UNIVERSITY OF SOUTHAMPTON

FACULTY OF LAW, ARTS AND SOCIAL SCIENCES

SCHOOL OF SOCIAL SCIENCES

# CHANGE AND CONTINUITY IN THE LIVES OF CARDIAC PATIENTS: A STUDY OF EXERCISE-BASED REHABILITATION

By

Patrick Partington

Thesis for the degree of Doctor of Philosophy

January 2005

UNIVERSITY OF SOUTHAMPTON

## ABSTRACT

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# CHANGE AND CONTINUITY IN THE LIVES OF CARDIAC PATIENTS: A STUDY OF EXERCISE-BASED REHABILITATION

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Following a cardiac event people are encouraged to lead a physically active lifestyle through Phase IV Cardiac Rehabilitation programmes. However, adherence to these programmes is low. The thesis sought to contribute to an interpretative understanding of the ways that cardiac patients choose either to adhere to a physically active lifestyle or not. An ethnographic methodology was adopted and fieldwork involved collecting material through a range of qualitative methods including semi-structured interviews, participant observation and opportunistic unstructured interviews. These data were analysed, and further data generated, through a method informed by grounded theory, within a symbolic interactionist framework.

Within the current culture that emphasises individual responsibility for health it is important to respond to illness in 'the right way'. This study found that cardiac patients, as social actors, biographically create the circumstances within which they can legitimately choose to engage in physical activity or not. Efforts to maintain continuity are central to both courses of action. For some cardiac patients, the only way of maintaining continuity and regaining their identity is to alter their lifestyle and engage in exercise. For others, continuity is maintained and identity regained by maintaining the same lifestyle. A key finding is that both types of biographical work have the same ultimate purpose of maintaining continuity. A cardiac event can be biographically disruptive and can disturb the roles that comprise one's identity. Central to identity are self-presentational concerns. These self-presentational concerns relate both to the micro perspective of the gym setting as well as the wider consideration of managing an impression to others. A self-presentational typology is presented.

Throughout the thesis attention is paid to structure and agency. These data suggest a dynamic relationship between social structure and human action, in as much as an individual is influenced *by*, but also has an influence *over*, guiding social structures.

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## ACKNOWLEDGEMENTS

I would like to thank my two supervisors, Graham Crow and Rose Wiles, for a number of reasons, but mainly for their expert guidance in all things sociological and all things methodological. Their friendship has contributed to my enjoyment of this work. Thanks to Paul Sweetman and Paul Bridgen for their constructive comments at key stages of the development of this thesis.

Thanks also go to the Leisure, Culture and Tourism Division of Southampton City Council who have funded this research project. More specifically, I would like to thank two managers from this organisation, Peter Fryatt and Mike Harris, my two successive line-managers who made this funding possible, for their support and enthusiasm for this study.

My wife Jackie deserves my thanks for supporting me over the past few years. Without her understanding, and that of Joe and Amber, I could never have maintained the necessary workload.

Lastly, I would like to express my gratitude to the participants of the cardiac rehabilitation programme who patiently gave up their time in order that this study could become possible.

# CHAPTER 1. INTRODUCTION: LOCATING THE STUDY

## 1.1 BACKGROUND

My interest in the field of exercise adherence is long established. In the early days of my career as a health and fitness instructor working with 'general populations', the high rate of dropout from exercise classes was always a source of frustration. It was interesting that someone could appear to be particularly keen in getting fit at one point in time, only to lose interest almost overnight, never to return to the gym. Clearly, things can happen to a person in the course of a lifetime that will initiate a resolution to 'get fit'. A 'landmark' birthday, wanting to lose weight for a special occasion, a particularly indulgent Christmas or holiday, or just the sudden realization of not being able to run for more than a couple of minutes without gasping are just a few examples of exercise 'triggers'. For many people, those "must get myself fit" thoughts often remain as just that; well intentioned thoughts. Of those who actually manage to take up the challenge, only a small percentage will still be exercising after three months and even fewer after six months and a year. For example, research has shown that exercise adherence among general populations is no better than fifty per cent after six months (Martin et al, 2000). Some people appeared to go through phases of exercise participation, working hard in springtime in readiness for the summer, only to give up in August and hibernate through the winter. However, there was never any shortage of new people waiting to take the place of these 'dropouts' and, as I didn't feel the need to take personal responsibility for the health and fitness of the whole community, I didn't overly concern myself with the problem.

In 1994 I became involved in 'Exercise on Prescription Schemes', which had become popular in leisure centres throughout the country during the early 1990s. The basic premise is a simple one: instead of (or sometimes as well as) writing out a prescription of medicine for a particular condition (typically diabetes, hypertension, arthritis, etc), a General Practitioner, or Allied Health Professional, can write out a 'prescription' for exercise. The patient will take this to their local leisure centre where a qualified health and fitness instructor will design an exercise programme with the specific aims of ameliorating the symptoms, and reducing the further development, of their illness condition. For the leisure centre, a niche market was exposed for them: people who had never exercised before and who would attend the gym at off-peak times, therefore levelling out the peaks and troughs of usage. For the local health authority, the well-researched health benefits of exercise (e.g. Berlin and Colditz, 1990; Van Baar, Assendelft, and Dekker 1999) could be accessed on a wider scale, supposedly alleviating the strain on an overworked health system. This also fits well with the type of illnesses, characterized by their chronicity, that dominate medicine today. Whereas the infection-related conditions that were prevalent in the early part of the last century could be treated and cured with medication, the chronic conditions of today can only be 'managed'. Exercise participation has become an important intervention in the management of such conditions.

A leisure centre that I was working in during the time of this rapid development of 'Exercise on Prescription' asked me to set up a scheme and I became the GP Referral

Liaison Manager. Exercise adherence then became more of an issue for me, as I needed to demonstrate the worth of the scheme to the local Health Authority, who were potential investors. Surely, when people are exercising on doctor's orders, and for reasons of health, adherence will be improved. It soon became apparent to me that this was not the case and, again, this is supported by research. For example, Dorn et al (2001) have shown that fifty percent of all cardiac patients who engage in an exercise rehabilitation programme will have dropped out within the first six months. This is a similar rate of adherence to that of general populations (Martin et al, 2000). It was at this time that I started to investigate the literature on 'models' of behaviour change, which I shall discuss later. Before this, though, it will be useful for the reader to be aware of the historical background of GP Exercise Referral Schemes, which in turn will provide an understanding of the workings of the programme from which I have recruited the sample of participants for this study.

## 1.2 GP EXERCISE REFERRAL SCHEMES

The sedentary lifestyles that currently prevail in the UK have been identified as a major public health problem (Health Education Authority and Sports Council, 1992), and is a problem that is thought to be replicated in most industrialized nations. Physical inactivity has been associated with a wide (and apparently ever increasing) range of health problems, such as heart disease, stroke, Type II diabetes, osteoporosis, and some cancers, to name a few (Dishman and Sallis, 1994). In terms of heart disease, the potential effect of physical activity upon the classic risk factors for CHD (for example, it has been found to be effective in lowering blood pressure and cholesterol, and in reducing obesity) has led the American Heart Association to acknowledge inactivity as a major risk factor for CHD (Fletcher et al., 1992). As a result of this research evidence regarding the efficacy and benefits of a physically active lifestyle, the early 1990s saw attention become focused on how best to deliver, and encourage adherence to, physical activity programmes. In short, a great deal of research existed to show that exercise is beneficial, but nobody was sure of the best way to deliver it.

The original impetus for GP Exercise Referral Schemes was undoubtedly driven by financial considerations. Leisure centre management saw the opportunity to tap into a niche market of potential customers who were able to exercise at off-peak times (because clients were predominantly middle-aged women, the elderly or those on sick-leave from work) thereby providing additional income during the quiet daytime hours of the facility. It was a local authority rather than a health authority that came up with the idea, when a leisure manager at 'The Oasis' centre in Hertfordshire proposed the initiative to representatives of his local health authority in 1992. This novel idea proved popular with other local authorities, who instructed their own leisure managers to initiate similar schemes, leading to a mushrooming of programmes across the country. For example, a 1996 directory of GP Referral Schemes (Chapman, 1996) stated that there were at least 200 schemes operating in England, and the author suggests that there were probably many more that had not been able to be contacted. However, what most leisure centres overlooked was the relationship between health and wealth, i.e. that those who were less healthy, and therefore most likely to be referred to such schemes, were also the less wealthy among the local community and, therefore, least able to pay for their leisure centre sessions. Further, local health authorities, while supportive of the concept, were reluctant to invest in such schemes because there was no evidence to demonstrate that GP Exercise Referral Schemes were effective in encouraging patients to maintain a physically active lifestyle. This criticism was not unfounded, and in 1998 the 'Riddoch Review' (Riddoch, Puig-Ribera and Cooper, 1998), as it has eponymously come to be known, demonstrated that such schemes had very little evidence, other than anecdotal, to support them. This led to many schemes being abandoned, as local authorities were unwilling to bear the cost of an initiative whose main beneficiary appeared to be the local health services.

More recently, certainly from the year 2000, Government legislation has encouraged partnership working between local authorities and their health counterparts. The various National Service Frameworks set targets, or 'milestones' as they were referred to, which required quantitative data demonstrating the impact of partnership working related to, among others, physical activity. Local health authorities, or Primary Care Trusts (PCTs) as they had become, had a responsibility to report back to central Government on the numbers of people who had received advice or who had actually been involved in a health intervention. For example, The National Service Framework for Coronary Heart Disease (Department of Health, 2000) set the following targets:

> Standard 1: “The NHS and partner agencies should develop, implement and monitor policies that reduce the prevalence of coronary risk factors in the population, and reduce inequalities in risks of developing heart disease”.
>
> Milestone 2: “By April 2001 all NHS bodies, working closely with local authorities, will have agreed and be contributing to the delivery of the local programme of effective policies on: a) reducing smoking; b) promoting healthy eating; c) increasing physical activity: and d) reducing overweight and obesity”.
>
> Milestone 3: “By April 2002 every local health community will have quantitative data no more than 12 months old about the implementation of the policies on: reducing the prevalence of smoking; promoting healthy eating; promoting physical activity; reducing overweight and obesity”.

It was at this time that GP Exercise Referral Schemes began to be examined more closely by PCTs as a vehicle for delivering on the physical activity targets that had been set. Schemes that had, in the meantime, been proactively evaluating the work that they had been doing, and that had been financially supported by their local authority, began to receive some financial investment from PCTs. For example, the ‘Active Options’ GP Exercise Referral Scheme, from which the participants of this study are drawn, is receiving an investment, from Southampton City PCT, of £30,000 per year for its service delivery.

The main problem arising from this alliance between ‘health’ and ‘leisure’ was the fact that fitness instructors did not have an organisation that maintains quality through providing a chartered status for its members, as is the case for physiotherapists. For a while, this meant that many health professionals were reluctant to refer patients to instructors who they could not be sure were competent to deal with that specific illness condition. To address this, the Government published a National Quality Assurance Framework (Department of Health, 2001) through which local authorities/PCTs could measure, and improve if necessary, the quality of service that they were providing. Fitness Instructors qualifications were standardized by a 'governing body', known as *The Register of Exercise Professionals* (REPs), which provided membership at three levels. Fitness Instructors working on GP Exercise Referral Schemes required a qualification that placed them at the upper level of '3'.

This provided the litigation conscious medical profession with the security, in terms of insurance, that they needed in order to feel confident when referring their patients for exercise. It also ensured that the training courses that were set up to meet the increased demand for 'level 3' instructors were of a sufficiently high standard, which meant covering education in anatomy and pathophysiology, as most good courses would do, but also in understanding behaviour change, which addressed the adherence concerns that this chapter began with. This education was aligned to the social/health psychology approach that is dominated by the 'social cognitive' paradigm. My own training as a Health and Fitness Instructor has been undertaken with the American College of Sports Medicine and the British Association for Cardiac Rehabilitation. The 'behaviour change' components of both training courses were based on the 'model' approach to understanding variables within a person's character that might predict their exercise adherence. A large body of research has emerged over the past two decades that employ various models, such as the health belief model, in experimental investigations into behaviour change. This has developed in line with the growth of sport and exercise science as an independent discipline, but also as a discipline that has made in-roads into other areas, such as psychology (there is now a Sport and Exercise section of the British Psychological Society) and health. This research study is, in part, a response to the quantitative methodologies and psychological models that are predominantly used by health researchers in understanding exercise participation and adherence, but also in understanding health behaviour in general. The aim of this study is to contribute a sociological understanding of exercise adherence in cardiac rehabilitation, from a lived experience perspective. However it will be useful to provide, at this point, an overview of some commonly employed psychological models of behaviour change so that my findings can be related back to these assumptions at a later stage in the thesis.

## 1.3 UNDERSTANDING BEHAVIOUR CHANGE AS A MODEL

It has been suggested (Conner and Norman, 1995) that the study of health behaviours is based upon two assumptions: the first is that in most of the Western World the leading causes of death are due to particular behaviour patterns, and the second is that these behaviour patterns can be modified. It is being increasingly recognised that individuals can make a significant contribution to their health and well-being through particular health-enhancing behaviours (such as exercise participation) and the avoidance of health-compromising behaviours (such as smoking). Government health policy, as will be discussed in the next chapter, has been guided by this basic premise which, in turn, has contributed to the 'healthist' society (that I would define as the overemphasis upon the individual to take responsibility for health) that we live in today and the culture of 'victim blaming' that accompanies it.

An old definition of health behaviours, but one that is regularly quoted in contemporary literature is that they are "any activity undertaken by a person believing himself to be healthy for the purpose of preventing disease or detecting it at an asymptomatic stage" (Kasl and Cobb, 1966, p.246). However, there are limitations to this definition, such as the omission of lay or self-defined illness behaviours as well as the behaviours that are carried out by people with recognised illnesses that are directed at self-management. The psychologists who employ the model-approach to researching health appear to accept the limitations of this definition, but need a basic definition to work from if they are to predict the effectiveness of interventions designed to alter behaviours. And this is the crux of the matter: the aim of the psychological model approach is to identify the variables, usually personal characteristics, which motivate us toward specific behaviours in order to enable health professionals to predict future actions. This is all the better for encouraging us to take individual responsibility for our health. So, what are these models and what are the variables that they are investigating? There are many different models, and variations of these models that have been developed over the past few decades, but I will outline three of the most commonly used, namely, the Health Belief Model, Self-efficacy Theory and the Protection Motivation Theory. These models appear dated, being developed as they were in the 1970s, but they remain, in their substantive form, the predominant methodological examples of research in the area, and they continue to be used in these forms.

The Health Belief Model (Becker, 1974) is based on two factors relevant to the individual: perceived threat and behavioural evaluation. Threat perception is composed of two beliefs, (1) perceived susceptibility to illness, and (2) the anticipated severity of the consequences of that illness. Behaviour change is initiated following the evaluation of possible alternatives, a process known as behavioural evaluation. Behavioural evaluation, similarly, is comprised of two further beliefs (1) the perceived benefits of a recommended behaviour and (2) and the cost of performance of the behaviour. Two further factors that the model proposes are that if appropriate beliefs are held, *cues to action* will trigger health behaviour. Typical of such cues are individual perceptions of symptoms, social influences and health education programmes (one of the aspects of this model is that people are amenable to educational interventions). The final factor is a person's *general health motivation*, or their readiness to change behaviours.

When applied to cardiac rehabilitation, a cardiac patient is likely to adopt exercise as a health behaviour if the perception of threat is such that the person believes another heart attack is likely and that the consequences will be severe. The cardiac patient will believe that exercise will be beneficial in avoiding the second heart attack and that the costs are not too great. A cue to action might occur to reinforce the behaviour, such as an education programme detailing the rate of second heart attacks among cardiac patients. Finally, the patient must be 'ready' to adopt the exercise behaviour so it would be assumed that the heart attack would have prompted a general rethink about the way that the person is living.

The Self-efficacy model (Bandura, 1977) proposes that the motivation toward, as well as the adoption of, a particular health behaviour is based upon three types of expectancies: situation-outcome, action-outcome and perceived self-efficacy. *Situation-outcome* expectancies represent the beliefs that a person holds regarding the consequences of non-action, e.g. the consequences of not adopting an exercise programme that, in turn, is influenced by perceived susceptibility. *Action-outcome* expectancy centres upon the belief that a specific behaviour will lead to a specific outcome. For example, belief that engaging in regular physical activity will lead to a reduced risk of a second heart attack. *Self-efficacy* expectancy is about the belief that a person holds regarding his or her capability of performing the behaviour. For example, the belief that a cardiac patient holds regarding the likelihood that he or she will be able to maintain a physically active lifestyle. The model proposes that if the patient is not confident of his or her ability to adhere to a cardiac rehabilitation programme, he or she will not even begin the behaviour.

Protection Motivation Theory (Rogers, 1975) attempts to predict the way that a person might deal with a health threat by examining two appraisal processes: threat appraisal and coping appraisal. *Threat appraisal* is evaluated by considering both the perceived susceptibility and the perceived severity of a particular illness. *Coping appraisal* is evaluated by considering the value of the proposed behaviour in reducing the threat. The coping appraisal is based upon two further factors: the person's belief that a certain action will be effective in reducing the threat (similar to the Health

Belief Model and the action-outcome variable from Self-efficacy Theory) and the persons belief in his or her ability to carry out the recommended behaviour (self-efficacy). It is clear that many factors overlap between the various models of behaviour change, not least is the similarity between this model and the Health Belief Model.

