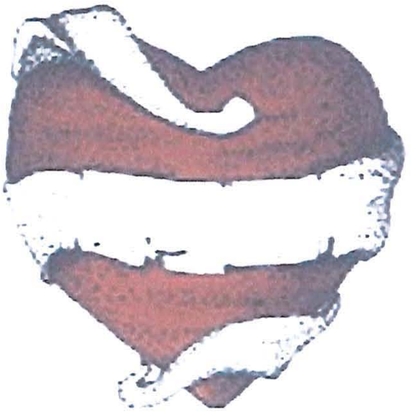
Martin (1992) conceptualises the body, as percept and in practice, as a correlate of the mode of production. It seems then that the body is perceived and practised through the filter of ideology, that it is the product of (or reflects) overarching socio-economic forces; in particular medical science, which produces models of the body according to the demands of the particular mode of production. It need hardly be mentioned that the body is the most obvious tool available to any given historical configuration of productive forces. Citing Gramsci, Martin (1992) depicts Fordism as an organisational form that penetrates the body in the most intimate manner, constructing 'new types of sexuality, reproduction, family life, moral ideals, masculinity and femininity' (Martin, 1992: 122). The type of worker required by this mode of production is thus a new type of person, with a new type of body, which, as previously suggested, has its origins in the mercantilism of the seventeenth century. It is a body that is tamed, disciplined, subject to reason, exhausted by its labours, and thus no longer unruly and dangerous.

New embodied habits required to meet the demands of the Fordist organisational form, acted out in different spatio-temporal settings, preserved 'a certain psycho-physical equilibrium which would prevent the physiological collapse of the worker, exhausted by the new mode of production' (Martin, 1992: 122). That these habits – that is, bodily dispositions – were impressed upon the body largely by means of coercion, for example, in the organization and management of time and space, and not least by way of scientific discourse, suggests that the Fordist body was Taylor-made for its tasks.

Now it seems that, in late modernity, a post-Fordist body is required; a body that is capable of a 'flexible response [to] rapidly collapsing time and space' (Martin, 1992: 134). As the labouring Fordist body was analogised as a machine, so the post-Fordist body finds its correspondence in discourses of, for example, immunology and artificial intelligence (Stafford, 1997). In times such as these, when HIV/AIDS and other viruses threaten the integrity of the body, when heart disease is the number one killer in the world, when aeroplanes pierce buildings and illegal immigrants penetrate borders, the threatened/threatening body is perhaps a more appropriately evocative trope.

The prominence of the body in modernity, as a cultural form associated with self-identity, is evident in the ways that bodies are 'hailed' by commodities, political regimes, and religions. Yet, as Martin (1992: 122) observes, it is principally medical science that writes the truth of the body. The contemporary body is precisely that of 'specialised responses and adaptability of skills' (Martin, 1992: 123). It is the marketable, communicative, flexible and reflexive body of the current epoch. As such, medical science has, Martin (1992: 134) claims, invested the body with agency.

Part Two



Three Narratives

The Red Balloon

It is 1999 and he (let's call him Bob, for academic convention demands that he be named) is about to have a balloon angioplasty to dilate an occluded coronary artery. This is a simple enough procedure, performed on the fully conscious patient. A deflated balloon catheter is introduced, by way of a vein in the arm, or the femoral artery in the leg, to the narrowed segment of the coronary artery. Then the balloon is inflated, thus transmitting circumferential pressure and compressing the plaque that has narrowed the artery. It shouldn't take too long, and then, the next day, after a period of bed rest, Bob will probably be allowed to return home. The success rate is very high and the patient will feel better almost immediately. Bob tells me that he lay staring at the ceiling while the surgeon and his assistants performed their tasks. Bob was nervous, but Valium softened the experience, and all was going well until suddenly he felt a change in the mood of the room, and then a crushing weight on his chest. The surgeon leaned close and asked him how he felt. Bob said that he'd feel better if the surgeon would only get off his chest, and then the last words Bob remembers hearing were "prepare for bypass...we're going in" (although, in retrospect, Bob isn't certain that he actually heard those exact words). The balloon catheter had ruptured the wall of Bob's artery and blood was rapidly filling his chest cavity. He would have been dead in minutes had the surgeon not opened him up and performed an emergency bypass on the damaged artery. Two days later, when he regained full consciousness, Bob's cardiologist told him that he'd had an open-heart procedure, that it had been a near thing, and that he'd need to stay in hospital for a week, and then the cardiologist asked Bob how he felt. Told that the surgeon wouldn't be coming to see him, Bob said, "don't I get to meet the man who almost killed me?", but in a half-joking manner, for he knows that the surgeon also saved his life.

Although extremely fearful of surgery, Bob's fine now, but he feels uncomfortable telling his story, although he says that he tells it often.

Ein Heldenleben

It is 1929, and Werner Forssmann, a young doctor in a rural hospital near Berlin, is determined to attempt cardiac catheterisation on a living human being – himself. He is familiar with the literature on the catheterisation of horses' hearts, and he is eager to find a way to deliver medication safely and directly to the human heart. Thus far, no one has catheterised a human heart. Unfortunately, he cannot convince his supervisor that a self-experiment is worth the risk, or indeed, ethical. However, young Werner manages to arouse the interest of the nurse in charge of theatre and she suggests that he perform the procedure on her. He agrees, and instructs her to lie on a trolley, tying her down, so as to minimise movement, he says. With the nurse lying immobile beside him, Werner inserts a urethral catheter into the antecubital vein of his left arm, then, feeling slightly unwell, and with the catheter dangling bloodily from his arm, he unties the nurse and asks her to take him to the radiography department where an x-ray reveals the presence of the catheter in his heart. Werner was heavily censured after this (although he became something of a local hero in the press, and therefore in the public imagination), and he moved on to other areas of medicine (settling finally in urology), never to touch the heart again. (Indeed, cardiac catheterisation was not attempted again until more than a decade later.) Werner's story, as the man who first catheterised the human heart, is reproduced in countless medical history textbooks: sometimes the details vary – was it the antecubital or brachial vein, and did the event take place in 1929 or 1930? – but the power of the story, that in an act of creative brilliance this daredevil first catheterised the human heart, is undiminished.

'The fire which in the heart resides' (Matthew Arnold, **Morality***)*

It is 1979, just a few weeks before Werner Forssmann's death, and I'm in hospital for an x-ray angiogram. My cardiologist wants to measure blood flow across my heart valves and, to this end, two catheters are inserted, one in my left arm and the other in my right leg. I can't feel the Valium but I can feel the distant scraping of the second catheter as it is inserted into my femoral artery. After a rather tedious round of tests the surgeon says that he wants to take a look at the blood vessels of my heart and that he's going to inject a contrast medium, which is opaque to x-rays. From a remote position behind a lead screen he injects the medium, instructing me to hold my breath while it goes in. Then he tells me to breathe out, warning me that I may experience some discomfort. A massive understatement, in my opinion, for as I breathe out it is as if all the fires of Hell are raging through me. For a few seconds I feel that fingers of flame are dissipating through the top of my head and flying from the fingertips of my left hand – a quite unique sensation – and then I am left with the worst headache in the history of headaches. And there I am, a twenty-six year-old man, I feel like eighty-six, what with my incompetent, stenosed mitral valve, and now, post-angiogram, I've got a limp too. But, I mustn't complain, for this is but a precursor to the surgery that will restore me to good health, and on my first day back home I decide to do some shopping, so I slowly climb the stairs from my basement flat. I am wearing a grey flying suit, trench coat, black Doctor Marten's boots (it is 1979 after all); my hair is short and spiky, dyed blonde (as I said, 1979). I use a walking stick to accommodate the limp, and I'm carrying an old-fashioned net shopping bag. As I reach the garden gate, some little boys playing in a tree across the road notice me and shout excitedly, "hey, look at that old guy done up like a punk!" If I had the energy I'd shake my stick at them. They seem like nice kids, and I think that I could tell them my story, but it's so involved, requires too much explanation of background, and I doubt that, aside from the gory details, they'd be interested.

Instead, I just smile, allowing them to own me with their words, and for a moment I catch a glimpse of myself through the eyes of others. I'm a young man in an old man's story.

Chapter Four: For Narrative

> My experience simultaneously seeks and flinches from its verbal expression. My words become other-for-the-other. Language is objectification, it is the occasion of the Other's appropriation of my subjective reality. [...] [T]he ontological truth of language is that...its structure is always that of being-for the-other. There is no private, interior language which does not have this structure. The inaudible utterances of my talking to myself reflect the way I am a quasi-other to myself.
> (Laing and Cooper, 1971: 20-21)

> Our experience of the world, both physical and cultural, is always mediated by conventions of enquiry, and that experience is equally mediated by conventions of writing.
> (Atkinson, 1991: 9)

> Not only are we born into complex communal narratives, we also experience, understand and order our lives as stories that we are living out. Whatever human rationality consists in, it is certainly tied up with narrative structure and the quest for narrative unity.
> (Johnson, 1990: 171-172)

The truth of Johnson's (1990) observation, that we are born into communal narratives, is evinced by Werner Forssmann's story inasmuch as it is comprehensible as an heroic narrative. Bob's story is that of tragedy averted, while mine, in the end, is one of mistaken identity. As sociologists, we are familiar with the grand narratives of enlightenment, capitalism and the class struggle, while as postgraduates we are told that our theses should 'tell a story', all of which goes to suggest that narratives are deeply embedded in our everyday lives and, as such, are intelligible because we are possessed of a narrative competence. Reading and telling stories are simply the means by which we *try* to make sense of other people's lives and the resemblances and differences among them. The construction of narrative – narrativization – is the delimitation, organization, and explication of experience (Ricoeur, 1991: 3). But, for the purposes of this thesis, I do not distinguish greatly between 'narrative' and 'story', and thus use the terms interchangeably.

If every story has its beginning I should state here what my central questions, the questions that drive this particular story, are. First, what purpose does narrative, specifically the 'illness narrative', serve? To this end I want to stress the constitutive role of the body, as a 'walking memory' (Turner, 1995: 250), in the construction of narratives. At its beginning, the illness narrative has a 'key embodied moment' (Hockey and James, 2003: 51), which I described previously as the fateful moment that marks the onset of illness and which unsettles the integrity of the body and self-identity. Second, I ask if remaking the body during the process of surgery, rehabilitation and recovery entails a remaking of the self, and whether the body is an essential component of self-actualisation. In short, do illness narratives possess a transformative, if not emancipatory, quality?

Illness Narratives

The conceptualisation of a difference between disease and illness, wherein the former is conceived as a pathology defined by medical science, and the latter as the experience of the disease (Radley, 2002: 3), has opened up the possibility for study of the patient's 'narrative activity' (Hydén, 1997: 48). Narratives give voice to illness in a way that medical science does not. As such, the illness narrative is not a recent phenomenon, as Epstein (1986) reveals in her discussion of the writer Fanny Burney's (1752-1840) letter regarding her mastectomy.

As an intimate confession and 'persona building' (Epstein, 1986: 131) exercise, Burney's writing on the subject represents a courageous and imaginative confrontation with the public – that is, medical – appropriation and violation of her body, in which she 'remembers and renders the event [surgery] not merely as a grim fact but as gothic melodrama overlaid with imaginative structure and symbol' (Epstein, 1986: 140). Significantly, Epstein (1986) argues that the memorial act of writing, the re-experience of the mastectomy as a literary event, *enables* Burney to address her suffering (at a remove). *Unable* to fully detach herself from her history – the actual experience of surgery – Burney distances herself, by way of the tools of her trade, in order to assert some degree of autonomy. Burney's 'illness narrative' – and it can be defined as such because the writer *makes* a story of her experience – represents one voice speaking out *for* itself (and *to* others – her friends and family). Thus 'aroused from [her] passively submissive state' (Burney, in Epstein, 1986: 147), the writer asserts her will by articulating her 'speechless agony'. (Interestingly, the doctors communicate by sign language during the procedure, so not to disturb the patient with *their* speech.) Epstein (1986: 162) concludes by stating that Burney writes to 're-undertake her own surgery…to control the knife…to speak for the wound's gaping unspeakableness…reopening and reclosing the incisions in her own body and in the body of her writing'. The language, or 'protolanguage' (Culbertson, in Kilby, 2002: 206), of trauma is here replaced by narrative language, and in this process the event experienced in memory becomes re-embodied.

Culbertson's (in Kilby, 2002: 206-207) main concern is that, in the demystification of the inchoate memories of the body, certain dimensions of experience are lost. Yet, she admits that there is no other way to distance oneself from trauma, to make sense of it, to recover a sense of continuity, both of the self and of community, and thence to universalise experience. For Culbertson (in Kilby, 2002), it seems that history is something to be disposed of, but as I intend to show, history remains with us, in the memory of the body and in the stories that we struggle to say and write.

It is pointless to deny that there is a 'non-verbal outside of language, by which it is conditioned, and upon which it acts' (De Man, 1979: 121). Experience does not correspond with the telling (or writing) of it, which is to say that there is always a gap between experience and its description. Nevertheless, narrativization represents the struggle to constitute (or reconstitute) experience comprehensibly, and is thus expressive of the narrator's attempt to assert a degree of autonomy, as evinced by Fanny Burney's narrative.

If, as we have seen, medical science has, during the course of the past two hundred years, produced docile subjects (Foucault, 1980a; 2003), and if the clinical gaze has been increasingly directed toward the interior of the body, then the language of organs has come to dominate, if not drown out, the speech of patients. Indeed, speaking during clinical examination is often discouraged; an observation exemplified in the statement, 'I can't hear you while I'm listening' (Baron, 1985), suggesting as it does that while the doctor is listening to one story the patient is speaking another. There is a time for listening but that moment is constantly deferred because the patient's story is so often considered flawed, too subjective, or tainted by emotion. In short, the patient's story lacks objectivity, and therefore, credibility (Hydén, 1997; Rimmon-Kenan, 2002). Yet, the impersonal attitude of modern medicine finds, or 'provokes' (Rimmon-Kenan, 2002: 11) its response in the *personal* narratives of the sick. I emphasise 'personal' because I wish to suggest that there are no wholly personal narratives. Narratives are social constructions and, while each of my informants' stories may seem personal, and may indeed feel personal to them, narratives are necessarily co-authored, constructed in a relationship with other people and 'organisations' (Williams, 1984: 181), even or especially those which appear to their authors to be products of a hermetic process.

Narrative aside for a moment, as Laing and Cooper (1971) point out, there is no personal language. Language is a shared medium, the structuring capacity of which determines a certain objectification of experience, a point which has already been observed in my discussion of the power of medical discourse, and in Starobinski's (1983) and Gioia's (2000) comments that everyday speech is already suffused with the language of medicine. To paraphrase Merleau-Ponty (2000: 190), language 'implants the *idea of truth* in us as the presumptive limit of its effort' [my emphasis]. Language is the very expression of the telic imperative to render the world meaningful; to have the final say on the subject, as it were. Language, particularly in the form of narrative, has the additional potential for *incorporation*, not only in the 'me too' response of recognition (Skultans, 2000: 8), in which people recognize that they too may have had a near identical experience, but in a more general feeling of mutuality; that is, 'some degree of transcendence of differences, [a] reaffirmation of common humanity' (Caplan, in Plummer, 2001).

> [W]riting about someone else always involves writing about yourself and vice versa.
> (Jolly, 2005: 215)

As a method of addressing not only the medical 'facts' of illness, but of discoursing on 'the exigencies of chance, necessity and the ways of rising to the unknown [the illness narrative] shares something with Simmel's idea of the 'adventure' as an experience where there is a dropping out of the ordinariness of everyday life, a brush with something alien that is yet connected to its centre' (Radley, 1999a: 780). If illness can indeed be considered an adventure – and narratives such as 'The Red Balloon' suggest that it can – it is perhaps because the experience of illness has extraordinary qualities: the heightened sensibility of the sick person, special treatments to be endured, medications to be consumed at specific times. Consequently, the sick person is endowed with a special, quasi-heroic status, much in the same way that Simone de Beauvoir regarded her sickly childhood friend Zaza (Pilardi, 1999). Certainly, the figure of the sick person as 'survivor' is a commonplace of cancer and HIV/AIDS narratives (Charmaz, 1983, 2002; Frank, 1995; Yingling, 1997). Equally, the terms 'sufferer' and 'victim' are used in many narratives, although as Charmaz (1983) points out, these terms tend to devalue the sick person's sense of self-worth, particularly those who 'hold ideologies…which reveal residuals of the Protestant Ethic' (Charmaz, 1983: 169). Notably, my informants, most of whom had endured some hardships during and after the Second World War, were quite adamant that they did not wish to be regarded as victims, and neither did they consider themselves, or their condition, in any manner special.