Clearly there is overlap between the variables that the models use, for example, perceived susceptibility and the assessment of pros and cons is evident in most models. In fact, if the variable of self-efficacy were added to the Health Belief Model, it would duplicate the Protection Motivation Theory. Health psychologists argue that the fact that the models use different combinations of the same variables is evidence that key variables have been identified. The following passage from *Predicting Health Behaviour* (Conner and Norman, 1996) demonstrates the way that health psychologists feel that this identification has been helpful in furthering their understanding of health behaviour.

> "This understanding is useful in enabling us to develop effective interventions designed to alter the cognitions underlying unhealthy behaviours. If these cognitions are causally related to behaviours then changes in cognitions should lead to changes in behaviours and so promote positive health outcomes" (p.15)

The descriptions of these models read in a rather mechanical way and their assumption is that their subjects respond in a similarly mechanistic fashion. Lupton (1999, p.21) uses the Health Belief Model to demonstrate the way that these "psychometric" studies "represent human action as volitional and rational, invariably categorizing risk avoidance as rational and risk-taking as irrational". However, most of us are aware that people tend not to act in such a predictable and controlled manner. We are not, as Lupton puts it "calculating and emotion-free actors" and an array of factors can influence our intentions. In support of this, I would argue that in their exclusive focus upon the cognitive variables of the individual, the psychological models outlined above pay insufficient attention to the social variables that influence our decisions on a daily basis. Further, our innate motivation toward maintaining continuity in our lives (Becker, 1993) is entirely overlooked.

An understanding of behaviour change in cardiac rehabilitation poses some very specific problems that need to be understood in close detail. For example, perceived susceptibility to illness and the anticipated severity of illness for someone who has already experienced a heart attack are two 'variables' that could quite easily be understood in the 'rational-actor' way (e.g. "I had better do something or next time I might not be so lucky), but this ignores the agency of the social actor to create new definitions of life in a manner understood through symbolic interactionism.

It is important, when attempting to develop an understanding of why some patients adhere to exercise-based cardiac rehabilitation while others do not, to be familiar with the rehabilitation process. The structure of the cardiac rehabilitation service is a standardized one throughout the country and is based very much on the medical model of treatment and health education delivered in the standard 'health promotion' way, which I will highlight, as defined in *The BACR Guidelines for Cardiac Rehabilitation* (Coats et al, 1995).

## 1.4 PHASES OF CARDIAC REHABILITATION

### *Phase I: In-patient stay*

This represents the period of hospitalisation following the cardiac event, which usually lasts for around one to four weeks (although this may not all be spent in hospital). The components include reassurance, information/education and risk factor assessment.

### *Phase II: Immediate post discharge*

This phase usually takes in weeks four to six post event and represents “a crucial time period for patients in terms of adjustment to change. It can be a time in which cardiac rehabilitation professionals capitalize on the patient’s motivation to change” (Coats et al, 1995). The BACR suggest that this is the ‘surveillance phase’, when education and behaviour change can be reinforced through follow-up telephone calls, home visits, individual counselling, group sessions and education sessions.

### *Phase III: Intermediate post-discharge*

This is the formal exercise training and lifestyle modification component, which is increasingly being delivered in community venues in order to demedicalise rehabilitation. It is probably the only ‘phase’ of rehabilitation that the patient will be aware of, as they will simply view the two preceding phases as standard treatment. Phase III is known as such by all patients and is viewed as ‘treatment’ accordingly. Most programmes are delivered in 8-week blocks of weekly two-hour sessions. The first hour is delivered in a lecture type format, providing the patient with reasons why, for example, eating an unhealthy diet is detrimental to heart health and why exercise is good. The second hour is when the low intensity exercise class is delivered in a circuit-type format.

*Phase IV: Long term maintenance*

Not all areas have a specific Phase IV programme and this is increasingly being delivered through GP Referral Schemes. Referral is made from Phase III, but it is not always clear to the patient that this represents the final 'phase' of their rehabilitation. In practice, the Phase III nurse will ask the patient, on completion of Phase III, if they would like to continue with exercise. If the answer is yes, they are referred on to the GP Referral Scheme and if the answer is no they will be given some information leaflets about how to lead an active life.

## 1.5 THE RESEARCH PROBLEM

The impetus for this study is rooted in two problems. The first is the need to understand why more than half of all cardiac patients who begin a medically endorsed exercise rehabilitation programme at Phase IV fail to adhere to it. The second relates to the psychological models of behaviour change that have dominated the research literature, in both exercise adherence and to adherence of health behaviour in general, to date. However, it should be noted that I will not attempt to address the practical barriers to participation, rather I will concern myself with the ways that cardiac patients make sense of, in a biographical context, the decisions that they make. As discussed, the difficulty with the 'psychological-model approach is that it assumes that human actors are "emotion-free" and rational in the way that they make their lifestyle choices. This study will give consideration to the experience of both illness, as well as the exercise itself, in rehabilitation, providing more contextual information that will inform the debate. With this in mind, then, an understanding of the qualitative literature that goes some way to providing an understanding of the lived experience of chronic illness is required. However, we do not experience and respond to illness in a vacuum. We are influenced by societal pressures, peer expectations and social structures that guide our decision-making processes. Taking a step back from this, there is the medical profession who advise that we 'do the right thing' and Government policy, grounded in economics, that to a large extent guide their thinking. In order to appreciate the ways that cardiac patients respond to exercise-based rehabilitation, it is important to have a broad understanding of all of these areas, to which I will now turn my attention.

# CHAPTER 2: LITERATURE REVIEW

## 2.1 INTRODUCTION

While this study does not work from any preconceived hypothesis, it is important to provide an understanding of the various sociological theories and debates that relate to the subject area. Turner (2001) has described three levels of analysis that he suggests are required in order to develop a sociological understanding and this provides a good starting point in a discussion of the literature related to my own study. Turner (2001, p.4) describes these levels:

> "First, medical sociology can provide descriptions of the experience of illness from the perspective of the individual... A variety of sociological perspectives – phenomenology and symbolic interactionism lend themselves to this task. At the second level, medical sociology would focus on the social construction of disease categories whereby individuals are classified and regulated by professional groups... the concept of the sick role is crucial to this form of enquiry. The third level of analysis concerns the societal organisation of health-care systems, their relationship to the state and the economy, and the problems of social inequality both within and between societies."

Development of a sociological analysis relating to an understanding of why some cardiac patients adhere to the recommended lifestyle advice provided by health professionals, while others choose not to, requires an exploration of these three distinct levels of analysis that Turner described. The health policy that has had such a strong influence over the issues to be discussed provides a useful starting point, which in effect, has informed the structure of this chapter. I will, therefore, take Turner's levels of sociological analysis in reverse order, beginning by mapping the wider picture provided by an examination of health policy. From this, I will build a picture of the way that medicine has shaped a culture that emphasizes individual responsibility for health in response to the targets set out in health policy that began with the Government White Paper: *Prevention and Health: Everybody's Business* (Department of Health, 1977). This recognised that the major threat to the nation's health, in terms of mortality but also in terms of financial burden, were the potentially preventable 'lifestyle' diseases typified by coronary heart disease. I will sketch out the ways that some critics have described the way that this policy has perpetuated the power of medicine in influencing health through the concept of lifestyle management, and by examining the organisation responsible for perpetuating surveillance medicine, namely the health promotion movement. The chapter will then move on to examine the way that sickness, rather than being the "narrowly defined biochemical malfunction of the organism" (Turner, 2001, p.37) that it was once viewed as, is fundamentally a social state of affairs. This is typified in the way that medicine 'manages' the socially deviant individual through the sick role where, although the gatekeeper may be the medical professional who will diagnose and 'legitimize' a medical condition, it is 'society', and the social actors within it, who perpetuate it. Finally, I will discuss the ways that chronic illness is 'experienced', which is a major challenge for my own research that explores the motives behind exercise rehabilitation to the cardiac patient. Throughout the chapter, I will be conscious of one of the central issues of sociological theory, that of the relationship of agency and structure.

## 2.2 HEALTH POLICY

In order to understand the current position of health policy in the UK which, it will be argued later, impacts directly upon the health choices of the individual, it is important to have a brief understanding of its origins and of how this position has been arrived at. The Government White Paper, *Prevention and Health: Everybody's Business* (Department of Health, 1977), which detailed the reorientation of health care delivery, made it clear that health is not just the business of GPs, nurses, and health professionals in general, but "everybody's" business. Various authors (e.g. Nettleton, 1999) have suggested that this report signalled a shift away from cure to prevention in health care but I would argue that the actual significance of this report was its role in highlighting the individual in health care by being explicit in emphasizing personal responsibility in the adoption of healthy behaviours. Further, it would appear, as argued by Bunton et al. (1995), that the paper ignores the influences of social and cultural factors on individuals in the maintenance of good health, which is typified by statements such as:

> "... many of the current major problems in prevention are related less to man's outside environment than to his own behaviour; what might be termed our lifestyle. For example, the determination of many to smoke cigarettes in the face of the evidence that it is harmful to health and may well kill them." (Department of Health, 1977, cited by Bunton et al, 1995, p.93).

Bunton and colleagues use this passage to demonstrate the early development of the so-called 'victim blaming' approach, which emerged as a consequence of individuals 'failing' to maintain good health. The "outside environments" are explicitly ignored, in terms of causation, in favour of the unhealthy behaviours, such as smoking, that are within the control of the individual. I would further suggest that it also marks a departure from the health policy of post war Britain that attempted to bring some equality across the classes to health care provision. Where once these "outside environments" were thought to be the biggest barriers to good health for the lower classes, by the mid-seventies these were being given less prominence. The intervening decades had, of course, seen great successes of medicine over the types of disease that were the main causes of mortality in post-war Britain, so the emphasis was shifting from cure to individual prevention. I would suggest *individual* prevention, rather than *prevention* per se, because the latter can be achieved by addressing the social and environmental factors that, without doubt, impact upon health and illness. The Public Health Acts of the 1920s that resulted in clean drinking water and effective sanitation are examples of this. To use the instance of smoking, many socio-economic factors influence smoking rates within the population, social class being prime among them (Blaxter, 1990), but these appeared to be less important in the White Paper *Prevention and Health: Everybody's Business*. Those from lower socio-economic classes often use smoking as a coping mechanism, or begin smoking for reasons of image and style, which again are overlooked in this policy. As Bunton and colleagues observed, a health policy that prioritizes telling people not to smoke over the placing of constraints on the tobacco industry are probably serving the interests of capital rather than health.

The publication of *Prevention and Health: Everybody's Business* prompted a dramatic increase in the number of policy documents and statements related to the issue of prevention, all focusing on the responsibility of the individual. The next landmark document was *The Health of the Nation* (Department of Health, 1992), because it set specific health targets in reducing rates of mortality and morbidity from the major "preventable" diseases, such as CHD and stroke, as well as cancers and accidents. This document attempted to bring back the structural, socio-economic influences into the picture by, for example, targeting ethnic minority communities for intensive health education campaigns. However, this document, again, has been criticized for its individual emphasis and the 'lip-service' that it appears to pay to the structural aspects of health:

> "How else can one explain a public health rhetoric which argues that social conditions affect health outcomes and then, in turn, argues that the appropriate solution is to eat better, exercise more, drink less and give up smoking?" (McQueen, 1999, p. 342)

Since *The Health of the Nation* White Paper, subsequent government health policy has continued, and even developed, this theme of individual responsibility for health. One concept that emerged directly from the White Paper was that of the 'expert patient', which the policy makers felt held the key to a healthier Britain. This extract from the foreword gives an indication of the thinking:

> "An observation often made by doctors, nurses, pharmacists and other health professionals who work with people with long-term medical conditions is that the patient usually understands the impact of their disease better than the health professional does. The knowledge and experience held by a patient is now considered to be a huge untapped resource that could, if channeled appropriately, greatly improve both the quality of the patient's care and their quality of life." (Department of Health, 2002)

The message here is quite clear, that the major problems associated with the conditions of chronic illness that predominate today, are all related to people's quality of life. The medical profession can prescribe pain killers to reduce the physical symptoms, but the biggest issue remains how to live a normal life in the face of disabling conditions. However, this isn't really the responsibility of the medical profession, more of a social services issue, but as many medical sociologists have observed, the medical profession has been reluctant to let go of anything to which it is related. Although my point appears contradictory – the fact that medicine is encouraging individuals to learn how to manage their own condition, while simultaneously I am suggesting that medicine is reluctant to relinquish control – I would argue control is maintained by this approach. Patients have been *employed* to give the health promotion message, rather than being *empowered* by the message. The "tightly scripted" (Bury, 2004) format of delivery ensures that patients lead their lives in the manner that the medical profession intends. The lifestyle advice provided is uniform to all conditions, centering on 'doing the right thing' in terms of diet and exercise. As such it promotes the 'healthist' society that Government Policy has striven to achieve.

The emphasis upon individual responsibility for health that has dominated health policy in Britain since the mid-seventies has not been exclusive to this country and, indeed, has actually been informed by wider global shifts. The World Health Organisation (WHO) has produced consultation documents, which have been similarly criticized. In turn, the *Alma Ata Declaration* (WHO, 1978) argued that, although governments have a responsibility for the health of their populations, this responsibility lies mainly in its role of providing relevant information to people so that they can take responsibility for their own health. The next obvious question to come from this arrangement was how best to deliver health education or, more specifically, how should health promotion be delivered? In the longstanding tradition that has seen the medical profession protect and expand its hegemony over all areas of health, a new 'profession' of allied medicine was created. The World Health Organisation, at a meeting in Ottawa, put together *The Ottawa Charter for Health Promotion* (WHO, 1986), and this became the catalyst for the health promotion movement that was to follow.

## 2.3 SOCIAL CONTEXT OF ILLNESS AND HEALTHCARE

### 2.3.1 Health promotion and the 'normalisation' of illness

The work of the health promotion movement, as defined by *The Ottawa Charter for Health Promotion* (WHO, 1986), purports to represent "the process of enabling people to increase control over and improve their health". Kelly and Charlton have critically argued that this involved recognizing that power and control are the central issues in health promotion and that these were in the hands, once again, of the medical profession: "for all the talk of empowerment, the experts remain firmly in control of the discourse of health promotion" (1995, p.82). Decades earlier, Freidson had described the way that medicine had an all-encompassing authority over any health related issue, thus 'medicalising' many areas: "The medical profession has first claim to jurisdiction over the label of illness and *anything* to which it may be attached, irrespective of its capacity to deal with it effectively" (1970, p.251, emphasis in original). This 'claim to jurisdiction' is demonstrated in the way that the health promotion movement has taken control of 'lifestyle' issues, which are treating the *potential* for illness rather than the illness itself (Tones, 1985). Cardiac rehabilitation programmes are a good example of this. Phase III cardiac rehabilitation, which is delivered by cardiac nurses and physiotherapists, involves participation in an exercise programme, in conjunction with health education sessions related to smoking cessation, healthy eating and stress management. Clearly, exercise is not, in the traditional sense, a medical treatment, any more than dietary advice is. What is being 'treated' is the potential for another heart attack, but it is being undertaken by medical professionals, supporting Freidson's assertion of long ago that medicine continues to control anything that might be attached to illness. In this context, it is the health promotion ethos, rather than the profession itself that dominates and this is reinforced in the way that cardiac rehabilitation is defined.

Definitions used in physical rehabilitation usually centre on the theme of returning the patient to pre-injury status in order that one can get back to normal and, most often, back to work, following an injury or illness. However, cardiac rehabilitation, perhaps because it is the consequence of a 'lifestyle' disease, has a definition that is much more all-encompassing:

> "The rehabilitation of cardiac patients is the sum of activities required to influence favourably the underlying cause of the disease, as well as the best possible physical, mental and social conditions, so that they may, by their own efforts preserve or resume when lost, as normal a place as possible in 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." (WHO, 1993)

The underlying cause of the disease, as health promotion views it, is an unhealthy lifestyle so rehabilitation, as discussed, must address this. However, it must be addressed “by their own efforts”, which once again highlights the victim blaming culture that the health promotion movement creates. The cardiac patient is now not only to blame for the original heart attack, but is responsible for ensuring that it never happens again. This has some resonance with Nettleton and Bunton’s (1995) argument, that one consequence of the development of the health promotion movement has been the construction of a new type of patient. Where, once, people entered the sick role as a consequence of a GP consultation, they can now interact with health-related community groups, media health campaigns or health promotion workers themselves, in learning how to best manage their own health regimes. The sick role becomes a socially constructed concept, rather than a medical one – we all have the knowledge to judge what is healthy and what constitutes unhealthy behaviours and, as a consequence, we bring these judgements to bear on peers who *appear* to be unhealthy. This brings the discussion on to *healthism*, a term that Skrabanek refers to as the situation that results when health “is no longer a personal yearning but part of state ideology” (1994, p.15).

As Burrows and colleagues have put it, “at a cultural level ‘healthism’ has become a central plank of contemporary consumer culture” (1995, p.1). They point out that in the 1960s a supply of ‘health-related’ commodities might have included aspirins, TCP and plasters, whereas today it would certainly include things like vitamin pills, exercise videos, tracksuits and trainers. It would seem that even our commodities have been converted from articles of ‘treatment’ to items of prevention and promotion. To understand this we need to return to the structural analysis of health.

One sociological critique of the health promotion movement comes from the socio-structural perspective (Nettleton and Bunton, 1995), which argues that in attempting to prevent illness and promote health, the movement has failed to consider the material disadvantages of people's lives. This has been discussed in the example of smoking, and the way that health policy (as well as the health promotion movement) ignores the habit as, for example, a coping strategy for those who face socio-economic disadvantages on a daily basis. Rather, the health promoters, who are themselves typically white, middle-class and healthy, bring their own value systems to bear upon their work, which leads to the marginalisation of certain social, or 'target', groups. Citing the research of Wang (1992), Nettleton and Bunton use the example of the way that a 'disablist' (a term used by Zarb, 1992) value system resulted in an injury prevention campaign presenting unintended negative consequences for disabled people. In short, the campaign promoted the message that it is better to be constrained by a seatbelt than by a wheelchair, i.e. the consequences of not wearing seatbelts can be catastrophic. The wheelchair-bound respondents in Wang's study felt that they had been "devalued" as people: "You know, frankly, I'll look at an advertisement like this and say what's so bad about using a wheelchair. And here we go getting the message again that we're not okay as wheelchair users" (Nettleton and Bunton, 1995, p.46). In effect, the health promotion message had acted "as a mechanism for deviance amplification" (p.46), reinforcing the stigma associated with disability. Disablement is seen as a personal tragedy rather than a socially produced state. Health promotion in practice, then, can serve to create structural divisions within society, between the disabled and the non-disabled, between the healthy and the un-healthy, and these divisions extend to the ways that people perceive others who appear to have failed in their responsibility for personal health. People who are overweight are thought of as being lazy (Shilling, 2003) whereas the slim person who engages in athletic pursuits has come to epitomize the layperson's perception of 'healthy' (Blaxter, 1990). Blaxter found that, generally, people thought that the slim and active person was less likely to experience heart disease than the overweight and inactive person. Similarly, Davison et al (1991) found that some people are viewed as 'candidates' for heart disease and that the characteristics for this, typified by overweight and cigarette smoking, were easily identified. Interestingly, just as the lay person can develop a 'risk profile' for coronary candidacy, so too does the medical profession, who suggest that this risk can be calculated in a predictive manner.

### 2.3.2 Risk factors and surveillance

Prevention programmes for coronary heart disease revolve around the identification and 'treatment' of "risk factors". The Royal College of Practitioners, in their report *Prevention of Arterial Disease in General Practice* (1981) suggest that the risk factors of high blood pressure, cigarette smoking, and obesity, should all be closely monitored in consultations. Various interventions attach a risk 'score' to people according to how likely they are to develop heart disease, resulting in a risk profile for each patient. This is intended to provide GPs with the opportunity to identify people who might be in need of medical care, although Calnan (1991) suggests that further evidence is needed before the efficacy of this type of intervention is supported.

This ‘surveillance’ type of health promoting activity has been criticized by, among others, Skrabanek who suggests that the introduction of risk factors is an example of “statistical trickery to provide an ‘explanation’ of causative mechanisms, which, in fact are not known” (1994, p.163). He continues by condemning the use of mass screening which, he proposes, lacks evidence to show any substantial decreased risk, and suggests that the practice actually does more harm than good, due to the many ‘false-positive’ tests that result in discrimination in, for example, employment, medical care, medical insurance and stigmatization:

> “Even though the majority ... may not suffer the expected consequences of ‘having’ a particular ‘risk factor’, once the risk factor has been identified, it is then reified into something real – part of the person’s constitution” (Skrabanek, 1994, p.162).

In effect, what this does is to take an apparently healthy person and diagnostically attach certain conditions upon him or her, such that the person is perceived as ‘unhealthy’. Further, the risk that a patient is understood to be under can change as the medical parameters are altered along with more current research. For example, a recent article in the British Medical Journal (Tanne, 2003) reports a change in US guidelines for blood pressure readings. The updated guidelines have included a new grading that defines a reading of 120/80 mm Hg, which had always been classed as “normal”, as now being classed as “pre-hypertension”. Whereas GPs would have told patients with this reading that they were healthy and sent them home happy, GPs now have to tell them that they have 'pre-hypertension'. The Social Issues Research Centre were quick to notice this:

> "Having contracted your 'new ailment' you now need to exercise, lose weight, reduce your consumption of sodium and alcohol and switch to a diet high in fruit, vegetables, potassium and calcium. Rather drastic measures you might think when just a week ago you were fine." (Social Issues Research Centre, 2003)

So, the 'medical model' approach to understanding the determinants of heart disease, and illness in general, appears to have been incorporated into peoples' perceptions, such that they hold very definite ideas about what makes a person healthy, as one of Blaxter's respondents put it: "I call her healthy because she goes jogging and doesn't eat fried food" (Blaxter, 1990, p.23). Similarly, people are able to 'construct' an image of the type of person who might be likely to experience heart disease (Cowie, 1976; Calnan, 1991). The task of the medical profession, however, is to monitor the risk factors of the population as a whole and to encourage us to change our unhealthy behaviours in favour of recommended lifestyles that will reduce our risk of developing lifestyle illnesses. In practice this is a massive task that would require substantial resources, so the aim then becomes one of encouraging the population to monitor their own health.

Foucault coined the term 'panoptic gaze' from Utilitarian philosopher Jeremy Bentham's prison model 'The Panopticon' (Foucault, 1995). The design of the panopticon, a tall tower from which the guards could watch while remaining unseen, left the prisoner subject to observation at any time by possible viewers and it was assumed that this surveillance would prevent those being watched from doing anything "wrong." An inmate who feared being watched would abstain, for instance, from behaviour that might otherwise be engaged in if no one was around to "see." Under such a gaze each prisoner, under its weight, will end up by 'interiorizing' to the point that he becomes his own overseer, something that Foucault referred to as 'disciplinary power':

> "Bentham laid down the principle that power should be visible and unverifiable. Visible: the inmate will constantly have before his eyes the tall outline of the central tower from which he is spied upon. Unverifiable: the inmate must never know whether he is being looked at in any one moment; but he must be sure that he may always be so. In order to make the presence or absence of the inspector unverifiable, the prisoners, in their cells, cannot even see a shadow" (Foucault, 1995, p.201)

Foucault envisaged power as being exercised continuously for minimal cost and the similarities with today's public health delivery, where cost is a major consideration, are obvious.

Health promotion workers are provided with legitimate access to more and more aspects of people's lives, as medical surveillance becomes, quite overtly, an increasingly important aspect of public health. Indeed, *The Faculty of Public Health Medicine* cites "surveillance and assessment of the population's health and well being" as number one in its 'ten key areas of public health practice' (Beishon, 2003). The analogy, it might be argued, is that today's health professionals can do their work from their 'towers' where they cannot be 'seen', but the individual can be found out if anything should go wrong. If we fail to heed the health educational advice, we may experience a lifestyle disease, which implies that we have not been leading a healthy life. Further, I would suggest that these metaphorical watchtowers are staffed, not only by health professionals, but also by peers, who are aware of the responsibilities that we hold toward health and how good health should be behaviourally achieved. Armstrong (1993) suggests that every sphere of modern life has been permeated by vigilance – we should choose low-fat food options, we should monitor our weight, we should have our blood pressure monitored and we should ensure that our cholesterol levels do not get too high. This recognizes that the task of surveillance has been handed to the individual and that, similar to the way that Foucault described the 'interiorizing' process, we have become responsible for our own health surveillance. The "health promoting self" (Nettleton and Bunton, 1995) has become the chief weapon in the 'fight' against lifestyle disease.

For Giddens (1991, p.15), "surveillance refers to the supervisory control of subject populations, whether this control takes the form of 'visible' supervision in Foucault's sense, or the use of information to coordinate social activities". Giddens, recognizing the importance of Foucault's ideas, argues that it is the expansion of surveillance capabilities that has become the main method of social control and this is no less relevant to health. Rose (1990) has argued that even our thoughts are created and guided by social institutions, what Nettleton and Bunton, (1995), following Foucault, refer to as 'technologies of the self' – health promotion being one among them. We are 'enabled' by the information and technologies offered to us, to achieve health, happiness and fulfilment (Rose, 1990, p.10). It is argued, then, that health promotion is one form of governance, which, via the establishment of appropriate social identities, forms one dimension of social regulation (Nettleton and Bunton, 1995).

Foucault has placed the body at the centre of surveillance medicine, referring to the 'medical gaze' in describing the way that the body (both the individual body and bodies of populations) is regulated by 'medicine' (Foucault, 1973). It has been suggested (Fox, 1997, p.41) that in Foucault's earlier writings, his ontological position on the body was that it was a passive object: "it cannot be allowed to be an agent: to provide it with such a capacity is to reintroduce the essentialism which Foucault wishes to deny". However, Fox goes on to discuss the way that Foucault's later work is noted for a turn in focus from the 'passive body' to 'the self', when he wrote of "individuals not as docile bodies but as reflexive, living, speaking beings" (Foucault, 1985, cited by Fox, 1997, p.41). This brings the discussion on to the degree of agency that we, as individuals, are able to exert over our own actions. Surely, if the panoptic gaze of medicine were as powerful as has been suggested, why are deaths from lifestyle disease, such as heart attack, still the biggest cause of mortality in western societies? Why do we not regulate our bodies as efficiently as we are advised to?

This puzzle has been discussed in relation to the health promotion movement in the way that, as a profession, it fails to reconcile the problem of agency and structure:

> "For health promotion, free will is held up as a guiding principle, embedded in notions of empowerment and facilitation, while at the same time defining the social structure as acting *on* people in a deterministic way ... Either we are all free or are all socially determined. You can't have it both ways. Because the health promotion movement wants it both ways, it finds itself attacked by both the free will school of the right and the structuralists of the left" (Kelly and Charlton, 1995, p.79)

Kelly and Charlton follow this criticism of the health promotion movement by suggesting that one way of understanding the problem is to consider Giddens's theory of structuration. This notes that social life is more than random individual acts, but by the same token, it is not merely determined by social forces (Gauntlett, 2002). Instead, Giddens suggests, human agency and social structure are in a relationship with each other, and it is the repetition of the acts of individual agents, which reproduces the structure. This acknowledges a social structure - traditions, institutions, moral codes, and established ways of doing things; but it also means that these can be changed when people start to ignore them, replace them, or reproduce them differently. To explain this Giddens (Giddens and Pierson, 1998) draws an analogy with language: although language only exists in those instances where we speak or write it, people react strongly against others who disregard its rules and conventions. In a similar way, it has been suggested that the 'rules' of social order may only be 'in our heads' - they are not usually written down, but nevertheless, people can be shocked when seemingly minor social expectations are not adhered to. Harold Garfinkel's sociological studies in the 1960s (Garfinkel, 1984) showed that when people responded in unexpected ways to everyday questions or situations, other actors could react quite angrily to this breach of the collective understanding of 'normal behaviour'. It is, therefore, the social structures, which are maintained by us all, that set the limits of action. In terms of health, we are guided by the responses of our peers and nowhere is this more evident than in the ways that we support or condemn those who are experiencing chronic illness. As a result, the notion of 'health as virtue' has emerged.

### 2.3.3 Health as virtue

I include the notion of 'health as virtue' in the social level of analysis because, I would argue, the social pressures that are exerted over the individual to act in a virtuous manner come from our peers who make up 'society' (who, in turn may be responding to the societal influences discussed above). This decision has been made with the acknowledgement that it is the response of the individual that ultimately decides the matter, and for this reason it straddles the two levels of individual and social analysis. More specifically, it relates to Giddens' structuration theory; whereby the actions of individuals actually create the social structures that, in turn, influence our actions. The term 'health as virtue' emphasizes the moral significance of health, or more specifically, the ways that people respond to illness in order to disassociate themselves from blame. A good starting point will be to examine Goffman's notion of 'the moral career' and how this can be adapted in situating the experience of heart disease within a 'moralistic' framework.

A moral career has been described as "a life trajectory defined in terms of public esteem" (Harré, 1993, p.206). It is constructed from the views regarding the way that the person is seen to cope with, what Harré refers to as, 'occasions of hazard'. These occasions of hazard are social events whereby the person will risk respect against contempt according to the resulting success or failure of the hazard. The example given by Harré is that of the examination, within the moral career accompanying education – a pass or a fail leading to respect or contempt – but it can equally be applied to such things as participating in a sporting event, taking a driving test, or experiencing chronic illness.

Goffman argues a general point about the moral career of the asylum inpatient, which he suggests, can be paralleled with other moral careers. Goffman sums up this point:

> "If the person can manage to present a view of his current situation which shows the operation of favourable personal qualities in the past and a favourable destiny awaiting him, it may be called a success story. If the facts of a person's past and present are extremely dismal, then about the best he can do is to show that he is not responsible for what has become of him, and the term sad tale is appropriate." (1961a, p.150)

Goffman's notion of a moral career is generally understood as being relative to institutions, such as the mental institution, or Asylum, that Goffman (1961a) examined in his essay, *The Moral Career of the Mental Patient*. However, he suggests that the term can also apply to "any social strand of any person's course through life" (Goffman, 1961a, p.127). I will argue that the health biography of a person is an equally relevant arena for its application. The moral imperative within the health biography is to disassociate oneself from any blame that might be attached to the illness and to establish its legitimacy, thus denying the representation of a 'sad tale'.

Both Blaxter (1993) and Cornwell (1984) have demonstrated the virtuous element associated with health. In her biographical approach to understanding the meanings of health among women from the North East of Scotland, Blaxter found not only a strong emphasis upon individual responsibility for health, but she also found a strong influence of poor health over identity. To these women, 'giving in' to illness demonstrated a weakness of character, the guilt of which would lead to a re-examination of 'who they were'. This "moral identity" as Blaxter (1993, p.206) describes it, relates not to the *fact* of illness, but to the way that a person deals with it, therefore to 'soldier on' in the face of adverse health is credible, whereas to give in demonstrates moral weakness. Similarly, Cornwell in her study of a working class community in the East End of London, found that responding in the 'wrong' way to the experience of chronic illness can "threaten not only the practical basis of their lives but also their moral reputation" (1984, p. 127). The virtue appears to lie in a person's stoic resistance to illness, so both Blaxter's and Cornwell's participants were keen to always refer to themselves as healthy, even though they actually experienced many illnesses.

When we apply Goffman's concept of the moral career to these studies, we can see that the development of a chronic illness is actually an occasion of hazard, within the person's health biography. Stoic confrontation of chronic illness will lead to respect from one's peers, whereas to "lie down to illness" (Blaxter, 1993, p. 139), as one of the respondents of Blaxter's research describes it, demonstrates failure that will lead to contempt. Similarly, in his case study of a female arthritis patient, Williams found that in her attempts to avoid the 'contempt' of visiting health professionals, this lady needed to develop 'coping strategies' that were based upon the "pursuit of virtue" (1993, p.96). This pursuit itself, revolved around the three themes of independence, cleanliness and financial solvency, the concerns of which surpassed the concerns of her own physical limitations. As Williams puts it: "the disadvantages relating to her arthritis were less the direct effects of her disease and more the product of her interaction with the social and physical world" (1993, p.105). This demonstrates the difficulties of living with chronic illness, which are as much about coping with a range of social influences and processes, as with coping with the condition itself.

The ways that we experience illness, then, has a profound effect upon the ways that we are viewed by our peers, which in turn, can have an effect upon our own self-identity. To live with illness in a morally acceptable way is to be commended, whereas to give in to illness is to incur contempt. This suggests that we are able to police ourselves, from our metaphorical 'watchtowers', in Foucault's terms, and we are also able to monitor others in the same way. An example of this, in practice, is provided by Parsons' (1951) concept of the sick role. This attaches a social significance to the sick person as well as a physical one, arguing that certain rights are granted if the sick person is not responsible for their illness. It has been argued that the sick role assumes that the sick person should want to get well (Nettleton, 1999) and respect can be gained from being a 'good patient'.

## 2.4 ILLNESS EXPERIENCE

### 2.4.1 Biographical disruption and continuity

Charmaz (1983) has described how the onset of chronic illness can assault both the physical self and also the sense of identity that brings into doubt the person's self-worth. Bury's (1982) concept of 'biographical disruption' takes a more broad view of the experience as a disruptive event, located within the wider context of a person's past life. In this sense, it is not only the body and the 'self' that is disturbed, but also the whole trajectory of the person's life. The notion also suggests that the disrupted biography of a person simultaneously disrupts social relationships and impacts upon the person's ability to mobilize the resources that might normally be used in coping. Bury relates the disruption of chronic illness to three aspects:

> First, there is the disruption of taken-for-granted assumptions and behaviours: the breaching of commonsense boundaries... Second, there are more profound disruptions in explanatory systems normally used by people, such that a fundamental rethinking of the person's biography and self-concept is involved. Third, there is the response to disruption involving the mobilization of resources, in facing an altered situation. (1982, p.169-170)

Bury concludes that the medical profession and the medical intervention is not necessarily the most important determinant of a chronically ill person's changed behaviour, rather, it is determined by many other factors. "The disruption of reciprocity, the problems of legitimating changed behaviour and the overall effects of stigma associated with chronic illness all affects the individual's ability to mobilize resources to advantage" (Bury, 1982, p.180). Relating Bury's concept of biographical disruption to the health behaviours of cardiac patients is, although useful, not unproblematic. Bury's respondents were rheumatoid arthritis patients and he describes the insidious nature of the disease by the way that it 'creeps-up' on a person. In contrast, cardiac patients find themselves in an immediately critical situation. Even those who do not experience a heart attack, but who undergo bypass surgery, experience an 'event' – a very real and life-threatening event of heart surgery.