That everyday life takes on a new significance, or that its significance is displaced, has already been observed, but the component parts or 'fragments' of life gain an 'additive weight as objects that have achieved an alien independence from the sick person' (Radley, 1999a: 782). Illness thus effects a 'double movement' of displacement *and* addition, and that which is most affected is the person's power and ability to engage in everyday aesthetics; for example, 'the ability to engage in fancies, to contemplate beauty and to create space and time for frivolous activity' (Radley, 1999a: 782). This argument, that in illness people lose their capacity for the realisation and appreciation of beauty (and fun), may seem flippant at best, but it is in this setting – of falling into a 'chasm between the mundane and the terrifying' (Radley, 1999a; 782), in which the unthinkable appears in the guise of the innocuous – that the condition for finding a voice, and the subsequent construction of narratives, is discovered:

> "I didn't think I'd survive the ordeal, to be honest. But, when I came through it in one piece I knew I had to make things better. It's not just a case of *getting better*. You've got to make yourself better. It was an effort at first, especially immediately after the op, and then going through rehabilitation, but I knew I

> had to put my nose to the grindstone, as they say. I made a promise to myself."
> (Elizabeth, 68)

> "You keep telling yourself you'll get through this. I think it was at its worst the month before the operation. I was in a terrible state. I wasn't sleeping much, I was having powerful dizzy turns, and I was gasping for air all the time. I kept wishing for the operation. I just wanted that chance to get better."
> (Frank, 68)

The virtue of the illness narrative resides not only in the way that it explains illness, but in the manner in which illness is portrayed, or symbolised; fashioning 'a *world of being* into which the account admits us, as readers' [emphasis in original] (Radley, 1999a: 784). The illness narrative does not provide simply a representation of life; it is instead a 'performative unfolding of the account' in which the reader is initiated into an 'aesthetic/ethical relationship' with the narrative object (Radley, 1999a: 791). To speak of an aesthetic is not to assimilate suffering with art, for that would be to romanticise the experience of illness. Rather, it is only to say that illness narratives draw upon the same reservoir of symbols that fertilize other spheres of 'art':

> [A]n account of illness should show not just what it means, nor just how it is what it is, but 'that it is what it is'.
> (Radley, 1999a: 793)

Themes and Motifs

> [C]onscious thinking of the aims and focus of interviews must destroy spontaneity, and make the whole process self conscious and almost unbearably artificial.
> (Beaumont, 1953: 475)

Interviews are the stock-in-trade of the qualitative researcher, but they can be 'unbearably artificial' in certain situations. The extracts reproduced in this thesis are all taken from interviews conducted either in the informants' homes or during walks in a local park. The setting in which the narrative is constructed contributes to its presentation and organisation. This is of particular relevance to this study because of the problems faced when interviewing informants within the hospital setting. Initially, I conducted some interviews with out-patients in rooms set aside for that purpose. The informants, generally tired after their rehabilitation session, were not always at their best, but the greater problem was their apparent suspicion of and deference toward me. It became clear that, despite my assertions to the contrary, the informants associated me with the hospital, and it appeared that they felt obliged to speak and behave as model patients.

Although generally grateful for the care they received while in hospital, my informants remained fearful of the setting, which may go some way to explaining why attendance at rehabilitation clinics is generally quite low (Farley et al., 2003; Page et al., 2005). It is not unusual for patients undergoing surgery to face a barrage of questionnaires during their stay in hospital, and although my questions were of a different sort, I believe that the interviews were perceived as extensions of medical inquiry. To remedy this problem, to dissociate myself from the hospital, I decided to conduct all other interviews outwith that setting.

> Often enough in studies of human lived experience, people confound our expectations, even after long and diligent research. They say one thing and do another, conceal what seems obvious, find the ineffable in trivia, dramatise the routine, and otherwise act in ways that to us appear mysterious, courageous, mean-spirited, beatific, or silly.
> (Charmaz and Mitchell, 1997: 193)

At times there is no greater obstacle to the process of research than the researcher himself or herself, by which I mean that the researcher may be too dedicated to a specific theory, or to a research agenda, to allow anything outwith the aims and objectives of the research to emerge, so that when the unanticipated does arise, he or she is at a loss to account for it. Semi-structured interviewing usually entails the exploration and development of specific thematic frames: the 'broad descriptive categories' (Silverman, 1997: 37) typical of qualitative research. The principal themes I intended to explore were: fatigue, anxiety, social dislocation, memory, and the body itself – its capacities and modalities. While these themes give form to the research, the necessary imposition of thematic limits constrains both the researcher and the researched, and obscures the emergence of other themes. However, certain *motifs* emerged during the course of the interviews, motifs that were consistent across the range of informants. As the researcher has an agenda, a plan to elicit certain aspects of social experience, and as that experience (of illness, surgery and recovery) is (objectively) common to all informants, it is inevitable that there will be some similarities in the informants' responses. I use the term 'motif' only to differentiate and draw attention to my informants' themes, *which I did not anticipate*. Whereas my themes were generally abstract – as is so often the way in sociology – my informants' motifs were without exception quite mundane and material: for example, staircases, mirrors, and parks.

Losing Oneself

Like Lyotard (1997: 15), that 'epigon[e] of post-structuralism' (Callinicos, 1996: 5), I adhere to the view that a self does not amount to much, and that it exists *only* in a fabric of relations. In other words, the self is a product of socialisation, constructed in social relationships, and is neither innate, nor need it be essentialised. The view that the self is 'fundamentally social in nature' (Charmaz, 1983: 170), that it is produced by way of a lifelong process of socialisation, need hardly be restated here at length. However, that the self is a social construction is not an opinion generally held by my informants. While I am reluctant to make too much of a distinction between the personal and the social, maintaining the view that the social is the precondition for, and is thus intertwined with the personal, and that the dividing line between the two is at best blurred, I nevertheless cannot ignore the persistence and pervasiveness of the belief in a personal, 'continuous', and coherent self that exists 'behind' the various roles that are assumed in everyday life (Gullestad, in Hockey and James, 2003: 210-211):

> [P]eople undeniably develop a sense of self – a sense of what characterizes, transcending time and situation.
> (Butt and Langdridge, 2003: 480)

> There is no inner man, man is in the world, and only in the world does he know himself.
> (Merleau-Ponty, 2000: xi)

I should restate my position, lest I trip over *myself* later, by admitting that I do not know this 'continuity of self'. The 'I' that does not know this – the 'I' of the 'I am' – is not identical with the self, or to cite Merleau-Ponty (2000: 347), 'I am never quite at one with myself'. The self is a character, a characteristic, 'implied reflexively', of the posited 'I'. The 'I', or rather the 'I am', just *is*, there in its simple immediacy (Ricoeur, 1994: 18). It could be argued then that the self is a consequence of the 'exploratory function' (Merleau-Ponty, 2000: 93) of this embodied 'I'. As an incarnate being I find myself immersed in an already meaningful – cultured – world, a world in which I act and am acted upon. Open to this world, I render it explicit in 'perceptual exploration' (Merleau-Ponty, 2000: 404), elaborating upon it by means of language, yet never quite able to grasp fully the experience of it, for as I take hold of this moment the next succeeds it, therefore I am forever engaged in the process of catching up with experience. Or, rather, experience is continually chasing after appearance. But it is in this cultural world that, 'alone of all expressive processes, speech is able to settle into a sediment and constitute an acquisition for use in human relationships' (Merleau-Ponty, 2000: 190). These relationships bear the form of a linguistic 'community' directed toward, or clustered around, specific phenomena, and the self is produced as an identity that is appropriate (or not) to those *situations*. Thus the self is thematised, realising itself in its communicative activity:

> It [the self] helps the person anticipate their social role while accommodating to what may be fragmentary and inconsistent social action.
> (Butt and Langdridge, 2003: 480)

Returning for a moment to the notion of an enduring, personal self, this phenomenon is predicated upon an awareness of the existence of others, and is no less than the outcome of a 'process of individuation' (Ferguson, 1997b: 1), a civilising process that, whatever its form, whether violent or passive (Elias, 1996: 450-452), focuses increasingly on the differentiated, self-contained, self-regulating 'individual'. The very notion of differentiation implies the presence of others. This awareness of, and openness toward, others is the simple condition that permits a sense of the autonomy and durability of the personal, *private*, self. Thus the fact of our being *homines aperti* is that which facilitates the conception of *homo clausus*. This civilising process is supported by the efforts of science, which seeks out uniqueness of identity, for example, in the building blocks of human biology, and of commerce, which produces commodities that are 'just for you'. The notion of a personal self is perhaps then only a sense of coherence *in* social identity, and that while we daily prove the existence of the social, we yet maintain the belief in a 'true' self.

When people say, 'that's not like me', they are referring only to a character trait, a characteristic that they *believe* they have either inherited or which they have developed over time. The self is then a 'self-concept' or a 'self-theory', which may be considered not as 'a set of internal cognitions, but as a narrative that the person uses in accounting for his or her action' (Butt and Langdridge, 2003: 480).

This notion of the truth of the self, however, is a phenomenon readily witnessed in, for example, reality television 'shows' such as *Big Brother* (the producers of which surely owe the estates of both Orwell *and* Goffman considerable royalties), in which one housemate is generally to be found complaining that another mate is not being himself or herself, that they are 'acting' (a somewhat odd notion *in itself*, given that this is a television show, albeit of a format that falls somewhere between melodrama and wildlife documentary). So, to declare 'that's not the real me' could mean that of all the selves to which 'I' give myself, that is not one of them.

There is no reason to believe that one's self is the same today as yesterday, or that tomorrow it will be the same as today (Rimmon-Kenan, 2002: 19). Kelly and Field (1997: 364) maintain that belief in a substantial, underlying self is a fallacy 'based on the physiology of the person'. Similarly, Burkitt (1999: 76) states that 'the self is primarily based on the feel we have of our body and the way it connects us to the world'. Regarding this sense of connectedness, belief in an enduring self may be founded upon the persistence of pre-modern modes of thought and previous forms of embodiment (Ferguson, 1997a). Thus, in various contexts this belief might be fully justified; for example, in close familial relations, or in friendship. Perhaps the best that can be said is that there is a multiplicity of selves, and some of them are real, until further notice.

'Mirror, Mirror'

> When I look in the mirror I see someone who's finding herself, who has said once and for all it doesn't really matter what role society said I should play. (Rosen, in Shilling, 1995: 7).

Shilling (1996: 7) identifies investment in the body as a 'tightening [of the] relationship between the body and self-identity'. The daily, mundane routines, attendant to the care and presentation of the self, represent, or rather, embody the struggle against time and inevitable death. Although this position has been criticised as 'simplistic' (Finkelstein, 1997: 153), attention to appearance goes some way to presenting a self that is possessed of social value. This is particularly significant in illness, when the fragility of existence is most keenly felt, and the patient's sense of self-worth is at its lowest ebb:

> "The night before the operation I took a shower and I was drying myself, and then wiped the mirror so I could, you know, do my hair, and you know how dark it is in there, in the bathroom, and I couldn't see myself very well, and just then I had this strong feeling that I was...fading away into the darkness...but I thought, 'no, no, don't be silly', and I wiped more steam off the mirror and looked carefully [laughs], really, to see that I *was* there. The funny thing is, it wasn't that dark but it just felt like it at the time...it *felt* dark."
> (Wilma, 62)
>
> "You know, lots of people have these mirror stories...in which they *really* look at themselves. Perhaps they're significant...do you think?"
>
> "I think I was just feeling sorry for myself..."
>
> "I *knew* you were going to say that."

> "Oh [laughs] I was...it was just in the shower, you know, time to think and that...everything was different and I was worried I suppose...about the next day...you know?"
>
> "When you say 'everything was different'...?"
>
> "Mmmm, well, it's as if it wasn't me...this is hard...but you know how sometimes you feel like parts of you aren't you? It was like I was washing something that wasn't me, but it felt like me too, I mean it *really* felt like me. It was a bit like watching myself, but not like one of those...um..."
>
> "Out of body experiences?"
>
> "Uh-huh, yes, not like that, no. I think it was just having the time to myself. I was on my own and I was scared."

The foregrounding of the body in illness is accompanied by a loss, or displacement of the person's sense of self (Charmaz, 1983). As the perceptual horizon shrinks, the everyday world of familiar things takes on a different aspect. I could cite various sources in which mirrors represent, for example, a means of seeing the future (in the film, *Dead of Night*), or the boundary between life and death (in *Orphée*). I could suggest that the mirror image is the person's double, albeit in reverse, but this would perhaps be to over-analyse and to draw too much of a comparison between the illness narrative and fiction. Instead, it would seem that this informant, facing the prospect of surgery, is expressing an anxiety about her future. Within the 'dehumanising, technologised environment' (Meerabeau and Page, 1998: 297) of the hospital the patient withdraws into an affectless state in which she experiences a loss of emotional rapport with the world, a loss of contact with normal oscillations of feeling. When the above informant states, "I was on my own and I was scared", she might be expressing the feeling of being disconnected from the larger, *collective* sphere of emotion. The mirror motif appeared in other interviews:

> "I've been on my own eight years now...eight years since my wife died. But...and this is what makes me think of M. [his wife] now...the way I felt in the weeks before the operation...and now too. She'd have said I was vain...she used to say that...you know...too fond of myself. I've always taken care of my appearance, still do...but in the weeks leading up [to his surgery] I kept looking at myself in the bathroom mirror. It's as if I was looking for something. But it didn't dawn on me for a while. You know when you look in the mirror, *really look*, and you don't recognize yourself? You see yourself in a different way. You're not looking at your face in a...oh...you know, checking for nicks and hairs and that. You see your face, like it's in the background. Oh, I don't know...does that sound daft? [...] Okay, I couldn't stop doing it. It was like a nervous tic. Every time I went to the toilet I'd look...check to see...I don't know...whatever I was looking for...see if it was there. [...] No, I don't do it as much...just now and then, to see if anything's changed."
> (Frank, 68)

Illness forces a particular realisation upon the 'sufferer', which is that, 'the variety of responses by family, medical or non-medical observers – of facing an 'abyss', a glass 'wall', etc. – can be seen as modes of self and other recognition, evoking an awareness of self in respect of its crucially constitutive moment: the other self' (Zaner, 1981: 246). Charmaz (1983) states that 'loss of self' is a fundamental form of suffering, engendered by heightened – and paradoxical – self-concern about who and what people see themselves becoming, and by the diminishment of valued self-images from their past. Doubtless the above informant values his self-image and seeks affirmation in his reflection. The informant cited below is quite clear about what she sees in the mirror:

> At times I'd get very tearful, especially when I caught sight of myself. I'd say I was quite disturbed for a while, before and after the operation, especially with the pain after. I was all hunched up. I was very withdrawn. I'd look at myself and I looked awful. I was turning blue. I'd see it in other people's faces, too. Some people said I looked really ill. They'd say, 'oh, you don't look yourself at all".
> (Marie, 64)

Coherence of self-identity across the lifecourse is not a matter of psychological continuity alone, as Gallagher (2001: 147) states. Indeed, the 'meaning' of illness is not to be found in the psychology or physiology of the person. It is found 'out there', in the social environments in which physiological states are lived. Meaning is 'located in the procedures people employ to understand their experiences, and in the cultural resources, categories, and folklore they summon to do so' (Hilbert, 1984: 39).

Narrative Identity

An affinity between narrative and identity is indicated within various disciplines – sociology, literary studies, psychology – but, like Rimmon-Kenan (2002), and after Ricoeur (1994), I replace the term 'identity' with 'narrative identity': a form (of identity) that is neither essentialised or static. It is curious that, contrary to current post-modern literary trends, which stress fragmentation and destabilisation of identities (Lash, 1996; McNay, 2000), illness narratives 'tend to preserve, even strive for, coherence and continuity' (Rimmon-Kenan, 2002: 19). The assumption of continuity may only be a recent (and specifically western) social phenomenon, and indeed, in the example of serious illness, a tacit adherence to stable identity may prove untenable. Equally, the biographical rupture engendered by illness may reveal that continuity is in fact something of an illusion (Rimmon-Kenan, 2002: 19). This position, I believe, complements Herzlich's (1973) statements regarding the continuum of health:

the best that can be said is that we experience health in flux, 'one day at a time' (Rimmon-Kenan, 2002: 19), and it should not therefore be assumed that the health status of a person is a given.