The lived experience of arthritis is also a contrasting one to heart disease: in the first instance, Bury's respondents viewed the impairments (swollen fingers, stiffness) as something of a "nuisance", its severity only emerging with time, whereas to the cardiac patient, perceived severity can appear to decline with the passing of time (Wiles, 1998). Social support and the involvement of others also observe an inverse relationship. The heart attack patient will often be in receipt of high levels of material support in the initial post-event period, which often reduces in time as the patient demonstrates competence in performing everyday tasks. However, the arthritis patient will not experience high levels of support until the very late stages of disease development, as it becomes increasingly apparent that everyday tasks are not easily undertaken.

These dissimilarities noted, the theoretical concerns that Bury applies to "a wider analysis of cultural and structural forms" (1982, p.169) of chronic illness, are similar. It is the *experience* of chronic illness and the ways that people attempt to make sense of their lives and their future behaviours that are of concern here. People with chronic illness, by definition, experience a long-term and often permanent condition that can be accompanied by pain, psychological distress and loss of independence. The nature of this suffering has been referred to as 'loss of self', described as "a crumbling away of former self images without simultaneous development of equally valued new ones" (Charmaz, 1983, p.168). A person's self identity becomes questioned and previously valued roles, responsibilities and activities are unable to be returned to.

In her study of 57 individuals with a variety of conditions of chronic illness, Charmaz found loss of self to be equally relevant to those experiencing outwardly visible disability, such as limb amputation, as it was to those with less obvious illness, such as heart disease. Those with a less apparent illness might experience discreditation associated with the restriction of their participation in the 'normal world', a restriction that results in fewer opportunities to construct a valued self. Charmaz illustrates this with the account of an elderly respondent with heart disease:

> "She felt it unwise to be any distance from her doctor so she stopped travelling. She believed that she needed to reduce stress so she stopped driving, except for occasional short errands. She thought that she might be vulnerable to break-ins so she moved to an apartment with a security entrance. She decided that her dog was too much trouble so she did not replace him after he died. Although she simplified her lifestyle, she did so at the cost of increased loneliness and boredom" (1983, p.174-175).

Bury (1988, 1991) has distinguished two aspects of the impact of chronic illness: 'meaning as consequence'; and, 'meaning as significance', the former being related to the practical aspects of life, such as disrupted work and domestic routines, the latter being related to the "connotations and imagery" (Bury, 1991, p.451) associated with the condition. It is the meaning as significance that influences the loss of self experienced by many of the chronically ill, and Charmaz, once again, provides an account:

> "A visitor asks the wife of a man whose recent heart attack has immobilized him, 'Has he been a good boy today?' followed by cooing direct questions to

> him: ‘have you taken all your medications; are you doing what your doctor tells you?’ Through tone of voice, the visitor implies that he is now reduced to a four year old or puppy dog status. Rather than feeling comforted by such interest, he feels alienated.” (1983, p.177).

There follows an increasing awareness of the changing nature of their identity, i.e. the new status as an ‘ill person’, that lies ahead of them and the previous status now lost. Charmaz suggests that this awareness results in the ill person scrutinizing encounters with others and looking for signs of discreditation that are often wrongly interpreted as such, therefore, increasing the loss of self being endured. It could be reasonably argued that the act of scrutinizing encounters might be a response to the need to ‘act normal’ so that the illness, and perceived stigma that might be attached to it, can remain hidden. This brings the discussion on to the ways that people try to live a normal life in the face of biographical disruption.

As a person’s biography becomes disrupted and one’s sense of self becomes threatened with the development of chronic illness, the need to maintain some semblance of continuity becomes evident (Becker, 1993). Various recent papers related to chronic illness and physical activity recommend continuity theory as a framework for exploring physical activity behaviour, sometimes among chronically ill older people (e.g. Hardcastle and Taylor, 2001). Continuity theory argues that as people age they attempt to maintain consistency in their lifestyle.

> “A central premise of Continuity Theory is that, in making adaptive choices, middle aged and older adults attempt to preserve and maintain existing internal and external structures and that they prefer to accomplish this objective by using continuity (i.e., applying familiar strategies in familiar arenas of life)” (Atchley, 1989, p.183).

Atchley contends that in middle and later years, people are impelled to link past experiences to present situations in an effort to maintain continuity through a lifespan of "normal aging". Continuity theory's emphasis upon 'normal aging' is perhaps where its suitability as a framework to be applied to those with chronic illness becomes problematic. Atchley states "normal aging can be distinguished from pathological aging by a lack of physical or mental disease" (1989, p.183). However, continuity theory may have relevance regarding self and identity via the component of the theory that Atchley describes as 'internal continuity', which he refers to as the persistence of an inner structure of self and personality. This internal consistency will persist through substantial changes in the person's life, because this is their core *identity.* Atchley cites Lieberman and Tobin (1983) who contend, "even institutionalization produced no discernible effect on older adults' capacity to maintain their perception of self continuity. Thus, it would be a mistake to overestimate the internal effects of external change" (Atchley, 1989, p.187).

However, the theory does accommodate the notion of 'discontinuity'. Although no examples are provided, it is to be assumed that only an 'internal event' would be sufficient to alter some aspect of identity, because he argues that nothing external, such as imprisonment, can detract from internal structures of identity. It is to be assumed that the disruption caused by chronic illness is such an event that would lead to internal discontinuity:

> "For example, lacking a perception of continuity can mean that the individual's life seems chaotic and unpredictable. Severe discontinuity means that the person has no standard with which to assess her or his life's integrity.

> The result can be severe anxiety and depression, a lack of hope borne of the inability to project one's future with any confidence. This often happens to people with dementia, AIDS or other diseases with serious but uncertain outcomes" (Atchley, 1989, p.188).

Here we can see distinct similarities to Bury's (1982) concept of chronic illness as 'biographical disruption', which is very much related to the 'lived experience' of illness. From the lived experience perspective, illness is very much an internal event that threatens the life trajectory and brings into question assumptions of 'self' and its meanings. Becker has suggested that continuity is "mediated through the person rather than through culture" (1997, p.224) and that the "ideology of individualism is concerned with continuity of the self rather than with cultural continuity" (p.99). Although I would not strictly agree with this (in as much as I think that the two are more difficult to separate because it is the culture that the person lives in that influences the individual to take responsibility), it does bring the discussion on to the extent of agency that the social actor exerts in the practice of maintaining continuity. As it is the responsibility of the person rather than society to maintain "normalcy" (Becker, 1997, p.99), by acting in what Giddens (1991) would refer to as a reflexive manner, we are able to bring our own definitions to bear on matters.

Research among cardiac patients (Cowie, 1976; Wiles, 1998) has demonstrated the ways that individuals are able to interpret certain acts in such ways that best fit their own biography and, it could be argued, these are aimed at maintaining continuity. For example, Cowie (1976) found that cardiac patients appeared to actively reconstruct the past in order to make their heart attack "intelligible", something that, with hindsight, should actually have been expected, making the event appear to be less threatening. The respondents in his study also compared themselves against other patients on the ward with reference to, for example, age and severity of symptoms, resulting in their own situation being perceived as being, once again, less ominous. These patients were then able to believe more readily that there is no reason to accept the lifestyle recommendations of health professionals who warn of the consequences should they not 'change their ways'. In the same way, Wiles (1998) found that cardiac patients would have great faith in the expertise of health professionals in the early stages of post-event recovery, but that this faith would diminish in time for a number of reasons. The patient's own personal experience would often not match the information provided by epidemiological studies, from which health professionals' advice derived - the 'lay epidemiology' appearing to be more persuasive. Similarly, when an individual's rate of recovery became out of line to that predicted by a health professional, the 'expert' knowledge was often brought into question and faith was lost. Therefore, the rationale for a person to resist the lifestyle advice that the health promotion movement is perpetually recommending can appear to be both appropriate and legitimate to individuals.

Drawing on Herzlich (1973), Radley and Green (1985) have discussed 'styles' of adaptation following heart bypass surgery. They developed a conceptual framework that addressed "the need to resolve the competing demands of bodily symptoms and those of society" (Radley, 1994, p.152). Radley and Green (1985) found that cardiac patients work at their biography such that illness is either 'fitted into self', or alternatively that 'self is fitted into illness'. Either way, a creative form of 'biographic work', in terms of adjustment, is undertaken in response to illness.

The ways that people are able to create their own theories in accounting for illness, drawing on what Davison, Davey Smith and Frankel (1991) refer to as the 'lay epidemiology' (whereby "individuals interpret health risks from formal and informal evidence" [p. 428] arising not only from 'official' sources but also others, such as television, magazines and personal experiences). This supports a reflexive quality of the individual. This reflexive nature of assessing one's own health, then reinterpreting the consequences to fit one's own biography, reflects the changes that Giddens has highlighted in today's modern society. Both Beck and Giddens propose that reflexivity is a response to the uncertainty and insecurity that dominates in late modernity, and central to Giddens's ideas on reflexivity is the notion of the reflexive project.

### 2.4.2. Working at health: actions and self-presentation

Giddens (1991) has observed that the modern individual's sense of self is reflexively understood in terms of one's own embodied biography. He highlights the abundant availability of resources that individuals can use in their own body 'project', such as self-help books in the areas of diet, exercise, therapy, relaxation, skin care, etc, as an example of the importance that is placed upon such self-care regimes. In a high consequence 'risk society', the body appears to provide a solid basis upon which a reliable sense of self can be built. Shilling builds upon Giddens' work, and proposes two areas of importance:

> "that we now have the knowledge and the technical ability in the affluent West to intervene in, and substantially alter, the body; and that growing numbers of people are increasingly aware of the body as an unfinished entity which is shaped and 'completed' partly as a result of lifestyle choices. The idea of the body as a project does not entail that everyone has the willingness or the ability radically to transform their body. It does presuppose that people are generally aware of these transformative developments, and that there is a strong tendency in the conditions of contemporary Western societies for people to become increasingly associated with, and concerned about, their bodies". (2003, p.200)

We are able, then, to reflexively 'work' on our bodies through the lifestyle choices that we make in our everyday lives. Lifestyle choices are at the centre of regimes of self-care, which today more than ever before is bound up with our self-identity. When we buy low fat foods we are maintaining efforts of self-care, which says something about the identity that we want to portray, both to ourselves and to others. This is particularly important in today's 'risk society', as Shilling (2003, p.5) suggests: "at a time when our health is threatened increasingly by *global* dangers, we are exhorted ever more to take *individual* responsibility for our bodies by engaging in strict self-care regimes" (emphasis in original).

Shilling (2003) observes that self-care regimes are not simply about preventing disease, but are also important in influencing the way that we feel about ourselves personally and also how we feel that others perceive us. Health, as discussed earlier, has become something that people are able to make instant assumptions about, both from our appearances and our actions. To look slim is to look healthy, but also *to be* *seen* to be pursuing a healthy lifestyle similarly holds its own virtue. As Shilling continues, "health has become increasingly associated with appearances and what Erving Goffman has termed 'the presentation of self'" (2003, p.5).

It has been suggested that the social self is constructed "through the investiture of social meanings" provided through interactions with others (Kelly and Field, 1996). Bury, who has written extensively on the subject of chronic illness and the self, notes that the relationship between self and others is a "precarious enterprise" and he cites Berger et al. (1974) who characterize this relationship "by high degrees of self-reflection, individualism and the manipulation of appearances" (Bury, 1982, p.178). The manipulation of appearances, or of how we would like to be viewed by others, is an important aspect of the ways that patients live with chronic illness.

Self-presentation (or impression management) derives from the writings of Goffman (1959) and his analysis of the ways that people will act, knowingly or unknowingly, in certain ways in order to create a favourable impression. Because many of people's social and personal outcomes are partly influenced by the way that other people perceive them (Leary, Tchividjian and Kraxberger, 1994) it is perhaps understandable that people should be concerned about the impressions that they produce. The notion of self-presentation can conjure images of purposeful manipulation or actions of conscious deceit. However, Schlenker and Weigold (1992) argue that this is uncommon, suggesting rather that people engage in a kind of tactical control of others' views through a selective presentation of sides of themselves that are most favourable. Further, people will, in the same way conceal information that goes against the image that they want others to form of them. Obviously some people will engage in deceitful self-presentation, but as this carries interpersonal risks (Goffman, 1959), this is the exception rather than the rule. Self-presentational failures, although to be avoided, are not uncommon and lead to embarrassment. Most impression management tactics have the purpose of portraying a person in a favourable light. However, Jones and Pittman (1982) suggest that some people will purposefully present an unfavourable impression of themselves, if there is some gain to be made from this, e.g. they will achieve important social goals.

## 2.5 CONCLUSION

The types of illness that prevail today are characterized by conditions of chronicity that can not be 'cured' by medicine. As a consequence, they have become a burden on the medical profession and the Government that funds it. Medicine, in its germ-theory approach to disease, has been successful in eradicating the diseases that once accounted for much of the mortality in the early part of the last century. For example, deaths in the UK from respiratory tuberculosis declined by 98 per cent between the years 1946 and 1984 (Wells, 1984, cited by Bury, 1997). Further, the demographics of society have seen a marked change with people living longer on average than ever before and, therefore, living longer with their chronic diseases and placing an increasing burden upon the finances of the medical profession. In the 1970s, it would appear, the Government recognised that it was going to be unable to keep pace with the demands that this would place upon them and published a series of White Papers that had the ultimate aim of bringing the individual in to the frame. This culminated in 2002 with the development of the *Expert Patient*, whereby the chronically ill learn how best to manage their illnesses. The emphasis of self-care was now squarely set upon the shoulders of the individual, but the obvious consequence of this was that a victim-blaming culture would develop. 'Individualism', then, has become a powerful social structure that influences our actions, and the ways that we live our lives, on many levels.

The demographic and cultural changes that occurred in the second half of the last century have been too inviting for sociologists to ignore. As a result we now have an abundance of contextual research information related to the ways that people's lives are disrupted by illness and the ways that people respond to and live with chronic illness. The need to 'do the right thing' is important, but so is the requirement to be seen to be doing the right thing. As Bury (1997) has detailed, the need to display 'cultural competence' has become a defining characteristic of today's society and is integral to the very nature of agency. The study of chronic illness, then, has a vital part to play in understanding the concepts of identity and social interaction as well as the relationship between agency and structure. An understanding of the choices that people make in their self-care regimes can then be developed, and the following chapter sets out the methodology that I employ to achieve this.

# CHAPTER 3: METHODS

## 3.1 AN ETHNOGRAPHIC UNDERSTANDING OF CARDIAC REHABILITATION

In deciding upon an appropriate methodology to use in understanding the exercise behaviours of cardiac patients, I needed to consider the best way of gaining the contextual information that would be required to 'get beneath the surface' of why patients chose the life courses that they did. What motivated some people to engage wholeheartedly in their exercise rehabilitation, while others resisted all efforts at encouragement toward behaviour change? An important consideration was that in understanding the lived experience of cardiac rehabilitation, I needed to spend some time close to the respondents, so that I could see what they were doing and so that I could make the most of opportunities to talk to them whenever possible. Turner (2001, p.205) has argued that illness should be understood in its cultural context, suggesting that, "sickness is something we do rather than simply something we have" and, in order to understand the ways that cardiac patients 'do' their exercise rehabilitation, I needed to observe them in their exercise sessions. However, this alone would be insufficiently sensitive to understand the lived experience of illness and its rehabilitation, and the meanings of each, to the patients. In the opening chapter, I described the psychological approach to understanding health behaviours and as my research is, in part, a response to the quantitative methodologies that they employ, I knew that they were insufficiently sensitive for my purpose.

In the last chapter I reviewed the literature around the sociology of health and illness, which has predominantly made use of the interview method in collecting the type of data that enables access to people's views, without imposing other points of view upon them. This type of research allows people to speak in their own terms and give meaning and substance to their views and if I was to collect the type of contextual data that I required I, also, was going to have to make use of interviews. My methodology, it became clear, needed to be ethnographic in nature, allowing for natural-setting observations, semi-structured interviews and opportunistic interviews in the field. Further, it would allow for data to be collected over a lengthy period, four years as it turned out, which allows time for themes to be fully explored and developed, providing as clear an understanding as possible of the ways that people 'do' their cardiac rehabilitation. From my experience as a fitness instructor, I was aware that people tend to move in and out of exercise participation, so the 'snapshot' in time that the interview provides needed to be complemented with the opportunity to observe exercising cardiac patients over a longer period of time. The ethnographic methodology enabled me to do all of these things and the definition provided by Brewer (2000) demonstrates this quite clearly:

> "Ethnography is the study of people in naturally occurring settings or 'fields' by means of methods which capture their social meanings and ordinary activities, involving the researcher participating directly in the setting, if not also the activities, in order to collect data in a systematic manner but without meaning being imposed on them externally". (2000, p.10)

The 'naturally occurring setting' for the exercising cardiac patient is the fitness suite where their rehabilitation classes take place. By observing these sessions, unobtrusively as a fitness instructor, I was able to make the necessary observations that were required in developing an understanding of the ways that patients ‘do’ their rehabilitation.

As regards my data, I needed a theoretical framework that would be complementary to the method that was to be used in data collection, and for this I was informed by prominent authors in the field. The grounded theory method has provided “a set of useful research strategies for studying the experience of chronic illness” (Charmaz, 1990, p.1161) and the collection and analysis of my own data were informed by this method. Whereas other methods can begin with a tightly framed pre-conceived idea, the grounded theorist begins with a general research question and this appeared to be where I was coming from. For example, my experiences as a fitness instructor to ‘special populations’ and previous education in psychological research methods led me to believe that people exercised for clearly defined reasons that either acted as motivators or disincentives toward adherence. However, my reading around the subject of medical sociology also gave me an understanding of the ‘lived experience’ of chronic illness, which was somewhat at odds with this ‘rational actor’ hypothesis. The complementary theoretical framework was provided by Charmaz who has successfully employed symbolic interactionism with grounded theory in many research-based papers exploring the ‘lived experience’ of chronic illness and its influence upon the ‘self’. Charmaz (1990, p.1161) has suggested that “symbolic interactionism assumes that human action depends upon the meanings that people ascribe to their situations” and that “these meanings derive from shared interactions”, which is vital to constructing an understanding of the ‘loss of self’ in chronic illness.

Similarly, I needed to understand these conceptual 'meanings', not only of the heart disease but also of the rehabilitation process and the influences of social interactions, both with other participants and health professionals, as well as family and friends. An understanding of the theoretical underpinnings of symbolic interactionism will be useful in order to make sense of some of my research findings that are discussed later in the study, and Craib (1992) has cited Herbert Blumer's (1969) formulation for purposes of succinctness:

> "1. Human beings act toward things on the basis of the meanings that the things have for them.
> 2. These meanings are the product of social interaction in human society.
> 3. These meanings are modified and handled through an interpretative process that is used by each individual in dealing with the signs each encounters." (1992, p.87)

Craib (1992) points out that all modern discussions of the approach give a central place to George Herbert Mead and that these three points correspond roughly with the three sections of his book *Mind, Self and Society*. In this Mead develops the notion that social interaction produces meaning to the 'symbols' that make up our world. Therefore, there is a sense in which we create our world by giving meaning to the symbols that are bound up in it. Craib gives an example: "a piece of wood is a piece of wood; in our daily activity it becomes a table. The word 'table' means the role that it plays in our interaction: something to eat off, work on, use as a barricade against the bailiffs" (1992, p.88). For Goffman (1959), who employs the symbolic interactionist perspective to understand the ways that people manage impressions of themselves, the symbols become rules (of asylums), roles and settings. These can be understood and interpreted in various ways and as these meanings change and develop, so does that person's understanding of the world change and develop. Similarly, I will use the term 'symbol' to refer to the things that become salient in the lives and rehabilitation of cardiac patients, such as a heart attack, health information, lifestyle advice and the roles that people play out in their everyday lives. This will become more clear in the later chapters when these concepts are used 'in action', as it were, but these symbols can be interpreted, and reinterpreted, in order to fit biographically with the patient's understanding of their world. For Mead, the self is a "social structure" (Mead's term, cited in Zeitlin, 1973) that develops within social experience and is further delineated by Mead's concept of the 'I' and the 'Me'. The 'Me' being myself as others see me, and the 'I' being the reflexive part that looks at myself. Craib suggests that "Mead sees this as the source of originality, creativity and spontaneity" (1992, p.88), which is an integral aspect of symbolic interactionism, which assigns agency to the social actor. A symbolic interactionist framework, then, allows for an analysis of data that is sensitive to the understandings of creative social actor who must respond to societal pressures to 'do the right thing' in response to individual health care. In the last chapter I discussed the societal influences of 'individualism' and the pressures that are exerted upon the individual to take responsibility for their health. For the cardiac patient, who has experienced a 'lifestyle' disease characterized by lack of self care, the pressures are, it would be assumed, greater still. Symbolic interactionism offers the opportunity to understand the ways that cardiac patients interpret and respond to the social structure of individualism and particularly how, from the health as virtue perspective previously discussed, they maintain their moral standing among their peers.

Before this though, I needed to collect the 'rich contextual' data required to develop an understanding of the lived experience of exercise rehabilitation and, as I have said the grounded theory approach is particularly complementary to the symbolic interactionist framework. As such, my data collection has been informed by grounded theory. I say 'informed by' because, although I have a systematic process of collection and analysis, I have tried not be constricted or inhibited by the potential criticisms of the grounded theory 'purists' (Charmaz, 1990). The nuts and bolts of my method will become clear as I progress through this chapter, so there is no need to be overly descriptive at this stage. However, it would appear sensible to provide a brief overview of the methodology that I have employed. Grounded Theory, because it is theoretical, provides more than the descriptive accounts provided by some other qualitative methodologies, since an analysis of the phenomenon under study must be developed. As the researcher, then, I will attempt to demonstrate how I have moved from the descriptive classifications of information gathered, to an analysis that understands the motivations and influences that have made an impact upon these cardiac patients as social actors. The 'grounded' aspect relates to the way that theory emerges from the data, as opposed to other methodologies whereby predetermined hypotheses are tested or theories explored. I will also attempt to demonstrate the way that this study begins with data relating to the lived experiences of cardiac patients, then how I "progressively develop[ed] more abstract classifications or categories which integrate and explain the data and organize the relationships within them" (Chamberlain, 1999, p. 184).

Rather than provide a textbook style presentation of Grounded Theory, demonstrating only my ability to paraphrase noted authors on the subject of research methods, I will describe these 'classifications and categories' as I move through the study. This will be interspersed with my own accounts of experiences and problems encountered, beginning where so many other researchers begin, with the Local Research Ethics Committee.

## 3.2 ETHICS APPLICATION

The sensitive nature of my research, i.e. encouraging people to recount life-threatening events that might still hold emotive memories, plus the fact that I was to access potential participants via a GP's referral, required me to apply for ethics approval. Despite spending several months putting together a protocol that, I thought, would be straightforward, my initial application was referred and the comments from the Ethics Committee threw up some interesting considerations for the revision of my protocol. Refusal was based around three issues: the first was that I did not accommodate non-English speaking patients, the second was that, because participants might get upset recounting their stories, interviews could not be undertaken in their own homes, and the third required me to seek GP's approval to contact their patients.

Taking the points in order, no non-English speaking cardiac patient had ever been referred to me in six years of providing Phase IV exercise sessions so I had no such participants to include in my sample (perhaps I should have pointed this out in my original application). However, Southampton City Council provides a translation service that I could access and this satisfied the Ethics Committee. In a meeting with one of the Ethics Committee's Board members, it was decided that all of the interviews should be carried out in my office at the leisure centre. In case of emergencies, first aid could be administered immediately and safety was maximized. No such emergencies occurred throughout my study and the problems associated with this interview setting are discussed later. I also agreed to contact the GP's of all potential patients to ask for permission to contact the patient with an invitation to participate in my study. Again, this is discussed in more detail in the next session.

## 3.3 RECRUITMENT OF PARTICIPANTS

Potential participants were identified through their involvement with the Active Options GP Referral Scheme, which operates out of six local authority leisure venues across the city of Southampton and is managed by myself. The sampling process involved taking the names of cardiac rehabilitation patients from the Active Options database in reverse chronological order, beginning from August 1999 – one year prior to the first interview. This meant that a period of one year had elapsed from time of referral and, consequently, those who had continued to exercise would be classed as long-term adherents (see the exercise adherence work of Dishman, 1988 for definitions). The patients who were invited to take part in the study had not necessarily been referred onto the scheme directly from their Phase III programme, so some respondents may have had their heart attack years before, but had only been referred for exercise in the past year.

Criteria for inclusion were that participants should:

- Have experienced either a myocardial infarction (heart attack) or a coronary artery bypass graft (CABG or 'bypass surgery').
- Should have completed a Phase III cardiac rehabilitation programme, in order that all participants will have been provided with standard lifestyle management advice, typical of such programmes.
- Be at least one year post-event (because the purpose of the research is to examine cardiac patients' long-term exercise behaviours).
- Be willing to participate (and be capable of participating) in a lengthy interview.

As highlighted earlier, the GPs of the cardiac patients who met the conditions set out in the inclusion criteria were contacted by a letter (Appendix 1), which was accompanied by an information sheet (Appendix 2), to ask for permission to contact the patient. This was undertaken as a condition of Ethics Committee approval, but proved to be problematic because the return rate from GPs was extremely poor. Of the one hundred and twenty letters that were sent out (I sent out batches of twenty at a time over an eight-month period) only twenty-eight were returned. All GP's who returned their approval slip did actually consent for their patient to be invited onto the study. It is my experience that writing directly to GPs can be problematic because often their mail is intercepted by administration staff who decide whether or not to forward it on to the GP. The fact that I had a large database of cardiac patients meant that I did not need to chase up the doctors who had failed to respond, but because I had enclosed stamped addressed envelopes in all letters the operation did prove quite costly. I think that the main implication of my experience of gaining GPs' consent is that around four times as many participants that are actually needed for the study should be available at the outset.

The twenty-eight potential participants whose GPs gave their consent to be approached were contacted by letter (Appendix 3) and invited onto the study. Patients indicated their willingness to participate in the study by returning a slip in a stamped addressed envelope included with the letter (Appendix 2). They were then contacted by telephone to organize suitable appointments for their interview. Three of the patients who were invited to participate refused to become involved in the study – unfortunately they did not provide any specific reasons for this, and I felt it inappropriate to chase them up.

## 3.4 STUDY SAMPLE

Recruitment onto the study occurred in a series of stages that, in keeping with the iterative nature of grounded theory, coincided with the development of interview schedules. A total of 25 participants were ultimately involved in the interview component of the study, the characteristics of whom are shown in table 1. The gender mix was represented as 10 women and 15 men, the average age of participants was 65 (range 33 to 81) and the average time since their cardiac event was 5 years and 4 months (range 1 yr and 2 months to 23 yrs).

Table 1: Sample characteristics

| No. | Name | Type of cardiac event | Status | M/F | Age |
|---|---|---|---|---|---|
| 01 | Ahmed | MI/CABG: 1993 | Adherent | M | 68 |
| 02 | Susan | CABG: 1999 | Non-adherent | F | 53 |
| 03 | Steven | CABG: 1992 | Non-adherent | M | 49 |
| 04 | Richard | MI/CABG: 1998/99 | Non-adherent | M | 81 |
| 05 | Puran | MI/CABG: 1995 | Adherent | M | 64 |
| 06 | David | MI: 1998 | Adherent | M | 55 |
| 07 | Les | CABG: 2000 | Adherent | M | 73 |
| 08 | Jane | MI: 1999 | Adherent | F | 80 |
| 09 | Mary | MI: 2000 | Non-adherent | F | 44 |
| 10 | John | MI: 1998 | Non-adherent | M | 66 |
| 11 | Louise | MI: 2000 | Adherent | F | 33 |
| 12 | Matthew | MI: 2000 | Adherent | M | 67 |
| 13 | Robert | MI: 1999 | Adherent | M | 61 |
| 14 | Betty | MI: 2000 | Non-adherent | F | 71 |
| 15 | William | MI: 1992 | Adherent | M | 51 |
| 16 | Margaret | MI: 1998 | Non-adherent | F | 51 |
| 17 | Edward | MI: 1996 | Adherent | M | 77 |
| 18 | Jim | CABG: 2000 | Adherent | M | 75 |
| 19 | Molly | MI: 1998 | Non-adherent | F | 73 |
| 20 | James | MI: 1979 | Adherent | M | 79 |
| 21 | Arthur | MI: 1990 | Adherent | M | 66 |
| 22 | Michael | MI/CABG: 1990 | Non-adherent | M | 71 |
| 23 | Phyllis | MI: 1992 | Non-adherent | F | 77 |
| 24 | Win | MI: 1999 | Adherent | F | 67 |
| 25 | Doris | CABG: 1997 | Non-adherent | F | 71 |

## 3.5 THE DATA

Symbolic Interactionism posits that, “the individual is continually interpreting the symbolic meaning of his or her environment (which includes the actions of others) and acts on the basis of this imputed meaning” (Bryman, 2001, p.15). Strauss and

Corbin (1998) describe one of the strengths of grounded theory as being its ability to explore the *human* nature of the social actors who are being studied. In generating data the researcher aims to gain an understanding of how social actors interpret not only their own actions, but also the actions of other actors. In the course of gaining this understanding, the researcher brings certain attributes to the research process, such as disciplinary or professional knowledge, as well as personal and research experience. Strauss and Corbin refer to this process as “theoretic sensitivity” (1998, p.173). They reason that the more theoretically sensitive the researcher is to certain issues, the more attentive he/she will be toward them, and this aspect of research will be given consideration throughout the following sections.

Grounded theory is an iterative process whereby the researcher moves between steps of data collection and data analysis – often with these steps merging into one another (Strauss and Corbin, 1998). It has been referred to as the ‘constant comparative method’ (Glaser, 1967) because of the way that data analysis informs further data collection, and analysis. The inextricable nature of this research process makes it difficult to describe the collection of data separate from its analysis and it is out of this consideration that I will describe the two together.

### 3.5.1 Interviews

Various authors have discussed the power relations in interview settings (Finch, 1984; Limerick, Burgess-Limerick and Grace, 2002) and I was aware from an early stage in the research design for the potential for such a problem. It has been argued that the interviewer holds a dominant position in the process, being the one who delves into people's thoughts and experiences, without being required to give anything in return. My own situation was particularly one-sided, in terms of power, as the interviews were held in my office at the Leisure Centre where the participants undertook their exercise class - a condition laid down by the Research Ethics Committee. I anticipated that this situation would be particularly threatening to the cardiac patients who had dropped out of the exercise programme who might be keen to provide the 'right' answers, which makes gathering reliable data a problem in health interviews anyway (Blaxter, 1990). The risk of developing themes based on 'public accounts' (Cornwell, 1984) was always going to be evident in such a setting, particularly as these respondents were talking to a fitness instructor where the 'right' answer might appear to be the one that the interviewer will want to hear. I was conscious that I had to take measures to reduce the impact of this problem, particularly considering my dual role of fitness instructor and researcher. However, it should be noted that, as is the case in most research settings, the responses of these cardiac patients will have been influenced by the two main points discussed above: the research setting and the fact that I could be viewed primarily as a health professional, as opposed to an independent researcher.

Following receipt of the participant's acceptance letter, I made telephone contact to arrange an interview appointment. In this first contact I aimed to assure the participant that I was not interested in providing a 'telling off' for not attending classes. In the general course of my work, I often telephone patients for information (changes in medication, etc) and it is extremely common for a first response to be "are you telling me off for not coming last week?" Although light-hearted, there is often a note of concern present, so putting people at ease was my first consideration. Common responses from participants were that they were planning to restart the programme "once the holidays are over", or "as soon as the doctor sorts this knee out". Although I told them that they were welcome to restart at any time, I assured them that this wasn't the reason for contacting them. I explained that I was interested in their experiences and that their views were important to my study – certainly as important as the views of people who had adhered to the programme.

This message was reiterated at the interview where I was careful to explain that there were no 'right' or 'wrong' answers to any of the questions and that I would appreciate their honesty as this would not only help my study, but also the way that I deliver the exercise programme. I considered this ground-work to be successful when interviewing my second participant, a non-adherent who explained to me that exercise was "boring" and she would come back once I had made it "not boring". I told her that her honesty was appreciated! The atmosphere in all of the interviews was relaxed and I felt that the participants were at ease. My feeling was that my relationship with the adherent cardiac patients (I had known them all for a considerable period of time), was particularly useful in receiving reliable accounts. This was possibly more so than if an outside researcher were to undertake the interview, where patients might be on their guard to provide responses perceived to be 'what they want to hear'.

Cornwell (1984), in her account of interviewing people in East London, argues that the things that people say, and the way that they say it, will vary according to who they are talking to and the circumstances that they find themselves in. She found that people spoke differently about the same events between first and second interviews, and she put this down to her own developing relationship with them. As she got to know her respondents better, bearing in mind that she became quite familiar with certain families in the community, she was able to gain their trust and, as a consequence, gain what she referred to as 'private accounts'. Because of the power relations of the expert - layperson relationship, building good rapport with her respondents was vital in Cornwell's attempts in gaining these private accounts:

> "The quintessential autonomous expert is the doctor, but academics also fit the description perfectly. In this study, the fact that I am middle class, have had further education, and am female, in a part of London where it is unusual for people to have been educated beyond secondary level and to have professional occupations, and especially unusual for a woman, made me into a kind of expert for the people I was interviewing. In East London, most middle class people are, after all, experts of one kind or another." (1984, p.14).

In spite of her position as an obvious outsider, she was able to make people feel comfortable in the interview setting. Personally, I don't think she became an 'insider' - the differences were too great – I feel that she gained private accounts because of her skills in putting people at ease, and that by the second interview respondents knew what to expect from the interview situation.

Cornwell refers briefly to Goffman when describing the ways that respondents manage their appearance in situations that are entirely new to them. In the first interviews that she undertook, respondents were keen to present a courteous 'best face' in their accounts, as such providing public accounts – the accounts that would portray them in the best light. The skill lies, then, in gaining what Goffman refers to as "the 'true' or 'real' attitudes, beliefs, and emotions of the individual" (1959, p. 13) and this is particularly difficult when eliciting beliefs related to health and illness because people are all too aware of the things that they *should* be doing for good health (Blaxter, 1990). To reiterate an earlier point, I feel that the relationship that I have developed with the adherent cardiac patients, as their fitness instructor, was sufficient for them to feel comfortable in talking to me and in providing 'private' accounts. They did not need to manage an impression of polite "good manners that conventionally mark social distance" (Cornwell, 1984, p. 13). As mentioned earlier, the non-adherents posed more of a problem for me and I am sure that there is a certain amount of narrative that would be termed 'public accounts' in the data, but I feel that the measures described earlier allowed me to also gather a good amount of rich contextual information that Cornwell refers to as 'private accounts'.