While narratives of fragmentation (Middlebrook, 1996), and 'chaos' narratives (Frank, 1995), address the issue of continuous existential disruption, and the near impossibility of 'writing chaos' as it is lived through, these are not the narratives of this study. The experience of heart disease has, for some, been disruptive, and has certainly brought chaos to their lives, for a while at least. But while some of my informants realise that, "I'll never be the same again", theirs are most decidedly stories of a quest for stability and community:

> "I wouldn't want to go through *that* again, but I must say, I've made lovely new friends, and I feel much more positive about myself...about everything. The rehabilitation clinic was great fun after all. I've had lots of support from people, and I'm enjoying my life now, which I didn't before. I've got my health back. A lot of good has come out of it. [...] I think it's changed me in some ways, yes. You can't go through something like that and not change. I don't know, maybe you can. I've met people at the hospital, and it's like water off a duck's back to them, but I think, 'no, you're kidding'. They're just putting on a show, pretending it was nothing. How could it be nothing? I don't think they really appreciate what they've got, what everyone's been through...their families and friends, and all that. It doesn't just affect *you*. [...] At my age, though, I doubt I'll go through that again."
> (Kate, 75)

Regarding continuity, it could be argued that the informants of this study, while aware of their existential fragility, nevertheless strive to regain at least some small sense of a previous self-identity:

> "Even if it comes back and if I have to go for more surgery...not that I'd want that, no, but, even if it happens all over again, at least I'll be able to remember how I coped with it. I hope I will. [...] It changes you, yes, but you slip back into the old routines. It's quite an ordeal, but you can get your life back again. It could be worse."
> (Robert, 59)

If illness narratives serve to bridge the gap between the before and after of illness, then narrative describes a continuity, 'governed by different emphases' (Rimmon-Kenan, 2002: 13), that redresses the disruptive effects of illness. Illness narratives more often stress continuity over fragmentation, and as such, are typical of the classical narratives of modernity. In seeking their 'happy end', such illness narratives are characteristic of the ideological, teleological thrust of the Enlightenment quest for emancipation, and as such, meet the telic demand – 'for interpretation *and repair*' [my emphasis] (Leder, 1990: 81) – of illness.

The already meaningful world is one of narratives. Some take the form of enduring, powerful, 'master narratives', upon which are modelled the various stories that we tell each other and ourselves. This is not to propose that master narratives possess a wholly normative function, for the 'narrative of resistance' enables the adoption of a critical stance toward, or non-identity with, dominant norms. Indeed, the 'narrative of resistance' is, arguably, the master narrative *par excellence* of the Enlightenment. That we recognize ourselves, understand ourselves, in and by way of these narratives, suggests an identity with narrative, or an identity that is forged in engagement with narrative, which, we must remember, is always constructed with others. A reconciliation is sought between 'master' (culturally approved) narratives and the sick person's own 'personal', or 'micro' narrative. In other words, in its encounter with narrative, the self seeks out its *virtual* and *actual* social identity (Goffman, 1990). That the self finds identity in and with the narratives of others supports the notion of mutuality, posited, for example, in some specifically feminist narratives (Martin, 1987; Salvaggio, 1999).

For Rimmon-Kenan (2002), the concept of narrative identity obviates the problem of the adequacy of the illness narrative as a method of explaining reality, because narratives of illness cannot be contained within generic categories: they are always changing form, altered by those who take them up.

The disruption caused by serious illness is, according to Rimmon-Kenan (2002: 21), often associated with recurrent motifs. These motifs suspend textual fragmentation, forming connections between past and present, between health and illness, and, in recovery, between illness (past) and health (present). For Fanny Burney (Epstein, 1986) the motif was the handkerchief her surgeon placed over her face. Her limited vision during surgery seemed to represent the distance that she sought from the experience, and which she attained (partially) in her writing. As for my study, if, for example, staircases present a problem during illness, and are identified as physical and psychic obstacles, then it could be said that the sick person forms identity through these objects. Initially, it is a negative association in that the object eludes the intention of the person, but later, the object is regained, as the following section reveals.

Walking the Walk (While Talking the Talk)

> Every story is a travel story - a spatial practice.
> (De Certeau, 1988: 115)

> Every site is haunted by countless ghosts that lurk there in silence, to be "evoked" or not. [...] Sites are fragmentary and convoluted histories...folded up ages that can be unfolded but that are there more as narratives in suspense, like a rebus: symbolizations encysted in the body's pain or pleasure. "I feel

> good here" - an effect of space, set apart from language, where it suddenly bursts into light.
> (De Certeau, 1985: 143-144)

> As long as you are not abandoned by your memories, you are free to be abandoned with them. [...] Do not waste the little time left. Retrace your steps. Your memories will come to your aid.
> (Bobbio, 2001: 12)

I turn now to the exploration of embodied practices such as movement, exercise, and my informants' activities outwith the setting of the cardiac rehabilitation unit. As we have seen, a consequence of heart disease is a decline in the ability to negotiate ordinary spaces such as stairs and inclines of any sort. Walking, sometimes even on flat surfaces, is itself quite a task. For many with heart disease, the ordinary activities of daily life become increasingly problematic. An essential aspect of their recovery of good health is the ability to return to the spaces – or more accurately, places – that the informants previously occupied with relative ease but, which in illness, became alien to them. To examine this further, as well as interviewing informants in their own homes, I used the 'go along' technique (Kusenbach, 2003), sometimes walking with informants in a local park as they went about their daily exercise routines.

During the course of home-based interviews it became apparent that parks were important locales for many of my informants: the park represented the opposite of the constrictive space of the hospital, and of illness itself (Leder, 1990: 80-81). I therefore decided to go along with some informants on their walks in and around one local park. It is one thing, particularly in these sedentary times, to talk about walking, but quite another to actually walk, and I wanted to find out if my informants really accomplished this task, or only talked about it.

It is argued that the 'go along' aids in accounting for 'the complex and subtle meanings of place in everyday experience and practices [and as such] brings greater phenomenological sensibility to ethnography' (Kusenbach, 2003: 455). (Recording interviews while walking presented only minor problems, for example, in the quality of recording, and the necessity to take occasional notes during and immediately afterwards as an *aide memoire* to the task of interview transcription.) My initial notes referred to just how much elderly people talk with each other (and engage strangers in conversation) during their walks. However, my informants did not at first wish to spend too much time in conversation with old friends and acquaintances, preferring instead to 'push on' with their walk. De Certeau (1985: 129) writes that 'history begins at ground level, with footsteps [...] a style of tactile apprehension and kinesic appropriation...spatial creations...they link sites one to another', and he continues by identifying walking with speaking. First, walking is a process of 'appropriation of the topographic system (just as the speaker appropriates and assumes language)'; second, 'it is a spatial realisation of the site (just as the act of speaking is a sonic realisation of language)'; and third, 'it implies relationships between distinct positions...(just as verbal utterance is "allocution")' (De Certeau, 1985: 130). The informants seemed very eager to reassert (and re-formalise) their position within the interaction order of the park, and an ability to walk briskly, to cope with the various circuits in the park, was a prime indicator of their competence as human beings. Walking was, at this point of re-entry, more important than talking. The park was to them a meaningful place, and as such, it was of great importance that they re-establish their relationship with it:

> "Yes, I went to the park three days after getting out of hospital, but that was far too soon. I couldn't walk very far and I didn't make it to the pond, which is where I usually end up...for tea and cake with friends. In fact, I barely managed to go a few steps beyond the main gates. I wanted to go there [to the park] to let everyone see I was back...you know, 'here I am'. I wanted it to be

> my park again. We spend so much time there, unlike the weekend walkers, as we call them. In fact, I don't always go at weekends, because of them."
> (Elizabeth, 68)

The 'transcendent and reflexive aspects of lived experience...grounded in place' (Kusenbach, 2003: 456) are quite apparent in the above extract, as are De Certeau's (1985) comments on appropriation, realisation and allocution. The walker 'takes up' the task of walking again, finds her style of walking, and establishes, or formalises, her position (in relation) within the setting. 'Finding a style' (of walking) entails a recovery and modification of appropriate embodied dispositions. At first, the informant cannot walk far, but during the course of visits to the park she regains strength and draws upon and reconstructs her *habitus* – that is, skills, body-schemas, and techniques – modifying it according to the objective conditions that prevail – for example, distance and time – until she attains a 'style' of walking that is appropriate, and which meets her needs. Finding her style was not restricted to this situation, for previously this informant (and others) stated that, immediately after leaving hospital, she found that staircases remained insurmountable:

> "For the first week I just couldn't manage the stairs...they're very steep...I found it was easier if I went up them on all fours, you know, with my hands out in front. I must have looked ridiculous, but I didn't care. Anyway, nobody saw me, and it worked. I could go up quite fast. Coming down was quite difficult, though. I tried coming down sitting...on my bottom, but that wasn't a good idea. So I'd come down the same as I went up, on all fours, backwards."
> (Elizabeth, 68)

In this situation the standard repertoire of culturally approved styles is not adequate to the task of 'getting around'. This informant, and others, used a style that was drawn from memory; that is, she used a style that was more appropriate to children. Thus, experience is modified by memory. It could be said that climbing the staircase became something of an adventure for this informant. While adults generally tend not to climb stairs in the above manner, the style is itself a 'body technique' (Mauss, 1979), that is, an effective and traditional (historical) bodily practice. This method of tackling stairs was effective in the specific situation of the informant's home, particularly as nobody saw her, but it is unlikely that she would have approached stairs in this manner in public, for that would doubtless have met with cultural disapproval. Another informant discussed her initial difficulties regarding mobility and motility:

> "Not long after the operation...a couple of days, I think...they [rehabilitation nurses] made me walk round the ward. I was slow, but it was okay...'just take tiny steps', they said. Then we were taken to the stairs the next day and we had to walk up one flight. It was terrible. I couldn't do it...my legs were like lead. They made me do it...lifting my legs *slowly*. It wasn't the pain...just the sheer weight. I couldn't believe how tired I felt...just a few stairs. [...] When I came home I didn't want to go anywhere. I just sat in this chair for a few days. Then I went to the park. That was nearly as bad as before. I was so slow, but I kept thinking, 'tiny steps, tiny steps'. You've just got to find your way again.
> (Anne, 65)

Some of my informants were not only attached to the park, because it was where they met up with their friends, but they felt that they had a place in the park itself. The spatial practice of walking is thus associated with a specific 'social architecture' (Kusenbach, 2003: 456). It is in the park, 'my park', that this informant reasserts herself, and reclaims this previously out of bounds space as her own:

> "It was good to be back in the park, but it felt strange at first, because I'd been away for so long. It all felt very new...it was like going there for the first time, seeing what a beautiful place it is, the way it's all set out. I felt a bit like an explorer at first. That feeling's passed now, but I still feel different here...better than before, even before I became ill."
> (Elizabeth, 68)

This informant's environmental perception has doubtless been altered by the experience of illness and recovery. What was for a while lost to her is now recovered as she traces out old paths, reacquainting herself with the environment, and clearly displaying her regained mobility and stamina. The body, in this situation, its 'management...central to the acquisition of status and distinction' (Shilling, 1996: 127), is a form of social capital. As such, the active body is a speaking body in that it says something about the person's self-worth, for as Shilling (1996: 85) notes, 'the vocabularies of body idiom used by people to classify others are also used for the purposes of *self-classification*' [emphasis in original]. Comparison with others is a significant aspect of recovery, for no matter how ill one feels, there is always someone who acts as an example:

> You know, it could be worse. I mean, there's S. [a friend], she hardly ever misses a day, even when it's raining, and she's had a terrible time of it...cancer, rheumatism, tinnitus, and goodness knows what else. If she can do it, so can I.
> (Elizabeth, 68)

Radley and Billig (1996: 221) note that a person's illness (or health) status should not be assumed as given, but that attention should be paid to the ways in which people 'constantly construct or reaffirm their own health in different circumstance and in different relationships [and that] health and illness are imputed'. As such, illness narratives articulate both person and world, such that the relation to others is always one of comparison.

It was evident that the motif in this section of the interviews was the park itself. While the rehabilitation unit was the 'springboard' to a healthier lifestyle, the park was where many of my informants felt most *naturally* at ease, and significantly, the place in which they were most able to assert their self-identity. As stated in chapter three, most cardiac rehabilitation regimes do not begin until twelve weeks after surgery, by which time the patient is, generally, fairly active. Thus the park, for my informants, provided the setting in which the serious business of rehabilitation was first taken up.

Many of the older people who use this park know that two-and-a-half times around the pond represents a walk of one mile. They know this because one of them, an informant of mine from a previous study, borrowed a pedometer from a park attendant and measured it. Now they refer to the pond as 'the bypass', and it has become the centre, the heart if you like, of this little community of people who have undergone coronary bypass surgery. Walking has, for them, become something of a game, which is not to say that they do not take their exercise seriously, because they do, but in framing their practice as play they 'amplify the experiential depth of their routines' (Kusenbach, 2003: 470). The purely functional aspect of exercise is 'thickened' by the additional layers of meaning that the informant adds to this rather mundane daily practice. That these mundane practices become 'so saturated with meaning and experiential depth that they turn into symbols of someone's personal identity' (Kusenbach, 2003: 471) was made apparent to me when I realised that, identified as a shifting companion, walking with different informants, tape recorder and notebook at the ready, I quickly became known as 'the heart guy'.

If walking in the park is a significant narrative element, it is at least because the ability to walk, the determination to reassert one's 'place' in the social architecture of the park, and to display a self that is competent and balanced – that is, in harmony with the body – are exemplifying practices which represent a 'showing forth of qualities' (Radley, 1999a: 780) that capture the narrator's newly established perspective.

The park, its history, its features, and the people in it, all potentially components of narrative, connote a totality in which the threads of the story are drawn together. The objects here are accorded a new power of signification, standing for something that they previously did not: for example, the pond is given a quantitative value – two-and-a-half laps equal one mile – that enriches the qualitative experience. These sensuously felt objects, both immanent *and* transcendent, then come to exemplify specific, that is, historical, modes of being. Thus the mundane and the sublime appear in concert, united by the memory of the body. The memory of place is always that of what one did there (De Certeau, 1985: 144), of a bodily relation in time and space:

> "I've been coming here [to the park] for over sixty years. I met my wife right there [points to the middle of the pond]. We used to skate on the pond in those days...a great way to meet the lassies. I haven't seen anyone do that for a long time...skate. It was great fun."
> (Tom, 67)

In illness the world is drained of significance, or rather, it is accorded a largely negative significance. It is a world of impossibilities, of dys-abilities, of spaces that cannot be walked, of stairs that cannot be climbed, of mirrors that reflect something other than oneself. Recovery entails a re-occupation of the spaces and dispositions that were lost to illness, so that they no longer 'stand out' as problems.

Keeping Oneself Occupied

Aside from the 'sick role', illness is an occupation, in two senses of the word. First, illness occupies the body, much as an invading force occupies a territory. This is evident in that terminologies of combat are employed in medicine and ordinary speech – for example, cells attack invading bacteria and viruses, one 'fights off a cold'. Describing the onset of rheumatic fever, Thomas Lewis (1944: 194) wrote, 'the modern conception of the disease is of an organism that invades the blood-stream…'. Interestingly, (or perhaps not), rheumatic fever, now rare (in the developed world) thanks to more sophisticated antibiotic therapy than was available to Lewis, is recognized as a condition that arises from a streptococcal infection. The body's own bacteria attack the infection, and in so doing, scar the valves of the heart (Drake et al., 1997: 107-108). The body thus attacks itself. Sawday (1996) also reminds us of the mediaeval figure of the body as a house or castle, and we are doubtless familiar with the expression 'my body is my temple'. Thus, like a temple, a house, or a castle, the body is something that must be defended.

Second, and more importantly, illness is an occupation inasmuch as the term denotes the work that goes into recovery, the effort that is required on the part of the patient to 'fight' illness (Herzlich, 1973: 119-125):

> "It's no use just thinking about it. You've just got to drag yourself out and walk. There are days when I just can't face going out. But, I force myself, and it usually works. I'm usually glad I did it. You've got to make an effort…otherwise, what's the point in having the operation."
> (Kate, 75)

Thinking of this informant 'dragging herself out', I am reminded of a line by Beckett (1958): 'If I had the use of my body I would throw it out of the window.' That I remember this line reminds me also that fiction informs life as much as life provides the subject for fiction.

'Welcome to the Zipper Club' (Krusty the Clown, in *The Simpsons*)

> "A young doctor told me that Mr. A. [informant's surgeon] does nice scars...he'd leave me with a thin straight scar. Mine's not straight."
> (Margaret, 65)

The surgeon's knife slices through skin and flesh, and then an electric saw cleaves the sternum (breastbone) from top to bottom. The ribcage is spread open and the heart lies fully exposed, ready for surgery. The patient on the table could almost be a partially dissected cadaver. In recovery, as a consequence of the sternotomy, the patient will experience significant musculo-skeletal discomfort, described in some manuals as musculo-skeletal insult. For a coronary artery bypass, the patient's own veins are harvested from the lower leg, thus the patient will have additional scarring on the calf. Something that belongs to one part of the body is taken out and moved elsewhere. In the case of valve replacement, something that is quite foreign to the body – a pig's valve or a mechanical prosthesis – is implanted.

The sternum scar, six to eight inches long, reveals the presence and activity of the surgeon: it is a (permanent) signature written on the body. In Western culture, the scar is generally viewed with some distaste – a sign of violence or disease – although Gilman (2001: 121-124) notes that the duelling scar, particularly in nineteenth and early twentieth century Germany, was a mark of distinction, of manliness and 'racial' purity, and that some who wished to 'pass' as German gentlemen actively sought cosmetic surgery to replicate the marks of the gentlemanly art of duelling. The scar, in Gilman's (2001) example, is a mark of authenticity and membership of a community, whereas the cosmetic scar, if detected, is the brand of a fraud.

Two years ago I attended a photographic exhibition of scars. The exhibition was held in a café used as a base by bicycle couriers, and the scars were theirs. I interviewed two couriers who both displayed their old wounds to me: 'car door, last April', 'dragged along by a bus, two years ago', 'altercation with a lamppost, February'. The couriers' bodies were like a map of the city, each scar corresponding to a spatial and temporal location. Their blasé attitude toward their bodies, their seeming fearlessness, was expressive of their sense of belonging to an élite group. Similarly, the sternum scar, although generally hidden, indicates membership, and is a topic of discussion among some former patients:

> "Yes, we compare scars. Silly, isn't it, they're all pretty much the same, aren't they? But at first it was really horrible. I cried when I first saw it. It made me realise just how much I'd been...ravaged...I don't think that's the right word, but it made me realise I'd been torn apart. I think it's because of that you want to show it to some people...'look what they did to me!' But it's like a badge too. Sometimes I see a little bit of a scar on someone, you know, if their blouse or shirt is unbuttoned, and I think, 'you've been through it too, you know what it's like'. Sometimes I want to say something, just a word of encouragement, but I don't. I'd be too embarrassed for them, in case they hadn't meant to show it. It's quite a private matter...the scar. I feel a bit ashamed sometimes, it's so...ugly. "
> (Jane, 62)

That the scar indicates some sense of shame is supported by Gilman (2001: 48), when he states that the surgical scar hides the patient's secret. But the presence of the scar may also reveal that secret. The very sense of a secret, of something hidden, may imply a degree of shame, and speaks of a moral value attached to bodily integrity. This is hardly surprising, given that in a culture of risk assessment and management, in which the social-behavioural basis of disease is stressed in order to heighten public awareness of personal responsibility regarding the care of the body, 'discourses of blame' (Morgan and Scott, 1993: 8) are attached to conditions such as coronary artery disease. The mark of disease on the body is thus perceived as a 'residue of indulgence' (Becker, 2000: 101):

> "I felt different about it before. If I heard of someone having a bypass I'd probably have thought that they deserved it somehow...that they'd not taken care of themselves...a heavy smoker, drinker, that kind of thing. But now I don't feel that way, but that won't stop people thinking about *me* that way. I've never smoked and I hardly drink at all...and I'm careful about what I eat...well, for a good while anyway. After the op I felt as if I'd been punished, it hurt so much, that deep pain in the bones...sheer agony for a while, I cried, and I still get the pain now, for shorter periods, but that's nearly a year since the op...and the scar, it's hideous. It's no use to think this way, but I still wonder sometimes what I did to deserve it.
> (Marie, 64)

The above informant previously associated heart disease with specific activities – drinking and smoking – and, as a non-smoking, occasional drinker, excluded herself from that 'stigmatised' group. The scar, however, is self-validating, representing something real (the presence of disease, and surgery) and saying something about the bearer (deserving or undeserving, violated, healthier).

I have already suggested similarities between the experience of heart disease and the ageing process – reduced mobility, shortness of breath, fatigue – and while I could question the distinction between the breathlessness associated with ageing and with that of heart disease, I must strongly assert that my informants did not think of themselves as old people, or if they did, then they did not regard their age as particularly problematic. We may wonder if people above the age of sixty are susceptible to cultural pressures regarding the care and presentation of the body, but, as Featherstone and Hepworth (1982, 1995, 1996), and Turner (1995a) have observed, ageing is not what it used to be:

> [T]here is an inherent tension between the inner reflexivity of the subjective self and the outer biological degeneration of the body.
> (Turner, 1995a: 258)

> "As you get older you expect things to go wrong. You can feel young in your head but you feel it in your bones, getting older. You just can't do what you used to do all the time. You slow down, you ache, and you start to sag in all the wrong places. It can't bother you, you can't let it bother you, but this surgery really did for me, and the scar...I always tried...still do...tried to take care of myself...but the scar, it's like the final insult. All these years I've been taking care of myself, and I'm not being vain when I say I looked good. I was never short of dancing partners when I was younger. I've started dancing again. But now I've this horrible scar...and it's not the only one, but it's where it is that gets me...and people joke and say, oh, you should have got them to put a zip on it'...I don't know how many times I've heard that one. Ha, bloody ha! I suppose the operation added years to my life...yes, it probably has done that, but it's taken something away from me too. I don't think you can ever feel the same again after something like that."
> (Eleanor, 67)

This informant experienced significant post-operative complications, and although she is much recovered, her experience was particularly traumatic. Her scar is quite ragged and she joked that her surgeon must have had a bad round of golf beforehand. The scar, for her, is more than just the locus musculo-skeletal 'insult'. It is an insult to the integrity of her appearance and of her image of herself. The surgical scar is a mark of inauthenticity (while simultaneously it represents something real), intimating that the bearer is flawed (Gilman, 2001: 124). While the possibility of further surgery lends some verity to the zipper joke, the scar also has a liminal quality I that it represents the boundary between the interior and the exterior, between the private space of the body and the public space of the social world. The scar reminds its bearer that the interior is but a cut away:

> "Yes, I worried about the wound opening up. I read a story about that happening. It scared the hell out of me."
> (Marie, 64)

> "I felt really tender for ages afterwards. I kept worrying that it [the scar] would burst open. I was really worried. I'd get these sharp pains at the top, where the wire is [surgical wire is used to bind the sternum] and I thought it was coming loose. You know how they tell you to sleep holding a pillow to your chest, to support the chest? I still do that."
> (Andrew, 66)

Fear of the wound reopened speaks of anxieties regarding the inside of the body – the 'anonymous visceral domain' (Leder, 1990: 38) – leaking to the outside, just as a sudden, inexplicable nosebleed may cause concern. The outside of the body is subject to 'a measure of personal command' inasmuch as 'I can' (Leder, 1990: 49) choose to pick this up, walk over there, jump up and down, and so on. In short, I have volitional control of parts of my body (Leder, 1990: 49). However, I cannot stop my stomach from 'rumbling', and neither am I aware of the circulation of blood in my veins, the action of my kidneys, liver, and other internal parts. The interior of the body is then a foreign land, its mysterious workings necessarily taken for granted. I catch glimpses of this mysterious interior, this 'hidden geography of the body' when I look at an X-ray of my chest, or an echocardiograph of my heart, but, somehow it is never 'my body'; rather it is 'the body' (Sawday, 1996: 7).

Doubtless the informants will eventually be able to gain the distance from their experience that Burney (Epstein, 1986) achieved, but the scarring of their bodies remains as a mark on their biography. The sternotomy scar meets the definition of stigma, as 'a mark made by a pointed instrument, a brand; a visible sign or characteristic of disease' (*OED*, 1990). It may seem excessive to focus upon such an unavoidable consequence of life-saving surgery, and given that some of the informants had other scars from previous, different surgeries, it may seem odd that they experience difficulties in coming to terms with the sternum scar. But, in a culture that stresses a youthful, healthy presentation of self (Featherstone and Hepworth, 1982: 118), to be older *and* in diminished health, and to bear the sign of age and disease, runs contrary to valorised images of embodiment. The interview extracts suggest that the scar, as an *aide memoire*, written on the body, is a constant reminder of the informants' status and vulnerability:

> "I think it's where the scar is, right down the middle like that. The left side always feels weaker to me. It's like I've got a good side and a bad side."
> (Margaret, 65)

Seventh Narrative: The Loneliness of the Long Distance runner

Do you remember Bob? Every now and then I meet Bob. Rather, I wave to him as he goes running by. After the disaster of the balloon angioplasty he decided to shape up and now he runs a few miles each day, sometimes as many as ten, he says. Bob's in his early seventies now, but he still works as a part-time college lecturer and, as a skilled carpenter his furniture is in great demand. But what Bob loves best is running. Sometimes he stops for a brief chat and I ask if his heart's still in good condition. He says that he's better, of course, but he admits to worrying about it much of the time. I ask if he isn't pushing himself too hard by running every day, but he says that running helps him to forget his anxieties about his arteries. I ask him what he thinks about his arteries, and he replies that he imagines them clogging up again, and he admits that he's a bit scared to remain stationary for too long. I believe him because I think that Bob is haunted by the memory of his terrible experience. I imagine him, solitary, running and running, never quite able to escape his memory. Or perhaps he's running after it, trying to catch up with it. I can tell that he's anxious to resume his run and I joke that the only exercise I take these days is lugging my book-filled briefcase to and from work – academic aerobics. Bob asks if I'm still working on my thesis, and he always inquires politely if he's going to be in it. I reply yes, of course, you'll run right through the story.

Chapter Five: Toward Interpretation

> The meaning of the story is not immanent in the text. The process of theorising, analysing, and categorising personal narratives is shot through and through with the imagination and ways of seeing of the interpreter.
> (Bochner, 2001: 136)

> [I]magination [is] as important as rigour, meanings as important as facts, and the heart as important as the mind.
> (Bochner and Ellis, 2003: 506)

Narrative analysis, as a form of sociological inquiry, has become increasingly (and problematically) privileged. Current attention to 'illness narratives' (among others, Atkinson, 1997; Ellis and Bochner, 1999; Frank, 1995, 2000, 2001; Kleinman, 1988; Radley, 1997, 1999a, 2002; Williams, 1984) is, perhaps, emblematic of a recuperation of the human subject, and marks a return to and recognition of the social actor's standpoint as a source of valid knowledge. Interest in narratives is indicative of a greater trend within the social sciences, which are currently witness to an efflorescence of alternative epistemologies that seek to challenge and subvert the orthodoxies of, for example, positivism, realism, and post-structuralism. The legitimisation of the illness narrative, as a form of social scientific inquiry, is illustrative of a general tendency, within late modern culture, that emphasises the significance of individual and lay beliefs (Emslie et al., 2001; Radley, 1996), and which is itself a consequence of 'the loosening of the authority of the grand narratives of science and medicine' (Bury, 2001: 265). Thus, the turn to narrative accounts of illness, and consequently it seems that every conceivable medical condition now has its corresponding narrative. (Perhaps we may soon look forward to a probing study of runny noses.) Despite, or perhaps because of the proliferation of illness narratives – which, as a topic of interest to sociologists, are a fairly recent addition to the discipline – they have yet to gain full approval (Atkinson, 1997; Atkinson and Silverman, 1997).

In this chapter, following an introductory discussion of narrative form, I propose firstly that, to some extent, social scientists are sceptical toward illness narratives because sociology, as a practice that lacks the authenticity of self-belief, is suspicious of voice, particularly of voice belonging to those of whom it writes. In the positivist view, ordinary speech lacks objectivity and is value-laden, while at the opposite end of the spectrum, post-structuralists, in their privileging of text, are critical of voice either because language 'speaks' its subject, or because subjects may express politically incorrect – racist, homophobic, or Eurocentric – views (Charmaz and Mitchell, 1997: 194). Ordinary speech is deemed to be either a flawed medium of description that cannot reliably describe phenomenal existence, or, which simply reproduces it by encoding existing forms of power.

Secondly, I want to stress that illness narratives are the ordinary tales of ordinary people, and that there is no reason why they should be accorded a privileged status over and above other forms of data-gathering (Atkinson, 1997: 326). However, in providing an insight into how experience is organized and explicated, and as a social structure by which intersubjectivity is actualised, narratives may yet, as Atkinson (1997: 341) urges, be regarded as social facts, and as such, recognized as legitimate topics of investigation.

I intend, therefore, to discuss some problems arising from the narrative turn. I do not argue that narrative provides unimpeded access to the human subject's reality, but neither do I adhere to the strictly objectivist view that the informants' truths can only reveal themselves through the 'transparent mechanism' (Charmaz and Mitchell, 1997: 194) of the scientific researcher. The researcher, as a human subject – an embodied person – is only as transparent as the subject of research, despite prevailing notions of scientific objectivity. Narratives of experience are 'as conventional and as artful as any other mode of representation', and therefore it should not be implicitly assumed that they provide 'untrammelled access to a realm of hyperauthenticity' (Atkinson, 1997: 341).

The illness narratives of this thesis are, in a sense, works in progress, which is to say that there are no final, unequivocal statements to be made about them, no grand sociological conclusions to be drawn from them, and little regarding future health care policy suggested by them. Rather, the purpose of this thesis is to evoke the world of illness in order to illustrate the mundane, therefore general, predicaments of ordinary people. The illness narrative may represent a political accomplishment, particularly if it embodies the voice of lay experience (Radley, 1996) speaking out against the inequities inherent to the practice of medical science. It is the capacity of such narratives to speak *in general*, to provide a universal voice that challenges, or engages in dialogue with, the master narratives of, for example, medicine, patriarchy, and class, that is of importance.

These illness narratives are quite clearly co-authored. They are the end result of semi-structured, in-depth interviews. My informants have never previously written about their experiences, but this does not mean that they have not employed narrative techniques to help make their lives more meaningful; for 'the concept of narrative is not limited to written or oral discourse [it is] one mode of experiencing, perceiving, and interpreting the world, as well as negotiating identities' (Rimmon-Kenan, 2002: 22). Even if the informants are not the sole authors of their own lives, it can be argued that they are, at least, competent readers. Certainly, in telling their stories they adhere to common, structured, recognisable forms of expression. When asked if they ever thought of their lives as narratives, the informants in this study replied similarly – with a look of mild puzzlement. I decided to revise the question:

> "Forget narratives. Could you or do you ever think of your life as a story?"
>
> "I don't see why not. People write biographies and autobiographies, so yes, why not? You're born, you grow up, work, get married, have children, then they have children, you become ill, and then later you die. That's a story for you."
> (Fred, 70)

While the above extract may contain the bare bones of a story, it requires some fleshing out. Although it depicts an ordered series of events, there is no detail, no real sense of a person telling a story; it is little more than a list. What constitutes a narrative, then? There is some agreement on the definition of narrative (Prince, 2001; Sternberg, 2001), that it is 'a spoken or written account of events, in order of happening' (*OED*, 1990). 'The distinguishing feature of narrative is its linear organization of events' (Cohan and Shires, in Franzosi, 1998: 519). Narrative may be 'defined as the representation of real or fictive events in a time sequence' (Rudrum, 2005: 195). According to these definitions, sequentiality (or time) is a fundamental constituent of narrative, but this on its own adds little to the above informant's statement, 'you're born, you grow up…and then later you die', although, as a sequence of events familiar to all, much is implied.

Sequentiality, or succession, as Todorov has it (1990: 28-38), is one of the two basic principles of narrative, the other being transformation. Succession – that one event follows another – implies the passage of time. It is worth noting that the passage of time, in narrative, is not necessarily a forward movement. Narratives may easily move back and forth in time. The second principle, transformation – that something changes significantly – suggests a shift in intentionality, a change of direction, or of one narrative component transformed into another. These two principles, while equally necessary to the construction of narrative, co-exist in a relationship of tension as transformation alters the character of events: for example, one is healthy, something happens, and one becomes unhealthy. In the illness narrative, transformation is essential. Without transformation, the illness narrative would merely be 'an issueless re-enactment of the traumatic events it narrates (or fails to narrate)' (Rimmon-Kenan, 2002: 23): it would indeed be little different to a clinical description of the trajectory of disease. Indeed, *some* narratives are just that: issueless and pointless.