In contrast to hypothetico-deductive methods of research, grounded theory is an inductive process whereby the researcher constructs theory from data that is grounded in the lived experience of participants (Charmaz, 1990). Working from as pre-suppositionless a beginning as possible in attempting to understand why more than half of all cardiac patients who begin a medically endorsed exercise rehabilitation programme fail to adhere to it, I felt that it was important that the initial semi-structured interview schedule (Appendix 4) began with a necessarily broad base. Therefore, it explored:

- The respondents' perceptions of the causes of poor health.
- The concept of 'healthism' (the overemphasis of individual responsibility for health).
- The issue of identity, specifically how identity may have been affected by the cardiac event and how exercise may have influenced this.
- The body and how the body may have 'let them down'.

Cornwell (1984) noted that her respondents gave different accounts in response to being asked direct questions, when compared to when they were invited to tell a story. More specifically, direct questions usually elicited public accounts, whereas story telling encouraged private accounts. I used a similar interview style, in as much as although I had a semi-structured interview guide, I was more concerned with the theme that was being developed rather than ensuring that I managed to fit in all of the questions on my sheet. This encouraged story telling, admittedly more successfully in relation to some questions than others, and often I would not ask all of my questions if I thought that the theme had been satisfied. By the same token, in order to encourage a conversation-like interview, as opposed to a question and answer session, questions would often be generated spontaneously by the flow of conversation. As Cornwell puts it "The interviewer cannot simply be a 'recording instrument' because who she is, what she is like, and the relationship she has with the interviewee affects the content of the interviews" (p. 17).

Rather than provide a detailed account of the way that each of my original themes were generated, I will use one example of the way that, from a broad base, a specific theme emerged from the data and was subsequently explored and developed. Early questions from my first five interviews began by exploring the respondents' perceptions of the 'meaning' of health because, as Blaxter suggests: "Clearly, concepts of health will affect ideas about responsibility" (1990, p.13). One of the first questions was taken directly from Blaxter's attempts to understand the meaning that health held for people: "try to think of someone you know who is healthy: why do you think of them as being healthy?" In Cornwell's terms of reference, this always provided responses cloaked in 'public' accounts. In other words, people would, talk of the functional aspect of health using terms like 'fitness' and 'ability', terms which Blaxter found common among her own respondents. I had anticipated that 'healthism' (the overemphasis of individual responsibility for health) might be a factor and had included some questions on the subject from the beginning.

The problem with asking direct questions regarding healthism is that they are, inevitably, destined to result in public accounts. For example, at the time of designing the initial interview schedule, a national advertising campaign was in full swing aimed at raising people's awareness of the dangers of leading an unhealthy lifestyle. Through flashbacks of a man's unhealthy behaviours, e.g. drinking, smoking and being a 'couch potato', intermingled with scenes of the same man in a coronary care unit, and with haunting voice-overs such as "I'll do something about it when I get a beer-belly", the message was clear: if you don't lead a healthy lifestyle you will have a heart attack. The overriding message was that we are all responsible for our own health. What then would cardiac patients make of such a hard-hitting advertising campaign?

Naively, I thought that asking my respondents what they thought of the advert might evoke responses of disappointment that they were being portrayed as irresponsible because they had 'allowed' themselves to have a heart attack. In actual fact, none of my cardiac patients took any offence to this line of 'healthist' education strategy. On the contrary, they actually supported the message of individual responsibility, although they always used examples other than themselves, or they pleaded ignorance:

> Well, I wish they had told us more, thirty years ago, what that advert is saying. I know you can't go back, but I wish I'd brought my kids up to eat healthier ... but I didn't know that my drinking would be a factor in my heart trouble (3: 135-137).

However, I found much more evidence related to the issue of individual responsibility for health from accounts that were unrelated to the direct question. Briefly, although respondents were unwilling to describe the way that they had, themselves, failed to look after their own health, they were more than willing to talk of the failings of others, and this ultimately led to the theme of a 'moral imperative' of cardiac rehabilitation. As discussed in Chapter 2, a failure to respond in the right way to illness is a failure to respond to an "occasion of hazard" (Harre, 1993, p.206) in the 'moral career', which is to incur the loss of respect that accompanies this. As will be discussed later, this loss of respect can be damning among fellow cardiac patients. With regard to data collection and the development of themes, I learned from this that some direct questions can almost be *too* direct and that if the data are not there, no amount of manipulating will elicit 'wanted' data.

Interviews were transcribed the same day in order that I could remain immersed in the data. For the same reason, I began to look for themes even while I was transcribing, by making notes of specific comments. That way, I was constantly thinking about my data, which enabled me to remember, when reading different academic texts later in the study, where comparisons could be made. The most important lesson learned about qualitative research is to know your data well, and this begins at the transcription stage – further reading and re-reading then reinforces what is already known. I decided, for the same reasons, that I was the best person to do the transcription work – even though I am a 'two-finger typist' and each hour of tape took around six hours of transcribing.

Data analysis drew upon a symbolic interactionist perspective, informed by authors who have used it as a framework in understanding the way that self-concept can be lost with chronic illness (e.g. Charmaz, 1983; 1990) and the ways that the self can be presented and conceived of through interaction (e.g. Goffman, 1959; 1961). In practice, this meant that I always had an eye on what these authors, and others like them, had found in their own research, and how my own data related to this. I also found that it was impossible not to bring something of myself into the data analysis. This, in turn, meant that I could not help but use my experience and knowledge of the subject to help me to generate questions that would allow me to generate new contextual data. Similarly, Charmaz (1990) found that her experience as an occupational therapist influenced her study of 'discovering' chronic illness. In the same way as Cornwell argues that researchers cannot simply be data recording 'instruments' nor can they be machine-like analysts.

The practical 'doing' of analysis involved highlighting passages of text in colours that identified the developing categories. In the first analysis (i.e. of the first five interviews) these categories were necessarily broad, but from these I was able to identify certain 'leads', which I felt were worthy of developing. This meant that some questions were dropped for the revised interview schedule and others included. This first phase of analysis that I have described is referred to as 'open coding', so called because categories are identified as data are broken up (Chamberlain, 1999). The second, revised interview schedule (Appendix 5) was designed to generate further data that could elaborate or confirm the categories already established. Although not entirely happy with some of the questions that I had asked relating to health perceptions and healthism in the initial schedule, I kept some of them in so that I could use them as prompts. My main aim, once again, was to encourage a story telling interview and I was able to encourage this following advice from one of my supervisors, an experienced health researcher. Her advice was to begin each interview by asking the respondent to talk about their cardiac event. This, in itself, did not provide particularly rich data, but what it did was to get people used to talking about themselves so that, when the more important questions were asked, they were not likely to answer in short, one-sentence responses. I found out, as my supervisor had suggested, that patients like to talk about their heart attacks and quite often it would be about ten minutes before I got started on my interview schedule.

Staying with the example of one of my initial areas of investigation, namely ‘health perceptions’, I looked for further data that would develop the category that I had provisionally named ‘health as virtue’, a concept previously developed by Williams (1993). Williams developed the theme of morality in chronic illness by locating his respondents’ accounts within a cultural framework that portrays health as a virtuous state. He uses the account of one particular respondent, ‘Mrs. Fields’, to describe how “coping strategies” designed to maximize normal activities in the home, “revealed a vulnerability and a sense of urgency” that amounted to the “pursuit of virtue” (Williams, 1993, p.96). In later chapters, I will talk of how my own data did not replicate this, but supported it in the context of rehabilitation from heart disease.

Analysis of these data led me to ask more directive questions, such as “what do you think was the cause of your own heart disease?” and this yielded particularly rich data regarding people’s efforts to recover from heart disease by ‘doing the right thing’. These data were revealed during the second phase of analysis, what Chamberlain (1999) refers to as ‘axial coding’, a process that resulted in my category being further refined and developed. As mentioned earlier, people were quite critical of those who had failed to look after their own health, particularly those who had dropped out of the exercise rehabilitation programme. In my next interview schedule, I added the question "why is it, do you think, that some people drop out of their exercise programme following heart disease?" which provided further rich and contextual data.

Further analysis of these data – the stage that Chamberlain (1999) refers to 'selective coding' - allowed me to develop a 'core category' that demonstrated a moral imperative toward rehabilitation, which appeared relevant to both adherent and non-adherent cardiac rehabilitation patients. Additional data required to develop this category further failed to emerge in subsequent interviews, and I decided that data saturation had occurred:

> "Saturation of the theory is considered to have occurred when no new categories are found which relate to the central issue or process being researched, and the theory can account for all the data that have been obtained." (Chamberlain, 1999, p. 186).

Throughout the data analysis process, literally from beginning to end, I engaged in memo writing – notes written to myself with the purpose of recording my thoughts and potential categories that were being developed (and sometimes discarded). These allowed me to rationalize and consolidate my ideas, and were useful to look back on in tracing specific decision-making processes throughout the study. Memo writing was particularly useful during the transcription phase because I think that a strong 'feel' for what people are saying can be gained while listening to the tape, as opposed to reading the transcribed interview in black and white. Strauss (1987) discusses the process of memo writing in detail, describing it as the core stage of grounded theory. In a similar way, Mills (2000) refers to keeping a journal in which thoughts are jotted down as crucial to the development of sociological imagination.

### 3.5.2 Observations

Bryman (2001) has discussed the way that the term 'participant observation' has been used interchangeably with the term 'ethnography'. He suggests that during the 1970's the term ethnography became increasingly detached from its previous association with social anthropology – whereby the researcher would live among a group, often in a foreign land, in order to "uncover its culture" (p.290) – becoming more closely associated with participant observation. Similarly, Brewer (2000) suggests that participant observation is probably the method of data collection most closely related to the ethnography of classical British anthropology and also the Chicago School of sociology. Observing people in their natural social environments is really the only way to understand people's 'social meanings': the researcher "watches and listens to what people say and do, engages people in conversations to probe specific issues of interest, takes copious field notes, and returns home to write up the fruits of his or her labour" (Bryman, 2001, p.290). From the earliest developmental stage of my study, I knew that the observation method offered the opportunity to gather data that would reflect the meaning of exercise rehabilitation to cardiac patients. Quite often, actions really do speak louder than words, so I needed to be around when they did.

Bryman (2001) discusses, in some depth, the issues surrounding the problems with gaining access into the environments and organisations where the observations will take place. Fortunately, the nature of my own research study, and my position within this environment, meant that this was never a real issue. For example, Bryman employs classic studies such as Whyte's *Street Corner Society* – an ethnographic study of life in one specific part of Boston – to demonstrate the difficulties of being accepted into a community. Whyte overcame this problem of access by gaining the trust of a key informant, namely 'Doc' who introduced him into the community, a strategy used by social researchers in the 1990's who were researching gangs of football hooligans. I didn't need to concern myself with this common challenge of participant observation, because I had an established place within the cardiac rehabilitation 'organisation' – I was their fitness instructor. Nor did I need to worry about the different ways that my actions might influence the actions of those who were being observed, because all I had to do was 'be' an instructor. Fitness instructors hold a fundamental position within this type of exercise setting, indeed some authors (e.g. Hardcastle and Taylor, 2001) suggest that their influence is one of the key aspects to participant satisfaction and adherence.

It should be noted that my observational research involved two types: the 'hanging around' and the more structured observations. The practical 'doing' of observational data collection involved me making brief notes during the actual exercise sessions, which were written up more fully immediately following the session's end. As a fitness instructor, I often carry a clipboard that I use for something to write on when designing exercise programmes for new patients. When making notes from my observations, I would simply jot something down on a sheet that was kept underneath the programme card. This allowed me the opportunity to jot down notes – key words and short phrases - whenever I observed something of interest, without people wondering what I was doing. My notes acted as an aide memoir to myself, but equally important was the time interval for writing them up, which had to be immediately following the session, or even during the session if I could find a pretext to go into my office (next door to the fitness suite), which wasn't difficult. The one occasion when I failed to write-up immediately was when I had to leave the session early to attend a meeting, which meant that I waited until that evening to elaborate upon my field notes. I found that some key words made little sense as the 'moment' had passed and I had difficulty relating the notes to the specific events, resulting in some lost data.

It should be noted that part of my approach to observation could be criticised as being covert and there are some ethical considerations about this (Herrera, 2003). All cardiac patients that were observed were told afterwards about my research and my reasons for observing their exercise session. Although I did not gain written informed consent, nobody expressed any concerns over this and, if they had, I would not have used their data in my study. The consent was therefore retrospective.

My position as an 'insider' in the research process had many benefits and these have been summed up by Bonner and Tolhurst (2002, p.8):

- Having a greater understanding of the culture being studied.
- Not altering the flow of social interaction unnaturally.
- Having an established intimacy between the researcher and participants, which promotes both the telling and judging of the truth.

An 'outside' researcher would, obviously, not have been able to make notes with such comparative ease, nor would he or she have been able to remain unobtrusive in the exercise environment. In fact, probably the only way to qualitatively observe such a specific group setting was to be one of the group. Bonner (Bonner and Tolhurst, 2002) was in a similar position as a nephrology nurse exploring the world of nephrology nursing:

> "Had I been an 'outsider', such as a mental health nurse, I would have expended time and energy trying to understand the fundamentals of what was going on, in particular, the interaction between patient, dialysis equipment and normal nursing roles and functions. In short, being an 'insider' made me theoretically sensitive." (p. 9)

My position was similar to Bonner's in as much as my understanding of the way that people 'go about' their exercise in their exercise environment was useful or, in other words, I understood "the fundamentals of what was going on". However, some might argue that bringing my own experiences of exercise to the study might also be considered as a disadvantage. I would have certain preconceptions that might lead me to erroneous conclusions, and I might be 'looking' for specific features that might not be present. This consideration led me to experience a heightened awareness of the accuracy of my data, checking and double-checking their appropriateness.

Much of my observational work occurred simultaneously with the interview research that I was undertaking and, consequently, I found it useful to be 'immersed' in the study. I was able to use the observations to further explore the themes that were emerging from my interview data and, by the same token, I was able to ask questions of my interviewees that would elaborate upon observational data. To this end, the themes and categories that emerged in my data analysis were from both sources of data collection. I was also able to undertake some ad hoc interviews of the cardiac patients who were being observed. For example, a chance statement from a cardiac patient enabled me to further explore the notion of 'role-distance' that I had begun to categorise from my interview data. The following passage from my written-up field notes demonstrates the relationship within the category, but it also demonstrates the way that I tended to write-up my notes, in a type of story telling style that was not preconceived but, rather, just happened:

> June 2002
> A chance statement from a patient got me thinking about the ways that people portray, or act-out, role distance in real world settings. I casually asked a gentleman "how are you?" as he entered the fitness suite, to which he replied "I'll be better when I've finished this", clutching his programme and nodding toward the machines. We chuckled as we passed each other, but I got to thinking about the comment. This man had been coming to sessions for more than a year, and seemed to have no problem with the programme, so why the negative attitude? I could only assume that he didn't want to *be seen* to be enjoying the exercise and, therefore embracing the role of 'exerciser'. He certainly didn't dress in traditional exercise clothes, in fact he wore outdoor shoes, trousers and a collared shirt rolled up at the sleeves.

> June 2002
> 'Glad to be finished man' came in again at the same time as last week. I had been thinking about role-distance this week, so I took the opportunity to speak to him again. I opened with the same line: "How are you?" to which he replied, with eyes rolling skyward: "Oh, you know".
> I asked if he was not enjoying the exercise programme.
> "Well I'm rehab' aren't I" he replied quickly, as if that explained everything. I nodded and he elaborated in a whisper: "I'm not one of *that* lot", pointing discreetly to a few fit looking people running and cycling. It wasn't the time to interrogate him, so I left him to start his exercise programme, while I made a few field notes.
> It was interesting that here was a man who turned up punctually to the leisure centre every week to exercise, but who didn't want to be seen as an exerciser. His self-presentation – in words, dress and actions were saying: "I exercise for rehab, but I'm not an exerciser".

Following this, I explained that I was undertaking a research study, and asked this gentleman if he would allow me an impromptu ten-minute interview, which he did. I didn't tape-record this type of interview, but made extensive notes throughout. In order to develop this "I'm not one of *that* lot" theme, I decided to ask other participants if they were finding it easy to adapt to their exercise lifestyle. Quite often a simple: "how's the exercise going?" would be enough to get people talking in a similar way to 'glad to be finished man'. Often, more specific probes were required, such as: "how do you find it in the public sessions?" (Newly referred patients would complete an initial 16-session programme in 'closed' sessions, then progress into public sessions, where they might exercise alongside the 'lycra brigade'.) There were, in fact, lots of cardiac patients who experienced difficulty with 'fitting in' – not only in the public sessions, but also the closed sessions where only GP Referred patients were exercising. The following comments were recorded from this line of inquiry:

> "Well, that lot can do what they like, but don't expect me to work like that" – elderly lady.
>
> "I try not to take any notice – they can be a funny lot!" – middle-aged lady.
>
> "I do like to watch them though, I find it quite amusing, running around and watching themselves in the mirrors" - middle-aged man.
>
> "Do they ever eat?" – elderly man.