These basic principles can further be elaborated. Todorov (1990: 29) identifies five obligatory elements of narrative: equilibrium, degradation of the situation, disequilibrium, quest and recovery, and re-establishment of the initial state of equilibrium. The illness narratives of the informants in this study broadly correspond with this, although theirs really begin with the second element, 'degradation of the situation', as shown in chapter one. As Radley (1999a: 769) observes, 'disequilibrium' is a distinguishing feature of such narratives, which begin near or at the point of diagnosis, thus rendering the 'before' of illness unavailable to the reader. Furthermore, citing the old saw that one cannot step into the same river twice, I would question the possibility of a complete return to the initial state of equilibrium:

> "After the heart attack the doctor said my heart was permanently damaged. It's like part of the heart's dead. No amount of surgery can fix that...unless you have a transplant, and I'm not that bad. And the arteries are fixed, but the [rehabilitation] nurse said they could clog up again. [...] It's worrying, yes, but you can't do much about it, apart from exercise and watch what you eat and drink."
> (Richard, 69)

For Todorov (1990), however, the most interesting aspect of any narrative is its gnoseological (or epistemical) quality. By this he means that the events described in narratives are of less importance than the perception of them – narratives should thus be evocative and productive of knowledge. Applied to the illness narrative, this is similar to Radley's (1999a: 791) observation that narrative, in fashioning a distinct world, 'lived as a totality…exemplifies significant meaning about life and how one lives it'. The illness narrative, then, is not only a story about something; it is also, and more importantly, a way of 'seeing as' (Radley, 1999a: 791). The illness narrative is not an account of, or a distortion of experience. It is an experience:

> Because it is a world, the world of the text necessarily collides with the real world in order to 'remake' it, either by confirming it or by denying it. However, even the most ironic relation between art and reality would be incomprehensible if art did not both disturb and rearrange our relation to reality.
> (Ricoeur, 1991: 6)

The illness narrative is not only a portrayal of *how* to live with illness, and a transformation of the 'mundane world of disease' (Radley, 1999a: 779), but is an exemplification of an aesthetic act, or 'project', which, among other things, 'allude[s] to qualities that figuratively capture the writer's spirit or outlook' (Radley, 1999a: 780). An aesthetic project, bearing some resemblance to, or drawing upon the same resources as fiction (Natanson, 1998; Ricoeur, 1991), the illness narrative is not a flight from reality. The recounted biography is a history, and therefore, is not unreal, but is, 'in the strict sense of the word, unverifiable' (Ricoeur, 1991: 7). Thus, narrative construction – narrativization – is of necessity then, an imaginative act.

Paul Ricoeur, in discussion with Erik Nakjavani (1981: 1085), states that 'what is to be understood in a discourse is the quality of the world, the dimension of the world...which is opened up by communication'. By discourse he means 'the messages we produce freely on the foundation and the structure of language' (Ricoeur, in Nakjavani, 1981: 1085). This 'production' entails a triangular relationship between the person who speaks, the person who listens and answers, and the world of things that are talked about. This would seem to suggest that it is not the literary qualities of a text that are of prime significance. Rather, it is the world which is evoked, the 'discovered reality which is made manifest by the dialogue' (Ricoeur, in Nakjavani, 1981: 1085). Eventually, the text frees itself from the limits of its production in speech: it survives the relationship that produces it, and therefore becomes autonomous, with 'a destiny distinct from that of its author' (Ricoeur, in Nakjavani, 1981: 1085). This is the virtue of the text, for it opens up the possibility of a relationship that is greater, more comprehensive, than the dialogue that produced it. Consequently, the text also opens onto an unlimited audience – anyone who can read may become a member of it. And the world that is revealed has 'an infinite horizon' (Ricoeur, in Nakjavani, 1981: 1086). If we think of Fanny Burney's mastectomy letter, written close to two hundred years ago, the text, written in (imagined) dialogue with her friends and family, describes an experience that has long passed into history, yet her words resonate today, 'opening up' a world for the reader.

Regarding narrative, Ricoeur's insight is to call attention to the 'work' that goes into the production of discourse (speech and text). This work is 'the activity through which we give form to matter'. From spoken, to written, to read, the text, as a 'kind of reality' which has made itself autonomous in relation to the initial situation in which it was produced, is amenable to 'a sort of appropriation which makes from something strange something appropriate and familiar' (Ricoeur, in Nakjavani, 1981: 1087). I will return to the issue of the 'work' that goes into the construction of narratives later in this chapter, in a discussion of Atkinson's (1997) critique of the illness narrative.

Voice(s)

The association of illness narratives with fiction is, for sociology at least, an unhappy one. This notion, that fiction exists in a sphere apart from 'real life', devalues such narratives, but what is of significance is that experience cannot be regarded as something distinct from the intersubjective acts of communication that produce it (Zaner, 2001: 138). Thus, the value of illness narratives resides in their communicative properties; in short, narratives not only provide a means by which people can talk to each other, but they also reveal a wealth of social and sociological detail that illuminates the grounds upon which such communication is made possible.

> [W]e can distinguish between writing's effort to master the 'voice' that it cannot be but without which it cannot exist, on the one hand, and the illegible returns of voices cutting across statements and moving like strangers through the house of language, like imagination.
> (De Certeau, 1988: 159)

The sound of voices haunts the written word, its residue felt, for example, in the rhythms of prose (Salvaggio, 1999: 20), insinuated into the text as a mark; 'an effect of metonymy…a transitory fugitive, an indiscreet ghost…a disturbing sound from a different tradition, and a pre-text for interminable interpretive productions' (De Certeau, 1988: 155). The written word, as an extension of, and to some extent a substitute for speech, never quite succeeds in capturing its 'phonic and oral' qualities (Cixous, in Salvaggio, 1999: 25), which is to say that text is less expressive than speech, it does not speak 'from the body'. In the same way, language cannot but fail to encompass that which it seeks to describe and explain:

> There can never be a complete utterance or language, encapsulating everything that can be said, for the simple reason that the ground of implicit

> sense is always larger than the explicit signification of words. [...] Speech is also fundamentally *allusive* or indirect, since every explicit signification makes reference to its horizon of possible senses, to say nothing of those layers of more primitive meaning which ground all linguistic meanings. [emphasis in original]
> (Spurling, 1977: 5)

That language does not find identity with its referent is, in a Bakhtinian sense, its saving grace, for its very ambiguity ensures the struggle toward the creation of new meaning. I do not wish to ascribe a privileged status to speech, nor imply that speech is originary, because it always responds to another, preceding utterance, and consequently it is formed in the conflict between the 'local need[s] of a particular speaker to communicate a specific meaning, and the global requirements of language as a generalising system' (Holquist, 1990: 60). Neither do I intend to oppose speech and text, to suggest that they are mutually exclusive; rather, I contend that there is always a gap between the telling of a story and its writing, and that telling (speech) is conditioned by the 'generalising' structure of language. But, as language is itself the site of contestation, its systematising properties subject to 'interminable interpretive' revision, ordinary speech and formal language are 'taken up' – that is, in practice – dialectically, to produce new significations.

Contrary to Cixous (in Salvaggio, 1999), Frank (1992: 167) writes that the student of the body cannot but gain an awareness of being a body, and that 'to write as a body is to express your embodiment in the text that your body is creating'. This points to a degree of reflexivity on the part of the researcher/narrator, and posits a demand that the unnameable aspects of embodied experience be addressed.

Perhaps the greatest problem in writing other people's stories – or indeed one's own – is the inadequacy of the text to render a description of the richness of experience. Richardson (2002) notes that the imperatives of the discipline (in this case, sociology) determine the form of academic writing, and that this form shapes the content of that writing. However, this form is 'simply a literary technique and not the only legitimate carrier of social scientific knowledge' (Richardson, 2002: 414). Seeking 'alternative representations' that 'colour outside the lines' of the discipline, and conceding that they are not the only or best 'way to represent all social research knowledge', Richardson (2002: 414-415) formulates a method of writing for both academic and non-academic readers. Acknowledging that language is a constitutive force, that it creates not a particular reality, but a particular *view* of reality, Richardson (2002: 415) states that writing is a form of ownership, and that 'no textual staging is ever innocent'. Given the impact of the 'cultural turn' upon the practice of social science, it seems unlikely that even the most determined positivist would imagine that his/her text was free of values, and personal and theoretical bias. However, the myth of the objectivity of authorial voice persists: indeed, 'silent authorship comes to mark mature scholarship...[t]he proper voice is no voice at all' (Charmaz and Mitchell, 1997: 194). The difficulty with Richardson's (2002) position is that although in general she approves of alternative representations, and claims that no one text is ultimately authoritative, she yet privileges *her* chosen form of expression, the memoir.

Richardson (2002: 417) claims that her memoir can be read as 'a crafted literary piece and as sociology', but the problem with this statement is that the intelligibility and impact of any text is dependent upon the reader's ability to find identity with or relevance in the text. How is the reader to know that the text is both scientific and literary? This position neglects the value of the reader to the construction of narrative. Narratives are not just stories told; they are stories shared. Richardson's (2002) writing is interesting and extremely personal – she asserts that 'the more concretely personal and detailed the text, the more its universality' (Richardson, 2002: 415) – but perhaps it is, in the end, only a literary text for sociologists rather than a sociological text for the literate.

The notion of scientific objectivity, that facts can somehow (be made to) reveal themselves, if only the scientist can find the correct distance from which to observe them, speaks not only of the privileging of vision – evidence of which is to be found in the increased reliance upon imaging devices in medical science – but is indeed the cornerstone of the (disembodied) scientific attitude.

If narrativization is an aesthetic project (Radley, 1999a), then it is the association of the aesthetic with the *seemingly* subjective that unsettles the scientific demand for objectivism, for as Hekman (1983: 104) observes, '[i]n the aesthetic experience the spectator is an intimate and inseparable part of the process of knowing [whereas] in the scientific model…the knower is defined as aloof from that which is known'. The position from which 'facts' can be observed – the Archimedean point – has been described as a view from nowhere (Harding, 1991), but scientific objectivity is hardly a voice from nowhere, because the language of science is quite distinct, for two reasons. First, it is a method that permits the complex interchange of ideas by way of a linguistically specific shorthand; second, it serves to render distinct the scientifically perceived world and the everyday world, for example, in the manner of Schütz's first and second order typifications.

It is, however, the greatly valued anonymity of science that is, according to Franzosi (1998), its undoing. The absence of clues to the identity of the scientific narrator (Barthes, in Franzosi, 1998: 541), the emphasis on the referential function and the suppression of the emotive and connotative qualities of language undermines the reality of the stories that science tells. Franzosi (1998: 541-542) argues that if science purports to do more than tell stories, such that facts are to speak for themselves, then the scientific 'narrator', who is compelled to remain anonymous, is nothing more than the writer of fiction, who is also absent from the text. What makes this admittedly intriguing statement less than convincing is that science, as a social practice (Kuhn, 1970), is no less subject to the play of power and the structuring influences of, for example, patriarchal discourses, than any other forms of expression. The narrative voice of science is then (ideally) absent from the text, yet present (politically) as the master's voice:

> Because social and political lives are built around the stories a people hear and tell each other, the question of discourse and mastery touches on the possibility of knowing how one is placed in the world. The alternative is not to adopt a discourse free of mastery, for no such discourse exists in our culture.
> (Foster, 1987: 135)

The Trouble with Narratives

> [M]emory, experience, time, and biography are constituted through conventional acts of narrating [...] the relationship between a life and a life history is far from simple.
> (Atkinson, 1997: 327)

Taking issue with *some* illness narratives (for example, Frank, 1995; Kleinman, 1988; Mishler, 1984; 1986), Atkinson (1997) and Atkinson and Silverman (1997) identify a 'stubbornly persistent Romantic impulse' toward a 'confessional' revelation and privileging of personal experience; an impulse that finds its correlate in what they refer to as the 'interview society' (Atkinson and Silverman, 1997: 304). This impulse is ubiquitous – from tabloid to broadsheet, on television and the Internet, and in health research and sociology – and, in its emphasis on the individual over the social, is founded upon an assumption of the existence and authenticity of an interior self, a self that is 'anterior to external valuation [and which can be] rendered visible through dialogue' (Atkinson, 1997: 327).

In questioning whether narrative self-revelation is inherently more valid than other forms of social investigation and interpretation, Atkinson (1997: *passim*) argues that the privileging of one form of experience over another – for example, the patient's over the doctor's – neglects the social context in which narrative 'work' is accomplished. Regarding sociological interest in illness narratives, the expansion of qualitative research, and the attendant increase in the use of the in-depth interview as a research tool has reduced the range of possible data sources to the extent that 'methodological discussions of the analysis of qualitative data all too often turn out to be based on the analysis of interview transcripts' (Atkinson and Silverman, 1997: 307). The persistent belief that interviews reveal 'depth' or attain 'deep disclosure' presupposes both ease of access to the psychic interior of the individual and the adequacy of language to accurately describe the private life of the speaking subject.

The trend toward confessional narrative, which 'place[s] the biographical… narrated self at the heart of social inquiry' (Atkinson and Silverman, 1997: 309), is representative of a 'revolt against monologic modes of authorship' that celebrates multivocality, and is expressive of a desire to 'empower otherwise muted groups' (Atkinson and Silverman, 1997: 308). However, the emphasis on subjectivity and 'lived experience' neglects the wealth of 'objective data' that is to be found in narratives (Atkinson and Silverman, 1997: 309), and is inevitably reductive in that the 'multiple modes of performance, of ordering, of remembering, of interacting' which comprise narrative construction are marginalized for the sake of realising a hyper-authentic self (Atkinson, 1997: 343).

Discussing the discursive production of the self, albeit in terms of machineries of State, Foucault (1983: 214) observes that the power exerted by institutions (such as medical science) is of 'an individualising and totalising form…a form that cannot be fully exercised without knowing the insides of people's minds…without making them reveal their innermost secrets'. The interview society to which Atkinson and Silverman (1997) refer is surely, then, of the same order:

> The interview society thus affirms the speaking subject, with an authenticity guaranteed as the author of his or her life. The life is offered, in the interview, as something to be revealed or rehearsed rather than accomplished or constructed.
> (Atkinson and Silverman, 1997: 310)

Radley (1997) too is critical of Frank (1995), arguing that it is not narratives that construct the world, but narrators. Narrativization is more than linguistic discourse that makes and unmakes body and world (Radley, 1997: 94); it is 'an enacted demonstration of a way of being that is "known in the doing", so to speak' (Radley, 1997: 96), an expressive activity rather than purely denotative. Narrative does not reveal an authentic life, but instead alludes to that which can be done.

The coherence of the 'interview society' is made possible by the 'civilising' process of individuation, the technology of confession, and the emergence of a health care system directed toward the psychology of individuals. Indeed, May (1992), after Foucault (2003), has already described the emergence of a therapeutic discourse in medicine that is directed toward fixing the patient as an individual and penetrating his or her most intimate dispositions (May, 1992: 591-600). The 'disassembly' and subsequent mystification of the patient during the process of medicalisation is redressed by way of a therapeutic strategy of talking, listening or counselling, the desired consequence of which is the reinstatement of a 'real' or 'authentic' self (May, 1992: 591). In addition, Armstrong (1995) identifies the current object of medical attention as the 'risky self', the precarious normality of which must be perpetually monitored. Thus, the self that is revealed in therapeutic discourse is deemed to be somewhat fragile and must therefore be renewed through self-revealing interaction with appropriate clinical agencies.

Atkinson (1997: 341) acknowledges that 'narrative formats…are among the cultural resources that are available for the social construction of health and illness [but] the ubiquity of narrative and its centrality to everyday work are not license simply to privilege those forms'. While I agree that the ubiquity of narrative is not reason enough to accord it a special status, its prevalence in the arts and human sciences demands that social science (at least) question narrative on methodological grounds. The authors of illness narratives criticized by Atkinson (1997) and Atkinson and Silverman (1997) neglect to observe that stories are only part of a greater reality, that 'all writing exists in a larger world of writing' (Foster, 1987: 129), therefore interpretation of narrative can never be more than provisional, 'always contingent upon a wider horizon of writing [thus] the meaning of a work cannot be found within its own boundaries' (Foster, 1987: 1). Intertextuality unsettles the integrity of the narrative, therefore narrative is limited to the evocation of a world, and not to the self-revelation of the narrator. A commitment to understanding narrative must be conditioned by an equal commitment to understanding forms of life (Atkinson, 1997: 332). To believe that narratives 'speak for themselves' is to adhere to a 'vulgar realism' (Atkinson, 1997: 327), which holds that the truth of the speaking subject can be elicited from a single vantage point. The task of the social researcher is to re-contextualise, that is, establish the speaking subject's social setting, and recognize how narratives 'grow' out of interaction. Referring to his earlier (1981) work on the clinical encounter, Atkinson (1997: 328) notes that although the clinical setting de-contextualises – that is, objectifies and translates the patient 'into a multiplicity of measurements and representations', the hospital is itself the site of 'orations, narrations and disputations', all of which goes to suggest that narratives (and narrators) do not exist in a vacuum:

> In the midst of a highly technologized, scientific profession, the anecdote is a clear reminder of the fundamental nature of medicine's 'raw material', the exigencies of the particular illness. [...] Something so pervasive and so contrary to medicine's scientific ideal as the anecdote must have a function in the everyday business of medicine.
> (Hunter, 1991: 70)

Thus far I have presented an image of medical science as an impersonal, monolithic (or monologic) structure of social control. I have omitted to state that medical practice is itself narrativized. What Hunter (1991) brings to this story is that the illness narrative cannot be properly understood without reference to its other, the medical narrative. Therefore, narratives cannot be properly analysed if they are conceived as individual productions. Rather, due attention must be given to the intertextual, situated nature of narrativization. It is thus vital that those who would endorse illness narratives take heed of the underlying structures that shape narratives, and the play of power that is their very foundation:

> [O]ur personal narrative is one contribution to the more broadly accepted narrative which is created by negotiation between the different participants in the setting and which is influenced by the power structure of the social context.
> (Stelter, 2000: 69).