On reading this back, it looks as if my questions were designed to 'create' divisions, but that was never the case, as I didn't mention other exercisers, either individuals or groups, in my comments and prompts. There is clearly, though, a feeling of them and us prevalent in the comments. Evidently, these cardiac patients demonstrate an unmistakable detachment from the role of 'exerciser' as they perceive it. Interestingly, all of these patients would wear normal, everyday clothing, almost in an attempt to maintain this disassociation. I will expand upon this in later Chapter 7, but I include the above passages to demonstrate the data collection processes that I went through.

The interview research provided an understanding of the different ways that cardiac patients accept or reject the role of exerciser, but they provide only a snapshot picture at a set time in a person's biography. This served its purpose, in as much as I was able to formulate a typology of cardiac patients regarding their physical activity choices, but it did not provide an understanding of how patients arrived at that stage, or if they passed through any other stages on the way. It may have been possible that fluctuations between stages were occurring, but the interview was not effective in providing such an understanding. However, the ethnographic nature of my study allowed for opportunistic interviews, such as when I would chance upon various participants outside of the leisure centre. This was particularly useful in developing an understanding of the ways that participants thinking regarding the relationship between exercise and health could change over time. For example, while out shopping I bumped into one elderly gentleman who had previously been attending exercise rehabilitation sessions regularly for two years. More recently he had not been attending sessions, so I had the opportunity to enquire, in a friendly way, how he was and why he had not been exercising. It was interesting the way that his opinions regarding exercise and health had been turned on their head and the category that I had placed him in following his interview had to be revised considerably.

It was felt that the best way to investigate the 'process' by which patients might have arrived at certain stages, or might have been defined as certain types, was through more structured observation. The original plan was to follow ten newly referred cardiac patients through their initial16 session programmes via observation of their exercise sessions. This provided some useful data, but I felt that the time-period was too short, as most had completed their 16-session programme within 8 to10 weeks. I decided to extend this focused observation to Christmas 2002, which would mean that the observation period would last for six months, a realistic amount of time within which to gather more contextual data. Selection of these patients was opportunistic, i.e. the first ten patients who were referred immediately following the decision to add this type of observation to the protocol were identified. They were asked at the initial consultation stage of their participation in the Active Options programme if they would like to be involved in the study and all agreed. Obviously these cardiac patients were aware that they were being observed, but the purpose was not to observe them in the same way as I was making my more general observations, as already discussed, rather, I wanted to use these 10 patients as informants who could provide opinions 'in the field', rather than in the interview setting.

Analysis of observational data did not follow the same coding system as my analysis of interview data. The main purpose of observational data collection was to develop the themes that emerged from the interviews that were being undertaken, so I did not go through the same rigorous coding system that I was using for this purpose. From the iterative process of asking questions, then backing data up with observations before asking more questions, I was able to develop the theme of self-presentational concerns of exercising cardiac patients, which I would have been unable to do by interview alone.

My data, then, were collected through an ethnographic amalgamation of interviews, participant observations of general Phase IV cardiac rehabilitation sessions and more focused observations of identified cardiac patients. Opportunistic interviews were made good use of and there were times when I would be in a different gym from the ones in which I work, exercising for my own purposes, but being aware of the things that were going on around me, particularly when these facilities were running their own GP Referral sessions. In the following chapters I will begin to elaborate upon the themes and categories that were developed throughout this research process, which are represented as the themes of 'maintaining continuity', 'cardiac rehabilitation as a project', the 'disruption and regaining of roles' central to one's identity and the 'self presentational concerns of cardiac patients'.

## 3.6 CONCLUSION

I began this chapter by asking: what motivates some cardiac patients to engage in exercise rehabilitation, while others were able to resist that behaviour change? The methodologies informed by the psychological-model approaches discussed in the opening chapter might conclude that some cardiac patients have low self-efficacy toward exercise or that they might not perceive themselves to be at risk of a secondary cardiac event. The cardiac patients might not believe that exercise is beneficial in reducing the threat of another heart attack or they may feel that they are already sufficiently active to benefit their health. I would not argue against these conclusions, as the accounts of many of the cardiac patients that I have worked with down the years appear to support these conclusions. However, I would argue that this highlights one of the weaknesses of the psychological-model approach to understanding exercise adherence. It simply tells us that those who believe that they will be successful in maintaining an active lifestyle are more likely to succeed than those who do not hold such beliefs. I will argue that it fails to get beneath the surface of the problem by understanding the lived experience of illness and the lived experience of exercise rehabilitation. The biographical work that cardiac patients engage in is unlikely to be appreciated by the psychological-model methodologies, although this study demonstrates that such considerations are vital in developing an understanding of why some cardiac patients continue with exercise rehabilitation while others choose not to. Further, most of the research that has employed the psychological-model methodologies tends to describe the two groups of patients simply as 'adherent' and 'non-adherent' cardiac patients, whereas the qualitative style used in this study has allowed me to be a little more descriptive in providing such labels. More specifically, I have been able to describe ' non-adherents' as those whose biographical work relates to creating the conditions for continuity, or for 'getting back to normal', whereas the 'adherents' can be seen as those whose biographical work relates, in varying degrees, to the development of a regained, or sometimes new, identity. As such, my labels have become 'biographical adjusters' and 'biographical architects'. This has been made possible by the symbolic interactionist framework that has guided data collection and analysis, which has allowed me to get beneath the surface of the problem, as opposed to identifying the variables that lie on the surface.

# CHAPTER 4: BIOGRAPHICAL WORK IN MAINTAINING CONTINUITY

## 4.1 INTRODUCTION

Bury's (1982) notion of biographical disruption is taken as a starting point for this chapter, and is progressed in the development of an understanding of how some cardiac patients engage in biographical work in efforts to maintain their identity. The basic premise of biographical disruption is that, following the onset of disease; not only the body and the 'self' are disturbed, but also the whole trajectory of the person's life. In this, and subsequent chapters, I will argue that biographical work is a common undertaking among all of the cardiac respondents of my study. The *type* of biographical work that they engage in reflects the lifestyle decisions that are ultimately made. In other words, the biographical work of those who adhere to a physically active lifestyle is markedly different from those who do not.

I began writing up this chapter with a good, but broad, understanding of the meaning of 'biographical disruption'. However, on reading a plethora of related studies that purported to use the notion, it became clear that writers in these fields had not given sufficient attention to the term 'biography', upon which the whole concept must surely be based. Pierret (2003) has suggested that most authors simply use the term 'biographical disruption as a "reference mark", using it as a framework within which their own data can be interpreted. It can be supposed that the term 'biography' is used in a similarly loose and flexible way. I needed then, to formulate my own understanding of the term ‘biography’, before I could discuss the ‘biographical work’ in which my respondents engaged.

In looking for clues I returned to Bury’s original paper (1982), which draws upon Giddens’ (1979) concept of the ‘critical situation’. Bury cites that: “we can learn a good deal about day-to-day situations in routine settings from analysing circumstances in which those settings are radically disturbed” (Giddens, cited by Bury, 1982, p.169). Bury observes that Giddens’ focus appears to be on “disruptions of the social fabric brought about by major events such as war”, but also points out that “biographically located events ... also have the same potential” for disruption (p.169). He contends that chronic illness brings about a similar radical disturbance: “even in the case of heart attack people report finding themselves in a critical situation of great uncertainty, where they may have little or no idea of what is happening to them” (p.170). Bury also suggests “there is rarely anything in the individual’s biography which provides an immediate basis for recognition of the illness *as* illness”. Here Bury can only be referring to *experience* – if a person has never experienced a symptom of a particular illness, it cannot be recognised as being related to that illness. A female respondent in Bury’s study sums this up when talking about the early stage of her arthritis: “well at first I thought that I’d broken, chipped the bone in the finger, with it being a knuckle ... it never dawned on me it would end up like this” (p.171). Because this lady had had no previous personal experience upon which to draw, she could not foresee the serious implications that arthritis would hold. Rather, she attempted first of all to fit the pain into her existing framework of understandings, and only when this proved inadequate did she revise her understandings to include the idea of her having arthritis. This new perspective involved a changed sense of who she was and disrupted her biography, as it was previously understood.

The term 'biography', then, can be thought of in terms of making sense of an accumulation of experiences. However, Bury's notion of biographical disruption relates not only to a person's previous life story, but also to what a person might reasonably expect that the future has in store. As such, chronic illness can disrupt the life-course, or trajectory of life, so that plans and expectations are interrupted and need to be re-thought.

Mike Bury reports that he has not seen the term 'biography' "exactly defined" in the chronic illness literature, which indicates that the concept is used in its everyday sense of an individual's life history. He does, however, provide his own more specific interpretation as referring "to the meeting point between self and society; to the individual lifecourse lived out under particular social (and historical) circumstances" (personal email correspondence, 2004). I would argue that Bury is relating to issues of identity - more specifically how the person views him or her self, and how they feel others view them. From this perspective, my data suggest that all of my respondents experienced an initial disruption to their biography. Their relationship with family and friends was disturbed - some friends stayed away, others felt uncomfortable. Family members would become overprotective and not allow them to undertake tasks that were a fundamental part of their identity, such as playing with grandchildren, doing housework, and gardening.

As I see it, 'biography' relates to identity – both self and social. A biography is a person's life story comprised of experiences that people hold, particularly those salient experiences that have helped to shape a person's identity. The ways that people interpret and utilise these experiences may represent one element of their biographical work and it is this biographical work that provides us with some sense of order and control. In his original paper (1982) Bury highlights the "disruption of social relationships" and when a biography becomes disrupted, we are conscious that others are making judgements and assumptions. Perhaps this is the "meeting point between self and society" that Bury describes.

I would also argue that it is associated with the roles that people perform and which comprise their identity. Goffman (1959) held that we are all 'bundles of roles' and I would argue that these roles - be it father, daughter, academic, postman, gardener, artist - also contribute to our biography. From this perspective, we can see how our biography might be disrupted, because we have expectations for how these roles may develop. When a cardiac patient is told that he or she can no longer pick up his grandchildren and throw them up in the air (Jim, interview 18) as they once did, expectations of what 'being a granddad' is all about become questioned.

I would like to discuss biography as a form of 'narrative'. Becker provides an interesting, and succinct, meaning of the term: "Narratives, the stories that people tell about themselves, reflect people's experience, as they see it and as they wish to have others see it" (1997, p.25). For many of my respondents, the research interview provided the first opportunity for them to talk about their heart attack in any depth and to reflect upon life both before and after the cardiac event. Although they would have recounted their tale of the chronology of the event many times (e.g. I collapsed … the ambulance rushed me to hospital … I was kept in for two weeks, etc) to friends and family, most often they would never have needed to formulate detailed ideas around causation and its relationship with lifestyle behaviours. Nor would they have been required to tell their story to an 'audience' that might judge them on their moral approbation. By this I mean that close friends and family are less likely to judge a person on their moral worth, as they are known, liked and probably respected by this audience, whereas in the interview situation one is presenting oneself to an 'outsider'. Along these lines, Williams (1984, p.178) presents two aspects of the term 'narrative': "the routine and the reconstructed."

> "In its routine form, it refers to the observations, comments, and asides, the practical consciousness which provides essential accompaniment to the happenings of our daily lives and helps to render them intelligible. In this sense, narrative is a process of continuous accounting whereby the mundane incidents and events of daily life are given some kind of plausible order."

With the onset of a biographically disruptive event, this routine narrative will no longer suffice in providing plausibility in accounts of illness. The narrative needs to be adjusted to fit the new situation and to help the individual to present a socially acceptable identity:

> "From such a situation narrative may have to be given some radical surgery and reconstructed so as to account for present disruptions. Narrative reconstruction, therefore, represents the workings of the discursive consciousness".

I would argue that it provides the opportunity to frame a cardiac event in such a way that others might interpret it as being morally acceptable. I would also argue that the interview narrative itself is an actual part of the patient's biographical work. The narrative provides the patient with an opportunity to legitimise their illness as well as their subsequent lifestyle choices. The narrative, I will argue, can be thought of as a biography in words and the experiences that have helped to shape our identity, as "narrative reference points" (Williams, 1984, p.175).

In today's world, personal responsibility for health is strong and people feel that they are accountable for regaining their health when they are ill. As Becker observes: "The question of what caused the illness raises a moral question for the ill person: is he or she responsible for the illness? Regardless of the answer to this, the person is seen as responsible for restoring normalcy." (1997, p.45-46). A significant aspect of this thesis, and one that is strongly reflected in my data, is the 'health as virtue' perception that people often hold. This appears to have a motivational effect upon my respondents, whether they adhere to exercise and physical activity or not. Later in this thesis I will discuss the ways that cardiac patients feel impelled to 'do the right thing', as regards taking responsibility for their rehabilitation and their health, and the strong views that they hold of those who fail to accept this responsibility. However, this perception is no less prevalent among the non-adherent cardiac respondents of this study, whose biographical work will ideally (from their point of view) provide the circumstances where they can choose to reject the lifestyle advice provided by health professionals but, at the same time, remain free from any blame. I will argue then, that the non-adherent (to lifestyle change) cardiac patients in this study work to create the *possibility* for continuity of previous identity. In other words, they create a framework within which they can justify their lifestyle choices without blame. They create an environment within which their actions can be situated whereby they can continue to lead the life that they did prior to their cardiac event while maintaining what Becker refers to as "moral authority" (1997, p.12).

Broadly speaking, the respondents of my study responded to biographical disruption in one of two ways:

- Those whose biographical work relates to creating the conditions for continuity, or for 'getting back to normal'.
- Those whose biographical work relates, in varying degrees, to the development of a new identity (for example, most people in this group appear to take on a new role within their identity).

The data, and my interpretations of the data, used in this chapter have been drawn from the interviews of the eleven cardiac patients who chose not to continue with their facility-based exercise rehabilitation programme. Their narratives appear to, initially, provide a legitimate aetiology for the 'cause' of their condition, which represents the first endeavour in the biographical work relating to continuity. An interesting difference between the narratives of the two groups of cardiac patients is that none from the first group attribute their cardiac event to anything that they could have had any control over, or responsibility for. Those from the second group were more willing to accept some of the 'blame' for their heart disease, but they could do this only because they were now engaged in a healthy lifestyle – they were in control of their health and so their health status had been legitimised. Bury has suggested that "medicine be treated as a cultural system" (1982, p.179) and, more recently, Becker has observed that "biographical narratives are *culturally* emplotted" (1997, p.181, italics in original). That a stoical response to illness is valued above 'giving in' to illness (Cornwell, 1984) represents a "process that is culturally informed" (Becker, 1997, p.13). Although Parsons's theory of the 'sick role' has been challenged – related to the fact that it is appropriate only for acute, short-term illness – the cultural aspects remain dominant, even when related to chronic illness. As mentioned, then, it is important that the biographical work of those who choose not to engage in long-term physical activity programmes following a cardiac event, begin with a legitimate, morally blameless, account of what caused it. From this starting point, biographical work can begin to provide a basis upon which the cardiac patient can maintain continuity.

In this chapter I will discuss the ways that cardiac patients appear to create, through narrative reconstruction, the circumstances and, in turn, the *possibilities* for continuity. By this I mean that in telling the story, "narrative may have to be given some radical surgery and reconstructed" (Williams, 1984, p.178) in such a way as to provide a backdrop against which the cardiac patient can be allowed to live the life that was valued prior to the disruption. They use narrative to help in the portrayal of a, retrospectively, blameless passage of illness, from cause to rehabilitation and the personal responsibility that accompany both. As Becker (1997, p.129) observes "People's understandings of their illness must be viewed in the context of their entire lives and their interpretations of their lives". For many of the cardiac patients in my own study, these contexts and interpretations of life are related to efforts at continuity of a valued, previously held, identity. Narratives are developed in such a way as to reassure both themselves and others that they are still the same person as before. Although they may have experienced a biographical disruption, the underlying identity, or self, remains.

My data suggest that the biographical work that they engage in is undertaken in a variety of ways (although these are not mutually exclusive):

- The cause of the cardiac event is placed within a context that implies a detachment from 'blame'.
- The severity of the cardiac event is redefined as being less severe than they had originally understood it.
- The health protective value of their existing lifestyle is redefined – everyday tasks take on new value.

- They rationalise that the cardiac event was actually something that should have been expected (e.g. "at my age").
- Heart disease isn't actually their main concern, e.g. other conditions of chronic illness are interpreted as being more disruptive to their lives.

## 4.2 A NARRATIVE RECONSTRUCTION OF CAUSE

In this section, I will argue that although cardiac patients' explanations of cause are framed in terms of the epidemiological risk-factor 'answers' put forward by medicine, these explanations may not reflect their 'beliefs'. For example, the presence of the 'lay epidemiology' can remain evident even when an "official" account has been offered and this can affect lifestyle choices. I would argue that aetiological explanations are 'provided' for the patient by the health professional. During the immediate post-event period, when biographical uncertainty may be at its height, these explanations are gratefully accepted and the need to act upon them, by engaging in the lifestyle behaviours that are advised, is clearly apparent. However, over a period of time some patients will undergo a reflexive readjustment where certain aspects of their previous lives are provided with meanings that no longer correspond with those that have been provided for them. This reflexive readjustment is an important part of the cardiac patient's continuing biographical work.