Morris (1998, 261-262) argues for a 'narrative bioethics', as 'a principle that respects – rather than a prejudice that automatically mistrusts or excludes – the evidence derived from human emotional experience'. Just as illness is an emotional experience – indeed, it could be argued that all experience has an emotional content/context – so language is suffused with emotion. Language has a history, a social life that is already moral and emotional. Thus our words bear the traces of a previous usage:

> Every word gives off the scent of a profession, a genre, a current, a party, a particular work, a particular man, a generation, an era, a day, and an hour. Every word smells of the context and contexts in which it has lived its intense social life.
> (Bakhtin, in Morris, 1998: 263)

To conclude this chapter, against the criticism that illness narratives are too particularistic, that in focusing upon the individual in his or her experience of a specific illness, the social context is lost, let me remind the reader of a dictum that is most often directed toward first year sociology students. A prime function of sociology is to find evidence of the general in the particular, to show that private troubles are indeed public issues, 'to find out what is going on in the world, and to understand what is happening in [ourselves] as minute points of the intersection of biography and history within society' (Mills, 1970: 14).

What Atkinson (1997) reveals most forcefully is that narratives are not 'personal accounts'; that they are entirely social in nature.

Conclusion

> Perception is the experience of what actually presents itself, and it is unintelligible without reference to the fundamental bodily activities that seek, solicit, find, and entertain that presentation as their object. Perceptual objects are thus discerned by the percipient not merely in fact, but *de jure*, as objects custom-tailored by and for him, as objects of, by, and for the body-subject. In this way the body contributes a categorical structure to perceptual objects...by providing *forms of actuality* satisfied by the kind of object that distinctively presents itself as actually existing. Functioning in this way, the body progressively fleshes itself out, determining not merely things but also itself as a being together with them in a common world. [emphasis in original]
> (Todes, 2001: 265)

This thesis has been concerned with writing *about* and, of course, *from* embodied experience. To adopt a perspective that takes full account of embodiment requires a conception of the body that, as a methodological figure, is non-dualistic. That is to say, body and mind must not be conceived as distinct, opposed, 'entities'.

However, as indicated throughout, experience is so often characterised by disjunction. It would be more accurate to say that experience is not *thought of* as embodied. It is, rather, a sometimes detached experience *of* the body. That is, the body is experienced as an object, as something exterior to the immediately present self. But, because it is not, in actuality, external to the person, the body *presents* itself as a problem: it is some*thing* that is either not there for us, or is felt as a burdensome presence. For example, a pain in some body part might be felt as something belonging to the part alone. The body part is objectified, yet at the same time, as long as the pain is felt, it cannot appear exactly as an object, that is, similar to other objects that 'do not appear to be mine' (Todes, 2001: 59). Thus embodiment is felt, and acted out or lived, paradoxically. The body is both present and absent; both subject and object (and *neither* subject nor object).

It would seem that we readily identify ourselves with our thoughts. Thought is something that 'we do inside our heads' (Steinberg, 2005: 18); the objects of thought are things that exist 'out there'. Subjectivity is associated with the thought, not with the objects of thought. Therefore, the self identifies with the introspective subject. Regarding the infinite regression that is inherent to thinking the subject/object distinction, the following question arises:

> If we can be aware of our thinking processes themselves, it seems to follow that this thinking-about-thinking-about-stuff is somehow a higher or more central activity than just plain thinking. But if it is, what part of us is thinking *about that*? [emphasis in original]
> (Steinberg, 2005: 18)

I have suggested that embodiment is a praxical orientation to and relationship with the world; that being and having a body is the condition of our being in the world. This world is already there-for-us; it is a social world prior to our entry into it. It does not need to be constituted in consciousness because its existence is the condition of our having a consciousness of it. There is, nevertheless, a tension, between the felt flow of experience as it is lived through, and reflection upon experience. In short, experience, for it to be understood as experience, must be accommodated and constituted meaningfully. The disruptive effects of serious illness heighten the tension between appearance and experience.

♥ ♥ ♥

> Social institutions and discursive practices cannot be understood apart from the real lived experiences and actions of embodied human beings across time

> and space. Social theory must therefore be rooted in the problems of human embodiment. Only on this basis can we put minds back in bodies, bodies back in society, and society back into bodies.
> (Williams and Bendelow, 1998: 209)

While the subject of medicine is, ostensibly if not in fact, the body, social science has only recently taken the body to its heart. For so long the exclusive property of medical science, the body is currently the site of social/political debate. This challenge to the authority of medicine marks a recognition of the foundational significance of the body – as the foundation for social action and social structure. The body is not only a medical(ised) object, but medicine provides an appropriate site in which to do battle for the recovery of the body, both in everyday life and, in the social sciences.

Consequently, social science has taken up analysis of illness narratives as a method of bringing the body back in to social theory. This demands an attentiveness to the ways in which the body is constructed as an object, and to the expressivity of the 'lived body'. Writing about recovery *from* heart disease entails the recognition that something *of* the body is recovered also. I have argued that narrativization is a fundamental, if not universal feature of social life. Narrativization is one way of constituting experience meaningfully and, importantly, of communicating and thus sharing experience. As a form, narrative provides a means of ordering and re-ordering the 'events' of which experience is comprised. As such, narrative is a means of thinking and enacting time, both past and present, and directed toward a future (Ricoeur, 1991). Experience is thus temporally organized by narrative:

> [T]here is always the presence and persistence of the past in the present moment of awareness, which is also simultaneously oriented toward a future that is partially scaffolded upon these preceding mnemonic structures.
> (Throop, 2003: 232)

It could be said that while the informants of this study may not think of their lives as narratives, they nevertheless structure their experiences according to culturally sanctioned forms of storytelling. The experience of serious illness – in this example, heart disease – is such that it demands interpretation (Leder, 1990). I have commented upon the individualising effects of illness, in terms of social dislocation and affective isolation. Todorov's (1990) theory of narrative form, applied to the illness narrative, reveals that narrativization presents the sick person with the opportunity to organize their past and present in a linear fashion, from the disequilibrium felt at the onset of disease to the eventual recovery of relative good health and, thus, the re-establishment of social equilibrium.

However, I argued that illness narratives generally stand in opposition to the larger, more powerful narratives of medical science. Medical narratives were written on the body in the sense that the body provided the foundation of medical scientific inquiry. As such, it could be said that medicine has appropriated the body, and sought to determine its experiential modes.
The contemporary medicalised body is a readable text. However, the body, at times ignorant of or resistant to such typifications, insists upon writing its own stories. The memory of the body is such that our present mode of embodiment is founded upon a larger and older history of the body. That experience is articulated by way of the mnemonic capacity of the body.

♥ ♥ ♥

Bauman (2002) observes that to question the social order, or indeed any aspect of the human world, is to be creative, and therefore questioning entails the breaking of rules. The writer of sociology (or anyone who questions) is thus a rule-breaker. Furthermore, the sociologist's job is to restore to view 'the lost link between objective affliction and subjective experience' (Bauman, 2002:

366). It is the 'suspension of self-questioning' (Bauman, 2002: 369) that, in this period of human history, bars human awareness of its own autonomy.
I suggest that the intensity of the experiences described in this thesis has, for some at least, invoked a determination to assert or reassert the questioning attitude.

> "I think I'm a lot more...determined now. I don't take as much nonsense off people as I used to. When you've been through that...being that ill, and then the whole process of getting over it, you think about your situation. I feel better than ever now, and I'm not going to do anything I really don't want to. I'm living more for myself now. [...] I'm not saying I don't care about anyone else. Just that I'm considering myself more. Thinking about what I want out of life."
> (Wilma, 62)

The emergence of the illness narrative as a form of resistance is a consequence of the lessening of the power of medical discourse (Bury, 2001) and, of the appearance of the reflexive consumer (Giddens, 1991). It could be said that medical science is spreading the burden of responsibility for health by publishing information in various forms; for example, television and the Internet. The question remains, however, of whether medical practitioners wish to recognize and engage with the knowledgeable patient, or if in fact such a patient is a myth.

♥ ♥ ♥

Drawing a comparison between surgery and the interviews of this study, I suggest that both involve an opening up of the body to examination. Just as the medical gaze reveals the mysteries of the body, so the interview provides insights into being and having a body. And just as anatomists found correspondence with the larger world, so we may find evidence of the general in the particularities of embodied experience.

Regarding future research, sociology has to date only scratched the surface of the body. Greater attention to the various historical forms of embodiment would perhaps yield knowledge of why the body is experienced as it is today. To this end, a social-historical analysis of the relation between modes of production and the experience of the body is recommended.

Further to this, it has been argued (for example, Martin, 1992) that our bodily dispositions are changing. Certainly, the body is not static; it is always in motion. The greatest accomplishment of medical science is that bodies now last longer. This study has shown that people in their sixties and seventies can survive that, which only thirty or forty years ago, would have proved fatal. Improvements in surgical techniques (for example, robot-assisted surgery), combined with technological developments such as prosthetic heart valves and, soon, reliable mechanical hearts, are effectively reshaping the human body. We may then ask, in wonder or concern: what is to become of the body?

Final Narrative: There's Something About Mary

I first met Mary at a bus stop. We met there a few times but, aside from polite nods and smiles, we had never really spoken. But that day there was something about her that urged me to speak. At first I said something like: "It's a nice day, isn't it? Have you been waiting long?" And then I said – and I could hardly believe such words sprang from my tongue – "I hope you don't mind my asking, but do you have a heart condition?" Mary looked surprised (and here I must stress that one should never surprise someone who has a heart condition) and said, "Yes, but how do you know?" I told her that her body gave her away, that her posture seemed imbalanced; that she was protecting her left side. I also said that her pallor was distinctly blue. Now, both of these signs could indicate something else, but I just happened to be right. Our bus arrived and, sitting together in the space reserved for the elderly and the infirm, Mary leaned close and told me her story. She had fainted at an airport. Wheeling her suitcase behind her it suddenly felt as if it were dragging her into the ground. That was the last thing she remembered before coming round in the medical treatment room. On returning home she went though the usual procedures and eventually she was put on a waiting list for bypass surgery. I asked her how she felt about that. She said that she was worried, but not too worried. Then she said, "it'll be a wee adventure", and I said, "yes, you're adventure's already begun". It was time for me to get off the bus. I turned to Mary and said, "end of the line", and she replied, "not for me".

References

Amundsen, G. B. and D. W. Ferngren (1983) 'Evolution of the patient-physician relationship: Antiquity through the Renaissance', pp. 3-46 in E. E. Shelp (ed.) *The Cilnical Encounter*. Dordrecht: Reidl.

Armstrong, D. (1983) *The Political Anatomy of the Body: Medical Knowledge in Britain in the Twentieth Century*. Cambridge: Cambridge University Press.

Armstrong, D. (1993) 'Public Health Spaces and the Fabrication of Identity', *Sociology*, vol. 27(3): 393-410.

Armstrong, D. (1995) 'The rise of surveillance medicine', *Sociology of Health and Illness*, vol. 17(3): 393-404.

Armstrong, D. (1999) 'Bodies of knowledge/knowledge of bodies', pp. 17-27 in C. Jones and R. Porter (eds) *Reassessing Foucault: Power, Medicine and the Body*. London: Routledge.

Aronowitz, R. A. (1998) *Making Sense of Illness: Science, Society and Disease*. Cambridge: Cambridge University Press.

Asendorf, C. (1993) *Batteries of Life: On the History of Things and Their Perception in Modernity*. Berkeley, CAL: University of California Press.

Atkinson, P. (1981) *The Clinical Experience: The Construction and Reconstruction of Medical Reality*. Westmead: Gower.

Atkinson, P. (1991) *The Ethnographic Imagination: Textual Constructions of Reality*. London: Routledge.

Atkinson, P. (1997) 'Narrative turn or blind alley?', *Qualitative Health Research*, vol. 7(3): 325-344.

Atkinson, P. and D. Silverman (1997) 'Kundera's *Immortality*: the interview society and the invention of the self', *Qualitative Inquiry*, vol. 3(3): 304-317.

Baron, R. J. (1985) 'An introduction to medical phenomenology: I can't hear you while I'm listening', *Annals of Internal Medicine*, vol. 103(4): 606-611.

Barthes, R. (2000) *Mythologies*. London: Vintage.

Bauman, Z. (2002) 'Afterthought: on writing; on writing sociology', *Cultural Studies↔Critical Methodologies*, vol. 2(3): 259-370.

Beaumont, J. (1953) 'Exchange work in the USA', *The Almoner: A Journal of Medical Social Work*, vol. 5(11): 473-477.

Becker, A. E. (2000) 'Nurturing and negligence: working on others' bodies in Fiji', pp. 100-115 in T. J. Csordas (ed.) *Embodiment and Experience: The Existential Ground of Culture and Self.* Cambridge: Cambridge University Press.

Birke, L. (1999) *Feminism and the Biological Body.* Edinburgh: Edinburgh University Press.

Bobbio, N. (2001) *Old Age and Other Essays.* Cambridge: Polity.

Bochner, A. P. (2001) 'Narrative's virtues', *Qualitative Inquiry*, vol. 7(2): 131-157.

Breakey, J. W. (1997) 'Body-image: the inner mirror', *Journal of Prosthetics and Orthotics*, vol. 9(3): 107-112.

Burkitt, I (1999) *Bodies of Thought: Embodiment, Identity and Modernity.* London: Sage.

Bury, M. (2001) 'Illness narrative: fact or fiction?', *Sociology of Health and Illness*, vol. 23(3): 263-285.

Butler, J. (1993) *Bodies that Matter.* New York, NY: Routledge.

Butler, J. (1998) 'Foreword', pp. ix-xvi in M. Natanson, *The Erotic Bird: Phenomenology in Literature.* Princeton, NJ: Princeton University Press.

Butt, T. and D. Langdridge (2003) 'The construction of self: the public reach into the private sphere', *Sociology*, vol. 37(3): 477-93.

Callinicos, A. (1996) *Against Postmodernism: A Marxist Critique.* Cambridge: Polity.

Cay, E. L. (1995) 'Goals of rehabilitation', pp. 31-53 in D. Jones and R. West (eds) *Cardiac Rehabilitation.* London: BMJ.

Charmaz, K. (1983) 'Loss of self: a fundamental form of suffering in the chronically ill', *Sociology of Health and Illness*, vol. 5(2): 1268-12912.

Charmaz, K. (2002) 'Stories and silences: disclosures and self in chronic illness', *Qualitative Inquiry*, vol. 8(3): 302-328.

Charmaz, K. and R. G. Mitchell jr. (1997) 'The myth of silent authorship: self, substance, and style in ethnographic writing', pp. 193-215 in R. Hertz (ed.) *Reflexivity and Voice.* Thousand Oaks, CAL: Sage.

Claessens, P., P. Moons, B. Dierckx de Casterlé, N. Cannaerts, W. Budts, and M. Gewillig (2005) 'What does it mean to live with a congenital heart disease? A qualitative study on the lived experience of adult patients', *European Journal of Cardiovascular Nursing*, vol. 4: 3-10.

Connell, R. W. (2002) *Gender.* Cambridge: Polity.

Connolly, M. (2001) 'Female embodiment and clinical practice', pp. 177-196 in S. K. Toombs (ed.) *Handbook of Phenomenology and Medicine.* Dordrecht: Kluwer.

Conrad, P. (1992) 'Medicalization and Social Control', *Annual Review of Sociology,* vol. 18: 209-232.

Crossley, N. (1996) *Intersubjectivity: The Fabric of Social Becoming.* London: Sage.

Csordas, Thomas (2000) 'The body as representation and being-in-the-world', pp. 27-47 in Thomas Csordas (ed.), *Embodiment and Experience: The Existential Ground of Culture and Self.* Cambridge: Cambridge University Press.

Cunningham, A. (1989) 'Thomas Sydenham: epidemics, experiment and the "Good Old Cause"', pp. 164-190 in R. French and A. Wear (eds) *The Medical Revolution of the Seventeenth Century.* Cambridge: Cambridge University Press.

Davin, S. (2003) 'Healthy viewing: the reception of medical narratives', *Sociology of Health and Illness*, vol. 25(6): 662-679.

De Certeau, M. (1985) 'Practices of Space', pp. 122-145 in M. Blonsky (ed.) *On Signs.* Oxford: Basil Blackwell.

De Certeau, M. (1988) *The Practice of Everyday Life.* Berkeley: University of California Press.

De Man, P. (1979) 'Semiology and Rhetoric', pp. 121-140 in J. V. Harari (ed.) *Textual Strategies: Perspectives in Post-Structuralist Criticism.* Ithaca, NY: Cornell University Press.

Diprose, R. (2002) *Corporeal Generosity: On Giving with Nietzsche, Merleau-Ponty, and Levinas.* Albany, NY: State University of New York Press.

Dock, W. (1944) 'The evil sequelae of complete bed rest', *Journal of the American Medical Association,* vol. 125: 1083-1085.

Douglas, K. (1972) *Collected Poems.* London: Faber and Faber.

Drake, W. M., P. A. Broadhurst, and D. S. Dymond (1997) *Cardiology Explained.* London: Chapman and Hall.

Elias, N. (1996) *The Civilizing Process: The History of Manners and State Formation and Civilization.* Oxford: Blackwell.

Elkins, K. (2003) 'Middling memories and dreams of oblivion: configurations of a non-archival memory in Baudelaire and Proust', *Discourse,* vol. 24(3): 47-66.

Ellis, C., C. E. Kiesinger and L. M. Tillmann-Healy (1997) 'Interactive Interviewing: Talking About Emotional Experience', pp. 119-149 in Rosanna Hertz (ed.) *Reflexivity and Voice*. Thousand Oaks, CAL: Sage.

Ellis, C. and A. P. Bochner (1999) 'Bringing emotion and personal narrative into medical social science', *Health*, vol. 3(2): 229-237.

Emslie, C., K. Hunt and G. Watt (2001) 'Invisible women? The importance of gender in lay beliefs about heart problems', *Sociology of Health and Illness*, vol. 23(2): 203-233.

Epstein, J. L. (1986) 'Writing the unspeakable: Fanny Burney's mastectomy and the fictive body', *Representations*, vol. 16: 131-166.

Eysenbach, G. (2000) 'Consumer health informatics', *British Medical Journal*, vol. 320: 571-577.

Farley, R. L., T. D. Wade, and L. Birchmore (2003) 'Factors influencing attendance at cardiac rehabilitation among coronary heart disease patients', *European Journal of Cardiovascular Nursing*, vol. 2: 205-212.

Featherstone, M. and M. Hepworth (1982) 'Aging and inequality: consumer culture and the new middle age', pp. 97-126 in D. Robbins (ed.) *Rethinking Social Inequality*. Westmead: Gower.

Featherstone, M. and M. Hepworth (1995) 'Images of positive aging: a case study of *Retirement Choice* magazine', pp. 29-47 in m. Featherstone and A. Wernick (eds) *Images of Aging: Cultural representations of Later Life*. London: Routledge.

Featherstone, M. and M. Hepworth (1996) 'The mask of ageing and the postmodern life course', pp. 371-389 in M. Featherstone, M. Hepworth, and B. S. Turner (eds) *The Body: Social Process and Cultural Theory*. London: Sage.

Ferguson, H. (1997a) 'Me and my shadows: on the accumulation of body-images in Western society part one – the image and the image of the body in pre-modern society', *Body and Society*, vol. 3(3); 1-31.

Ferguson, H. (1997b) 'Me and my shadows: on the accumulation of body-images in Western society part two - the corporeal forms of modernity', *Body and Society*, vol. 3(4): 1-31.

Ferguson, T. (1997) 'Health online and the empowered medical consumer', *Journal of Quality Improvement*, vol. 23(5): 251-257.

Finkelstein, J. (1997) 'Chic outrage and body politics', pp. 150-167 in K. Davis (ed) *Feminist Perspectives on the Body*. London: Sage.

Foucault, M. (1980a) 'The Politics of Health in the Eighteenth Century', pp. 166-182 in Colin Gordon (ed.) *Power/Knowledge: Selected Interviews and Other Writings, 1972-1977*. Hemel Hempstead: Harvester Wheatsheaf.

Foucault, M. (1980b) 'The confession of the flesh', pp. 194-228 in Colin Gordon (ed.) *Power/Knowledge: Selected Interviews and Other Writings, 1972-1977*. Hemel Hempstead: Harvester Wheatsheaf.

Foucault, M. (1983) 'The subject and power', pp. 208-226 in H. L. Dreyfus and P. Rabinow *Michel Foucault: Beyond Structuralism and Hermeneutics*. Chicago, IL: University of Chicago Press.

Foucault, M. (1991) *Discipline and Punish: The Birth of the Prison*. Harmondsworth: Penguin.

Foucault, M. (2003) *The Birth of the Clinic: An Archaeology of Medical Perception*. London: Routledge.

Frank, A. W. (1995) *The Wounded Storyteller. Body, Illness, and Ethics*. Chicago, IL: Chicago University Press.

Frank, A. W. (1999) 'Relations of power and "informed choice": commentary on Rose Weitz's "Watching Brian die"', *Health*, vol. 3(2): 239-246.

Frank, A. W. (2000) 'The standpoint of the storyteller', *Qualitative Health Research*, vol. 10(3): 354-365.

Frank, A. W. (2001) 'Experiencing illness through storytelling', pp. 229-245 in S. K. Toombs (ed.) *Handbook of Phenomenology and Medicine*. Dordrecht: Kluwer.

Franzosi, R. (1998) 'Narrative analysis - or why (and how) sociologists should be interested in narrative', *Annual Review of Sociology*, vol. 24: 517-554.

Fridlund, B. (2002) 'The role of the nurse in cardiac rehabilitation programmes', *European Journal of Cardiovascular Nursing*, vol. 1: 15-18.

Fullagar, S. (2002) 'Governing the healthy body: discourses of leisure and lifestyle within Australian health policy', *Health*, vol. 6(1): 69-84.

Gallagher, S. (2001) 'Dimensions of Embodiment: Body Image and Body Schema in Medical Contexts', pp. 147-175 in S. K. Toombs (ed.) *Handbook of Phenomenology and Medicine*. Dordrecht: Kluwer.

Gerhardt, U. (1987) 'Parsons, role theory, and health interaction', pp. 110-133 in G. Scambler (ed) Sociological Theory and Medical Sociology. London: Tavistock.

Geyer-Kordesch, J. (1989) 'Passions and the ghost in the machine: or what not to ask about science in seventeenth and eighteenth century Germany', pp. 145-163 in R. French and A Wear (eds) *The Medical Revolution of the Seventeenth Century*. Cambridge: Cambridge University Press.

Giddens, A. (1991) *Modernity and Self-Identity*. Oxford: Polity.

Gil, J. (1998) *Metamorphoses of the Body*. Minneapolis, MIN: University of Minnesota Press.

Gilman, S. L. (2001) *Making the Body Beautiful: A Cultural History of Aesthetic Surgery*. Princeton, NJ: Princeton University Press.

Gioia, D. (2000) 'Warner Brothers "Fat Men"', pp. 203-212 in L. Santé and M. Holbrook (eds) *O.K. You Mugs: Writers on Movie Actors*. London: Granta.

Goffman, E. (1990) *The Presentation of Self in Everyday Life*. Harmondsworth: Penguin.

Goodman, H., E. Peters, R. Matthews, A. Geraghty, J. Godden, and C. Shuldham (2003) 'A pilot study using a newly developed manual in a programme of education and support for patients waiting for coronary artery bypass surgery', *European Journal of Cardiovascular Nursing*, vol. 2: 27-37.

Gothill, M. and D. Armstrong (1999) 'Dr. No-body: the construction of the doctor as an embodied subject in British general practice 1955-97', *Sociology of Health and Illness*, vol. 21(1): 1-12.

Gray, S. (2005) *The Smoking Diaries*. London: Granta.

Guillemin, M. (2004) 'Embodying heart disease through drawings', *Health: An Interdisciplinary Journal for the Social study of Health, Illness and Medicine*, vol. 8(2): 223-239.

Harding, S. (1991) *Whose Science? Whose Knowledge? Thinking from Women's Lives*. Milton Keynes: Open University Press.

Heidegger, M. (1982) *The Basic Problems of Phenomenology*. Bloomington, IND: Indiana University Press.

Hekman, S. (1983) 'Beyond humanism: Gadamer, Althusser, and the methodology of the social sciences', *Western Political Quarterly*, vol. 36(1): 98-115.

Henwood, F., S. Wyatt, A. Hart, and J. Smith (2003) '"Ignorance is bliss sometimes": constraints on the emergence of the 'informed patient' in the changing landscapes of health information', *Sociology of Health and Illness*, vol. 25(6): 589-607.

Hepworth, M. (1998) 'Ageing and the emotions', pp. 173-189 in G. Bendelow and S. J. Williams (eds) *Emotions in Social Life: Critical Themes and Contemporary Issues*. London: Routledge.

Herzlich, C. (1973) *Health and Illness: A Social Psychological Analysis*. London: Academic Press

Hilbert, R. A. (1984) 'The acultural dimensions of chronic pain: flawed reality construction and the problem of meaning', *Social Problems*, vol. 312(4): 365-378.

Hill, B. H. jr. (1965) 'The grain and the spirit in mediaeval anatomy', *Speculum*, vol. 40(1): 63-73.

Hirschauer, S. (1998) 'Performing Sexes and Genders in Medical Practices', pp. 13-27 in M. Berg and A. Mol (eds) *Differences in Medicine: Unravelling Practices, Techniques, and Bodies*. Durham, NC: Duke University Press.

Hockey, J. and A. James (2003) *Social Identities Across the Life Course*. Houndmills: Palgrave Macmillan

Holquist, M. (1990) *Dialogism: Bakhtin and His World*. London: Routledge.

Holzner, B. (1974) 'Comments on Heap and Roth "On Phenomenological Sociology"', *American Sociological Review*, vol. 39(2): 286-289.

Horgan, J. and H. McGhee (1995) 'Cardiac rehabilitation: future directions', pp. 244-257 in D. Jones and R. West (eds) *Cardiac Rehabilitation*. London: BMJ

Howell, J. (1994) 'Concepts of heart-related diseases', pp. 99-101 in K. Kiple (ed.) *The Cambridge World History of Human Disease*. Cambridge: Cambridge University Press.

Howson, A. and D. Inglis (2001) 'The body in sociology: tensions inside and outside sociological thought', *The Sociological Review*, vol. 49(3): 297-317.

Hunter, K. M. (1991) *Doctors' Stories: The Narrative Structure of Medical Knowledge*. Princeton: Princeton University Press.

Husserl, E. (1999) 'Transcendental aesthetics: perception, spatiality, and the body', pp.

163-185 in D. Welton (ed) *The Essential Husserl: Basic Writings in Transcendental Phenomenology*. Bloomington, IND: Indiana University Press.

Hydén, L. C. (1997) 'Illness and Narrative', *Sociology of Health and Illness*, vol. 19(1): 48-69.

Jager, E. (1996) 'The book of the heart: reading and writing the mediaeval subject', *Speculum*, vol. 71(1): 1-26.

Jewson, N. D. (1976) 'The disappearance of the sick-man from medical cosmology, 1770-1870', *Sociology*, vol. 10: 225-244.

Johnson, M. (1987) *The Body in the Mind: The Bodily Basis of Meaning, Imagination, and Reason*. Chicago, IL: University of Chicago Press.

Jolly, M. (2005) 'Speaking personally, academically', *Feminist Theory*, vol. 6(2): 213-220.

Julian, D. G. (1995) 'Medical background to cardiac rehabilitation', pp. 4-30 in D. Jones and R. West (eds) *Cardiac Rehabilitation*. London: BMJ.

Kavanagh, T. (1995) 'The role of exercise training in cardiac rehabilitation', pp. 54-82 in D. Jones and R. West (eds) *Cardiac Rehabilitation*. London: BMJ.

Kelly, M. P. and D. Field (1996) 'Medical sociology, chronic illness and the body', *Sociology of Health and Illness*, vol. 18(2): 241-257.

Kelly, M. P. and D. Field (1997) 'Body image and sociology; a reply to Simon Williams', *Sociology of Health and Illness*, vol. 19(3): 359-366

Kilby, J. (2002) 'Redeeming Memories: the Politics of Trauma and History', *Feminist Theory*, vol. 32(2): 201-210.

Kirmayer, L. J. (1992) 'The body's insistence on meaning: metaphor as presentation and representation in illness experience', *Medical Anthropology Quarterly*, vol. 6(4): 323-346.

Kleinman, A. (1988) *The Illness Narratives: Suffering, Healing, and the Human Condition*. New York, NY: Basic Books.

Komesaroff, P. (2001) 'The Many Faces of the Clinic: A Levinasian View', pp. 317-330 in S. K. Toombs (ed.) *Handbook of Phenomenology and Medicine*. Dordrecht: Kluwer.

Kotarba, J. A. (1977) 'The chronic pain experience, pp. 257-272 in J. D. Douglas and

J. M. Johnson (eds) *Existential Sociology*. New York, NY: Cambridge University Press.

Kott, J. (1985) 'The Infarct', pp. 76-83 in M. Blonsky (ed.) *On Signs*. Oxford: Basil Blackwell.

Kott, J. (1992) *The Memory of the Body: Essays on Theatre and Death*. Evanston, IL: Northwestern University Press.

Kuhn, T. (1970) *The Structure of Scientific Revolutions*. Chicago, IL: Chicago University Press.

Kusenbach, M. (2003) 'Street phenomenology: the go-along as an ethnographic research tool', *Ethnography*, vol. 4(3): 455-485.

Laing, R. D. and D. G. Cooper (1971) *Reason and Violence: A Decade of Sartre's Philosophy 1950-1960*. London: Tavistock.

Lakoff, G. and M. Johnson (2003) *Metaphors We Live By*. Chicago, IL: University of Chicago Press.

Laqueur, T. (1992) *Making Sex: Body and Gender from the Greeks to Freud*. Cambridge, MASS: Harvard University Press.

Lash, S. (1996) *Sociology of Postmodernism*. London: Routledge.

Lawton, J. (2002) 'Colonising the future: temporal perceptions and health-relevant behaviours across the adult lifecourse', *Sociology of Health and Illness*, vol. 24(6): 714-733.

Leder, D. (1984-85) 'Toward a phenomenology of pain', *The Review of Existential Psychology and Psychiatry*, vol. 19: 255-266.

Leder, D. (1990) *The Absent Body*. Chicago, IL: University of Chicago Press.

Leder, D. (1998) 'A tale of two bodies: the Cartesian corpse and the lived body', pp. 117-129 in Donn Welton (ed.) *Body and Flesh: A Philosophical Reader*. Malden, MASS: Blackwell.

Le Goff, J. (1989) 'Head or heart? The political use of body metaphors in the Middle Ages', pp. 12-27 in M. Feher, R. Naddaff, and N. Tazi (eds) *Fragments for a History of the Human Body*. New York, NY: Zone..

Lewis, T. (1944) *Diseases of the Heart*. London: Macmillan.

Longino, H. E. (2002) *The Fate of Knowledge*. Princeton, NJ: Princeton University Press.

Lukkarinen, H. and H. Kyngäs (2003) 'Experiences of the onset of coronary artery disease in a spouse', *European Journal of cardiovascular Nursing*, vol. 2: 189-194.

Lyotard, J. F. (1997) *The Postmodern Condition: a Report on Knowledge*. Manchester: Manchester University Press.

Mackenzie, C. (2001) 'On Bodily Autonomy', pp. 417-439 in S. K. Toombs (ed.) *Handbook of Phenomenology and Medicine*. Dordrecht: Kluwer.

Mamet, D. (1997) *True and False: Heresy and Common Sense for the Actor*. London: Faber and Faber.

Martin, E. (1987) *The Woman in the Body: A Cultural Analysis of Reproduction*. Milton Keynes: Open University Press.

Martin, E. (1991) 'The Egg and the Sperm: How Science has Constructed a Romance Based on Stereotypical Male-Female Roles', *Signs: Journal of Women in Culture and Society*, vol. 16(3): 485-501.

Martin, E. (1992) 'The end of the body?', *American Ethnologist*, vol. 19(1): 121-140.

Mauss, M. (1979) *Sociology and Psychology: Essays*. London: Routledge and Kegan Paul.

May, C. (1992) 'Individual Care? Power and Subjectivity in Therapeutic Relationships', *Sociology*, vol. 26(4): 589-602.

May, C. and C. Fleming (1997) 'The professional imagination: narrative and the symbolic boundaries between medicine and nursing', *Journal of Advanced Nursing*, vol. 25: 1094-1100.

McDonald, C. and M. McIntyre (2001) 'Reinstating the marginalized body in nursing science: epistemological privilege and the lived life', *Nursing Philosophy*, vol. 2: 234-239.

McNay, L. (2000) *Gender and Agency: Reconfiguring the Subject in Feminist and Social Theory*. Cambridge: Polity.

McWhinney, I. R. (2001) 'Focusing on Lived Experience; The Evolution of Clinical Method in Western Medicine', pp. 331-350 in S. K. Toombs (ed.) *Handbook of Phenomenology and Medicine*. Dordrecht: Kluwer.

Meerabeau, L. and S. Page (1998) 'Getting the job done: emotion management and cardiopulmonary resuscitation in nursing', pp. 295-312 in G. Bendelow and S. Williams (eds) *Emotions in Social Life: Critical Themes and Contemporary Issues*. London: Routledge.

Merleau-Ponty, M. (2000) *Phenomenology of Perception. London: Routledge.*

Middlebrook, C. (1996) *Seeing the Crab: A Memoir of Dying*. New York, NY: Basic Books.

Miklaucich, M. (1998) 'Limitations on life: women's lived experiences of angina', *Journal of Advanced Nursing*, vol. 28(6): 1207-1215.

Mills, C. W. (1970) *The Sociological Imagination*. Harmondsworth: Penguin.

Misztal, B. (2001) 'Normality and trust in Goffman's theory of interaction order', *Sociological Theory*, vol. 19(3): 312-324.

Mol, A. and M. Berg (1998) 'Differences in medicine: an introduction', pp. 1-12 in M. Berg and A. Mol (eds.) *Differences in Medicine: Unraveling Practices, Techniques, and Bodies*. Durham, NC: Duke University Press.

Moons, P., S. De Geest, and W. Budts (2002) 'Comprehensive care for adults with congenital heart disease: expanding roles for nurses', *European Journal of Cardiovacscular Nursing*, vol. 1: 23-28.

Morgan, D. and S. Scott (1993) 'Bodies in a Social Landscape', pp. 1-20 in S. Scott and D. Morgan (eds) *Bodies That Matter*. Brighton: Falmer Press.

Morris, D. B. (1998) *Illness and Culture in the Postmodern Age*. Berkeley, CAL: University of California Press.

Mulhall, A. (1997) 'Nursing research: our world not theirs?', *Journal of Advanced Nursing*, vol. 25: 969-976.

Mulholland, A. (1997) 'Assimilating sociology: critical reflections on the "Sociology in nursing" debate', *Journal of Advanced Nursing*, vol. 25: 844-852.

Nagler, A. M. (1952) *A Source Book in Theatrical History*. New York, NY: Dover.

Nakjavani, E. (1981) 'Phenomenology and theory of literature: an interview with Paul Ricoeur', *MLN*, vol. 96(5): 1084-1090.

Natanson, M. (1998) *The Erotic Bird: Phenomenology in Literature*. Princeton, NJ: Princeton University Press.

Nietzsche, F. (1980) *On the Advantage and Disadvantage of History for Life*. Indianapolis, IND: Hackett.

Nietzsche, F. (2001) *The Gay Science, With a Prelude in German Rhymes and an Appendix of Songs*. Cambridge: Cambridge University Press.

Page, T., C. Lockwood, and T. Conroy-Hiller (2005) 'Effectiveness of nurse-led cardiac clinics in adult patients with a diagnosis of coronary heart disease', *International Journal of Evidence Based Health*, vol. 3: 2-26.

Paley, J. (1997) 'Husserl, phenomenology and nursing: Heidegger, ontology and nursing research', *Journal of Advanced Nursing*, vol. 26: 187-193.

Paley, J. (1998) 'Misinterpretive phenomenology: Heidegger, ontology and nursing research', *journal of Advanced Nursing*, vol. 27: 817-824.

Paley, J. (2000a) 'Body-Mind Expertise: Notes on the Polarization of Health Care Discourse', pp. 103-121 in Kathryn Ellis and Hartley Dean (eds) *Social Policy and the Body: Transitions in Corporeal Discourse.* Houndmills, Basingstoke: Macmillan.

Paley, J. (2000b) 'Against meaning', *Nursing Philosophy*, vol. 1: 109-120.

Parsons, T. (1951) 'Illness and the role of the physician: a sociological perspective', pp. 609-617 in C. Kluckhohn and H. A. Murray (eds) *Personality in Nature, Society, and Culture.* London: Jonathan Cape.

Parsons, T. (1952) *The Social System.* London: Tavistock.

Pellegrino, E. D. (1983) 'The Healing Relationship: The Architectonics of Clinical Medicine', pp. 152-172 in E. E. Shelp (ed.) *The Clinical Encounter.* Dordrecht: Reidel.

Pendleton, S. (1991) 'Curriculum planning in nursing education: towards the year 2000', pp. 1-57 in S. Pendleton and A. Myles (eds) *Curriculum Planning in Nurse Education.* London: Edward Arnold

Petersen, A. (1998) 'Sexing the body: representations of sex differences in Gray's *Anatomy*, 1858 to the present', *Body and Society*, vol. 4(1): 1-15.

Pierson, W. (1999) 'Considering the nature of intersubjectivity within professional nursing', *Journal of Advanced Nursing*, vol. 30(2): 294-302.

Pilardi, J. A. (1999) *Simone de Beauvoir Writing the Self: Philosophy Becomes Autobiography.* Westport, CONN: Praeger.

Plochmann, G. K. (1963) 'William Harvey and his methods', *Studies in the Renaissance*, vol. 10: 192-210.

Plummer, K. (2001) 'The Call of Life Stories in Ethnographic Research', pp. 395-406 in P. Atkinson, A. Coffey, S. Delamont, J. Lofland and L. Lofland (eds) *Handbook of Ethnography.* London: Sage.

Porter, R. (1985) 'The patient's view: doing medical history from below', *Theory and*

Society, vol. 14(2): 175-198.

Porter, R. (1997) *The Greatest Benefit to Mankind: A Medical History of Humanity from Antiquity to the Present.* London: Harper Collins.

Pouchelle, M. C. (1990) *The Body and Surgery in the Middle Ages.* Cambridge: Polity.

Prince, G. (2001) 'Recent concepts and variables of Narratology', *Narrative*, vol. 9(2): 230-233.

Rabinbach, A. (1992) *The Human Motor: Energy, Fatigue, and the Origins of Modernity.* Berkeley, CAL: University of California Press.

Radley, A. (1996) 'The critical moment: time, information and medical expertise in the experience of patients receiving coronary bypass surgery', pp. 118-138 in Simon J. Williams and Michael Calnan (eds) *Modern Medicine: Lay Perspectives and Experiences.* London: University College London Press.

Radley, A. (1997) 'The triumph of narrative? A reply to Arthur Frank', *Body and Society*, vol. 3(3): 93-101.

Radley, A. (1999a) 'The aesthetics of illness: narrative, horror and the sublime', *Sociology of Health and Illness*, vol. 21(6): 778-796.

Radley, A. (1999b) 'Abhorrence, compassion and the social response to suffering', *Health*, vol. 3(2): 167-187.

Radley, A. (2002) *Making Sense of Illness: The Social Psychology of Health and Disease.* London: Sage.

Radley, A. and Billig, M. (1996) 'Accounts of health and illness: dilemmas and representations', *Sociology of Health and Illness*, vol. 18(2): 220-240.

Richardson, Laurel (2002) 'Writing sociology', *Cultural Studies↔Critical Methodologies*, Vol. 2(3): 414-422.

Ricoeur, P. (1991) *From Text to Action: Essays in Hermeneutics, II.* London: The Athlone Press.

Ricoeur, P. (1994) *Oneself as Another.* Chicago, IL: University of Chicago Press.

Rimmon-Kenan, S. (2002) 'The story of "I": illness and narrative identity', *Narrative*, vol. 10(1): 9-27.

Rombalski, J. J. (2003) 'A personal journey in understanding physical touch as a nursing intervention', *Journal of Holistic Nursing*, vol. 21(1): 73-80.

Rothman, D. J., S. Marcus, and S. A. Kiceluk (eds.) *Medicine and Western*

Civilization. New Brunswick, NJ: Rutgers University Press.

Rudebeck, Carl Edvard (2001) 'Grasping the Existential Anatomy: The Role of Bodily Empathy in Clinical Communication', pp 297-316 in S. K. Toombs (ed.) *Handbook of Phenomenology and Medicine*. Dordrecht: Kluwer.

Rudrum, D. (2005) 'From narrative representation to narrative use: towards the limits of definition', *Narrative*, vol. 13(2): 195-204.

Sacks, O. (1991) *A Leg to Stand On*. London: Picador.

Sakalys, J. A. (2000) 'The political role of illness narratives', *Journal of Advanced Nursing*, vol. 31: 1469-1475.

Sallis, John (1995) *Delimitations: Phenomenology and the End of Metaphysics*. Bloomington, IND: Indiana University Press.

Salvaggio, R. (1999) *The Sounds of Feminist Theory*. Albany, NY: State University of New York Press.

Saunders, J. B. de C. M. and C. D. O'Malley (1973) *The Illustrations from the Works of Andreas Vesalius of Brussels*. New York, NY: Dover.

Sawchuck, K. A. (1995) 'From gloom to boom: age, identity and target marketing', pp. 173-187 in M. Featherstone and A. Wernick (eds) *Images of Aging: Cultural Representations of Later Life*. London: Routledge.

Sawday, J. (1996) *The Body Emblazoned: Dissection and the Human Body in Renaissance Culture*. London: Routledge.

Scheper-Hughes, N. and M. Lock (1985) 'The mindful body: a prolegomenon to future work in medical anthropology, *Medical Anthropology Quarterly*, vol. 1(1): 6-41.

Schiebinger, L. (1986) 'Skeletons in the Closet: The First Illustrations of the Female Skeleton in Eighteenth-Century Anatomy', *Representations*, vol. 14: 42-82.

Schilder, P. (1950) *The Image and Appearance of the Body*.

Sheets-Johnstone, M. (1994) *The Roots of Power: Animate Form and Gendered Bodies*. Chicago, IL: Open Court.

Shildrick, M. (2002) *Embodying the Monster: Encounters with the Vulnerable Self*. London: Sage.

Shildrick, M. and J. Price (1994) 'Splitting the difference: adventures in the anatomy and embodiment of women', pp. 151-179 in G. Griffin, M. Hester, S. Rai, and S. Roseneil (eds) *Stirring It: Challenges for Feminism*. London:Taylor and Francis.

Shilling, C. (1996) *The Body and Social Theory*. London: Sage.

Shusterman, R. (1991) 'Beneath Interpretation', pp. 102-127 in D. R. Hiley, J. F. Bohman, and R. Shusterman (eds) *The Interpretive Turn: Philosophy, Science, Culture*. Ithaca, NY: Cornell University Press.

Shusterman, R. (1999) 'Somaesthetics: a disciplinary proposal', *The Journal of Aesthetics and Art Criticism*, vol. 57(3): 299-313.

Silverman, D. (1997) *Interpreting Qualitative Data: Methods for Analysing Talk, Text and Interaction*. London: Sage.

Siraisi, N. G. (1997) 'Vesalius and the reading of Galen's Teleology', *Renaissance Quarterly*, vol. 50(1): 1-37.

Skultans, V. (2000) 'Narrative illness and identity', *Anthropology and Medicine*, vol. 7(1): 5-13.

Smith, K. (2002) 'Increasing roles for nurses', *European Journal of Cardiovascular Nursing*, vol. 1: 19-21.

Spiegelberg, H. (1976) *The Phenomenological Movement: a Historical Introduction, vol. 2*. The Hague: Martinus Nijhoff.

Spurling, L. (1977) *Phenomenology and the Social World: The Philosophy of Merleau-Ponty and its Relation to the Social sciences*. London: Routledge and Kegan Paul.

Stafford, B. M. (1997) *Good Looking: Essays on the Virtue of Images*. Cambridge, Mass: MIT Press.

Starobinski, J. (1983) 'The body's moment', *Yale French Studies*, vol. 64: 273-305.

Steinberg, M. (2005) *The Fiction of a Thinkable World*. New York, NY: Monthly Review Press.

Stelter, R. (2000) 'The Transformation of Body Experience into Language', *Journal of Phenomenological Psychology*, vol. 31(1): 63-77.

Sternberg, M. (2001) 'How narrativity makes a difference', *Narrative*, vol. 9(2): 115-122.

Stillman, R. (1995) 'Hobbes's *Leviathan*: monsters, metaphors, and magic', *ELH*, vol. 62(4): 791-815.

Svenaeus, F. (2001) 'The Phenomenology of Health and Illness', pp. 87-108 in S. K. Toombs (ed.) *Handbook of Phenomenology and Medicine*. Dordrecht: Kluwer.

Synott, A. (1993) *The Body Social: Symbolism, Self and Society*. London: Routledge.

Throop, C. J. (2003) 'Articulating experience', *Anthropological Theory*, vol. 3(2): 219-241.

Todes, S. (2001) *Body and World*. Cambridge, MA: MIT Press.

Todorov, T. (1990) *Genres in Discourse*. Cambridge: Cambridge University Press.

Toombs, S. K. (2001) 'Phenomenology and medicine', pp. 1-26 in S. K. Toombs (ed.) *Handbook of Phenomenology and Medicine*. Dordrecht: Kluwer.

Turner, B. S. (1990) 'The anatomy lesson: a note on the Merton thesis', *The Sociological Review*, vol. 38(1): 1-18.

Turner, B. S. (1995a) 'Aging and Identity: Some Reflections on the Somatization of the Self', pp. 245-260 in Mike Featherstone and Andrew Wernick (eds) *Images of Aging: Cultural Representations of Late Life*. London: Routledge.

Turner, B. S. *with* C. Samson (1995b) *Medical Power and Social Knowledge*. London: Sage.

Turner, B. S. (1996a) 'Recent developments in the theory of the body', pp. 1-35 in M. Featherstone, M. Hepworth and B. S. Turner (eds) *The Body: Social Process and Cultural Theory*. London: Sage.

Turner, B. S. (1996b) *The Body and Society: Explorations in Social Theory*. London: Sage.

Van Manen, M. (2001) 'Professional practice and doing phenomenology', pp. 457-474 in S. K. Toombs (ed.) *Handbook of Phenomenology and Medicine*. Dordrecht: Kluwer.

Vigarello, G. (1990) 'The upward training of the body from the age of chivalry to courtly civility', pp. 148-199 in M. Feher, R. Naddaff, and N. Tazi (eds) *Fragments for a History of the Human Body, Part Two*. New York, NY: Zone.

Wijngaard, M. van den (1991) *Reinventing the Sexes: Feminism and Biomedical Construction of Femininity and Masculinity 1959-1985*. Delft: Eburon.

Wiklund, L., L. Lindholm, and U. Lindström (2002) 'Hermeneutics and narration: a way to deal with qualitative data', *Nursing Inquiry*, vol. 9(2): 114-125.

Williams, G. (1984) 'The genesis of chronic illness: narrative re-construction', *Sociology of Health and Illness*, vol. 6(2): 175-200.

Williams, S. J. (1996) 'Medical sociology, chronic illness and the body: a rejoinder to Michael Kelly and David Field', *Sociology of Health and Illness*, vol. 18(5): 699-709.

Wilson, L. (1987) 'William Harvey's Prelectiones: the performance of the body in the Renaissance theatre of anatomy', *Representations*, vol. 17: 62-95.

Winters, C. A. (1997) 'Living with Chronic Heart Disease: A Pilot Study', *The Qualitative Report*, vol. 3(4): 1-23.

Witz, A. (1992) *Professions and Patriarchy*. London: Routledge.

Yingling, T. E. (1997) *AIDS and the National Body*. Durham, NC: Duke University Press.

Zalm, J. E. van der, and V. Bergum (2000) 'Hermeneutic-phenomenology: providing living knowledge for nursing practice', *Journal of Advanced Nursing*, vol. 31: 211-218.

Zaner, R. M. (1981) *The Context of Self: A Phenomenological Inquiry Using Medicine as a Clue*. Athens, OH: Ohio University Press.

Zaner, R. M. (2001) 'Thinking about Medicine', pp. 127-144 in S. K. Toombs (ed.) *Handbook of Phenomenology and Medicine*. Dordrecht: Kluwer.

Zola, I. K. (1991) 'Bringing Our Bodies and Ourselves Back in: Reflections on a Past, Present and Future "Medical Sociology"', *Journal of Health and Social Behaviour*, vol. 32(1): 1-16.