When we hear that someone has had a heart attack, we immediately attempt to provide a causal explanation for it. As Davison et al put it:

> In the first place the general kind of misfortune requires explanation: how and why does it happen? In the second place, the site and time of the particular misfortune require explanations: how and why did it happen to this person at this time? (1992, p.682)

For respondents in my own study, this need for causal explanations was clearly evident as almost all of my respondents described the uncertainty caused by their cardiac event and the search for explanations that followed. This extract from Ahmed's account is typical:

> I was worried when I was told that I had had a heart attack, you know, and naturally I think what's wrong with my heart? What have I done wrong? You know, and all of these things come into my mind. Then, moreover I wanted to know exactly what caused my heart attack. What's the problem with my body, where have I failed or what is the deficit with my body? (1: 149-153)

For the cardiac patient, the disruption of biography is an immediate one and Ahmed puts across extremely well the shock and uncertainty that he experienced at that time. Before he can plan any kind of strategy for recovery, Ahmed must first understand the things that caused his heart attack. Williams (1984) has suggested that the need to understand the aetiology of an illness must be understood as a "comprehensive imaginative enterprise" (p. 175) a prime consideration in narrative reconstruction. To reconstruct one's narrative following a heart attack is common, and one role of the reconstructed narrative is to provide the illness with a "genesis". Williams notes that

> "People may well draw upon some common-sense version of science and the medical model, but when Gill [his respondent] asks: 'Where have I got to? There's nothing left of me', she is asking a question that breaks the bounds of traditional scientific discourse and shifts into a complex social psychology and practical morality". (p. 177)

Similarly, when Ahmed asks where he has "failed", although he may have an answer in the 'risk-factor understanding', his question actually goes much further than this. Throughout the narratives of these cardiac patients, there is a certain tension between the classic risk-factor understanding of causation and the established beliefs that these patients appear to hold. I will argue that in the initial post-event phase of recovery, patients will use risk factors to explain the cause of their heart disease, but later their biographical work in maintaining continuity will necessitate a reworking of these understandings. The relevance of the explanations, which I would suggest have been 'provided' by health professionals, are no longer salient and no longer fit into their life story as they understand it.

The tension between what a patients thinks of as being 'healthy' and what they have been educated about is apparent in Phyllis's narrative. When asked if she thought of herself as being healthy prior to her heart attack, she replied: "Well I would have thought so, I (emphasis) would have thought so, but I don't know what others would have made of it – doctors, I mean." She was not a 'sick' person, "always went to work, never a day off with illness" (23: 185) and she "never noticed that I had trouble with illnesses and such ... I just used to get on with things really" (23: 197). She then engages in an explanation of causation, which is framed in the classic medical risk-factor understanding:

> I drink, I do like my drink and I used to have a drink at lunchtime and I'd have a couple of drinks in the evening. It's just the life that we lived, which was a very hectic life, I mean we've retired now but it was a very heavy social life. So I suppose, looking at it, I smoked too much, drank too much and took no

> exercise at all. Not a very healthy lifestyle really, looking back at it. (23: 40-46)

So "looking back on it" as she is now impelled to do, she can find explanations for what caused her heart attack, but these have been provided for her at Phase III education sessions and it doesn't appear that Phyllis has entirely accepted them. The conflict between medical accounts and intrinsic beliefs progresses when Phyllis talks of her experiences with heart disease in the past, particularly with her own family history:

> Well Dad went just like that with the heart attack and that's the way it used to be. You probably hear more of it nowadays, but back then you didn't stand a chance, you just went with it. But if you're talking about healthy, well he was the healthiest you could get – he did smoke mind, but fit! He was fit all right. Never drank a drop, always out on his bike, worked like mad… (23: 240-246).

So although Phyllis has received health education and has been 'provided' with some answers as to what was the cause of her heart attack, her conflict between the two ways of looking at heart disease remain unresolved. She doesn't appear to be convinced that her unhealthy lifestyle was really the cause of her problems. From the passage cited above, it would appear that Phyllis has a quite fatalistic view of illness, but this was not something that struck me during the interview, nor upon re-reading the transcript in its entirety. For Phyllis, good health is related to the absence of illness and disease, which she simply does not associate with health behaviours. However, it is also important for Phyllis to maintain some level of 'moral authority' (Becker, 1997). Even though she cites the classic risk factor aspects of heart disease, she is reluctant to actually say that this had any direct bearing on her own heart attack. Throughout her narrative she carefully navigates her way around the acceptance of blame and even when she talks of her (what would now be termed) 'unhealthy' lifestyle behaviours, she manages to qualify things by adding proviso's such as "course, in those days we didn't know anything about that, being bad for you or anything" (23: 209). In fact she goes on to talk about the ways that such behaviours were actually encouraged, "for the men, well they used to say that it put hairs on your chest, type of thing" (23: 223). In simplistic terms, through her narrative, if Phyllis was writing a story about her health, and if her experiences and observations of health represent her data, then her data were collected in a different cultural context, one that appears to have encouraged some of these behaviours. Medicine is a "cultural system" (Bury, 1982, p.179) and so too is the biographical work in which patients engage in maintaining continuity in their lives.

It is also worth emphasizing that Phyllis's heart attack was very disruptive to her life, bringing into doubt basic understandings of identity. Early in the interview, when talking about her cardiac event she becomes quite despondent about things:

> They should have finished me off at the time, because what's the point... I'm not allowed to do anything now, I can't drive and that's the thing that really upsets me, I can't get about any more. But the heart disease, I don't know, I mean one minute I was just sitting there and the next I was doing all sorts of funny things, five seconds later I was in the hospital and they told me that I'd had a heart attack. That's me really, that was the end of it. (23: 15-21)

In what seems like "one minute", Phyllis's life had changed forever. Her biography had not only been disrupted, in as much as she was unable to continue doing the things that she had taken for granted and which were valued by her, but she perceives her identity as coming to an end – "that was the end of it". She develops this theme, later in the interview, when asked how the heart attack changed her life:

> Immensely so, I can't read now … I can't drive, and that's my biggest bone, and they've told me quite clearly that I will never drive again and I said "perhaps one day" and they said no. That's changed me completely because I used to be a fly-by-night, gadding about, going everywhere. And that's changed me because I've got nigglier and impatient, I'm very impatient now because I'm frustrated, what's the point of it all I wonder. Sometimes I'm fine and then I remember and I get very snappy. I've gone through all sorts of things … hatred for people, very jealous … yes I have. You see I've lost my freedom for one thing haven't I and I can't do anything and I want to … I want to break all the rules and get back in my car and go driving, but I know I can't. So yes it has altered me a lot. (23: 135-144)

Bury (1982, p.180) has observed that "disruptions in biography are, at one and the same time, disruptions of social relationships" and when a person has led a "very heavy social life" (23: 44), as Phyllis has, the disruption is that much greater. Indeed, for Phyllis, "that was the end of it". From such a disruption, a great deal of biographical work and re-working is required if continuity is to be maintained. Clearly, Phyllis can not return to her previous identity of 'fly-by-night, gad-about', but neither can she accept a new identity recommended by health professionals and characterized by healthy behaviours, such as regular exercise. As a consequence, she takes a line that falls somewhere in between these two extremes - the biographical work of that begins by providing an account of causality that, at one and the same time, absolves her of blame and allows her to make sense of her subsequent lifestyle.

Another way of explaining the cause of heart disease that was prominent among my respondents was to emphasise the non-modifiable risk factor of heredity. Some patients have gone into some depth with regard to their family history, when they are citing it as a cause for their own heart disease. Take Steven, for example:

> A couple of uncles on my mum's side have died and my cousin, exactly the same age as me, died about three years ago. Used to work for the telephone people and he pulled up in his van, looked up at the telegraph pole and just went - just like that - he was 48. Yes, I think it's hereditary because his dad, who was my mum's brother, was a fire officer in Wales and he died in his 40's, and my mum's other brother he died in his 40's, or was he in his 50's, well 50 isn't old is it? But none of them have got over 60 anyway, none of them at all. (3: 103-109)

Steven has gone into great detail in explaining the way that his family has experienced heart disease and the tragic consequences to them. Interestingly, Steven was unaware of the relationship between family history and heart disease prior to his Phase III cardiac rehabilitation, heredity as a risk factor being something that he had learned there. Mary provides a similar account:

> "My dad died of a heart attack but we didn't know that it was hereditary, I mean his brothers all had heart disease and that's how they all died, but we weren't told that it was hereditary until I went into hospital."
>
> *Do you mean that you didn't realise that heart disease could be hereditary or that you didn't realise that it was in your own family?*
>
> "I didn't realise that it was in my family, because when I went to the hospital they said that my cholesterol was extremely high and I never really ate greasy foods or anything. I just had a basic diet of normal meals really … and yes, they said that it was hereditary." (9: 32-42)

This suggests a lay acceptance of medical knowledge, and Parsons and Atkinson (1992, p.454) found a "demonstrable relationship" between medically defined risk and the lay use of 'high' or 'low' measures. However, they also suggest that a great deal of information is lost in the translation process and this provides Mary with a cause for her heart attack from which she can maintain some distance from blame.

Indeed, the theme of a virtuous, blameless life prior to her heart attack appears to dominate the whole of her narrative. provides Mary with a cause for her heart attack from which she can maintain some distance from blame. Indeed, the theme of a virtuous, blameless life prior to her heart attack appears to dominate the whole of her narrative. When asked if she considered herself to be an active person prior to the heart attack, her immediate response was: "Yes, people always used to say that I should slow down because I used to rush around everywhere!". In putting together a narrative, it is often insufficient simply to respond with a personal account, as in 'yes I think I was active', rather, to cite other people's opinions appears to add some authority to the account. She continues:

> "I used to do an awful lot of walking, even when my children were little because we never hopped on a bus with a push-chair, we used to walk from Totton to Millbrook and into Shirley with the shopping. We never used to get on a bus ... supposed to keep you healthy (laughs) but I went wrong somewhere. But mine was family history so it's one of those things I suppose." (9: 135-139)

Even when Mary is tempted to question the value of an active lifestyle, as she does when she suggests that she "went wrong somewhere", she immediately gets things back on track with the family history explanation.

Both Steven and Mary were provided with risk factor explanations for their heart disease but rather than use this information as a motivating force for behaviour change, they actually employ it in the opposite way. They appear to be able to rationalise the fact that they were unaware of these risks at the time, and were therefore not to blame for their condition. They can then justify their present lifestyle choices by suggesting that, regardless of what they do, their risk will always remain the same – as Mary puts it: "it's one of those things that I have to put up with basically" (9: 255). A similar strategy is to identify a classic risk factor that was present at the time, then rationalise that the absence of this risk factor now means that the risk is no longer as salient.

Richard found the 'answer' to what caused his heart attack – something that he was interested to find out: "well you always try to analyse it, 'I wonder what brought it on?' sort of thing" – at Phase III cardiac rehabilitation. At around the time of his heart attack, he was having building work done on his house and he had been promoted at work, which were two things that he felt increased his levels of stress. He learned at the education sessions at Phase III that stress can be a factor in heart disease:

> "yes, it (stress) was a big factor in my problems at the time, and I learned at the rehabilitation how important stress is in heart disease – we learned all about that sort of thing" (4: 111-113).

Richard is able to make sense of his heart attack as being something that was brought on by stress. However, his situation has changed considerably since then and, accordingly, his risk has now reduced. Despite learning how to lead a healthy lifestyle at the rehabilitation health education sessions, Richard remained quite uncertain about how his lifestyle could be improved. He felt that his diet was 'not bad' and he had always led an active life so his cardiac event caused a great deal of uncertainty: "It took me a whole year to get over that, gradually my confidence - and it's all to do with confidence – came back...". This confidence returned once he had been able to take stock of his life by redefining the health protective value of his lifestyle, particularly regarding physical activity.

I would argue that these cardiac patients have been 'provided' with causes for their heart disease and these explanations have been interpreted in ways that fit the patient's biographies. Understanding the cause of one's cardiac event in a particular way, does not necessarily relate to the way that cardiac patients respond in their long-term rehabilitation. For example, it would be simplistic to think that all patients who put their heart attack down to a poor lifestyle then go on to engage in physical activity in order to reduce the risk of another heart attack. Nor that those who can find no reason for their heart attack, putting it down to bad luck or "just one of those things", then believe that engaging in exercise is pointless. Rather, the important thing appears to be how they 'make sense' of their risk of having another cardiac event.

Johnson (1991) has observed that cardiac patients appear to undergo a process of reflection in "making sense" of their heart attack, which provides them with a sense of control that had been lost. After a period of time, when the patient has been able to put the cardiac event into some kind of perspective, the risk-factor explanation appears to be less convincing - the patients begins to think, 'my lifestyle wasn't *that* bad'. Susan provides an example of this when using the risk-factor explanation to account for her own bypass surgery: "well, they said it was smoking, eating the wrong types of food – a fatty diet I suppose, and stress (counts them off one by one on fingers)".

Susan's account is clearly coloured by her health education at cardiac rehabilitation - the fact that "*they said*" it was these things, stands out. However, later on in her interview, she observes that she was physically active and healthy because of this: "I think that's very important (exercise), like I say, before my surgery I was very active and I was very healthy because I was slim". Wiles (1998), in her study of patients' perceptions of heart attack and recovery, similarly noted that the epidemiological evidence offered by the cardiac liaison nurses played a central role in providing information regarding the cause of their heart attack and their future risk of a second event. I would suggest that, while the patient takes on this information, if it cannot be made to square with the person's life story (or biography) it will not feature in this sense-making process. Susan's view of her own pre-event identity was one of a healthy person. She was slim, she exercised and she regularly went away on scuba diving weekends. Then after her cardiac event, she was told that, well actually she wasn't healthy at all, she didn't lead a healthy lifestyle, but if she wants to avoid another heart attack she must alter the way she is living. As I will discuss in later chapters, Susan's case is actually quite complicated and she had others reasons for not leading a physically active lifestyle, but her account does help to illustrate the ways that patients make sense of aetiological concerns within their own biographies.

Understanding the personal aetiology of heart disease is the first step in the process of the biographical work undertaken by the cardiac patients of this study. In my interviews, I asked the question "what was the cause of your heart disease?" and I found that almost every response was informed by the classic risk factor understandings provided by medical epidemiology. So everyone could provide me with a 'reason' for having had their cardiac event. However, further into the interviews, many respondents began to describe other aspects of their biography that seemed to provide a 'better fit', and the non-modifiable risk factors, such as family history and age, came to the fore. As Williams (1984, p.196) found with his respondents "this question was explicitly translated into more substantive biographical questions. It was not that they were 'personalizing' the question they were transforming the meaning of it". Although, in the interviews that I undertook, this didn't happen immediately, a similar feature emerged in time. An understanding of cause was not simply a common sense place to begin an analysis of my findings, or a basic chronological consideration, but more a vital reference point to be established. Understandings of cause will inform subsequent considerations of other 'symbols', specifically the symbolic interpretations of lifestyle behaviours, which in turn, will influence decisions related to heart disease and lifestyle.

## 4.3 RETROSPECTIVE RECONSTRUCTION OF SEVERITY

Once a cause has been provided for the cardiac event, an understanding of severity is the next thing to be addressed, and provides the second theme for discussion in this chapter. As Wiles (1998, p.1478) has observed "people's expectations about recovery, their beliefs about the salience of lifestyle change and their motivation to adopt lifestyle change will vary according to their perceptions of the nature of heart attack". One of the major "perceptions of the nature of heart attack", for the respondents of my study, related to the severity of the event.

In understanding the severity of a cardiac event, we are able to draw upon several sources of knowledge. The 'classic' or 'textbook' image, often portrayed on television, of the victim clutching the chest and falling to the ground in a heap, is foremost in our understanding of how heart attacks happen. Observations of others who have had a heart attack can be drawn upon and, once again, severity can be compared. Stories from other patients, often embellished in the retelling, can provide information about how a heart attack should be experienced. When the patient's own heart attack does not manifest in a way similar to the stereotypical one, patients can reason that their own event was not as severe. Goffman talks about the way that we know how to react to being stigmatized (or developing a disability) through the experiences of how we ourselves once acted toward those with similar stigma. For example, we know how to act as a cardiac patient, because we know how we once acted toward other cardiac patients. If we offered sympathy and support, then we know that sympathy and support may be offered to us, as cardiac patients. However, if we feel healthy enough not to 'deserve' such gestures, we can rationalize that we are not as 'ill' as we perhaps should be and, therefore, our condition is not as serious as others'.

Becker (1997) suggests that as the identities of her respondents continued to change, so too did their views of the past. Many of my respondents appeared to engage, over a period of time, in a practice of re-defining certain key elements of their illness in attempts to rationalize their actions and opinions. While the common view of a heart attack might be one of the dramatic event depicted often enough through the media, some of my own respondents portrayed a stark contrast to this from their own experience. Michael provides an illustration: It's not been the classic text book way for me, I mean I thought I'd just pulled a muscle in my chest when I'd actually had a heart attack. (22: 391-393)

Not having had the "text book" heart attack provides Michael with the perception that his heart attack was not particularly serious. When he talks of people changing their lifestyle following a heart attack, he implies that this is undertaken through a certain degree of trepidation: "I think it's fear ... I think that they are scared more." (22: 405) He links this fear with having experienced a severe heart attack, the "text book" type of heart attack that he did not experience and, therefore, he does not exhibit the same level of fear related to the consequences. He implies that those who engage in exercise and other health related behaviours are "scared" – either of the heart attack or the consequences – but that he is not. Others among my sample also relate the severity of their heart attack to their own image of how they *should* be treated following such an event:

> Well I don't think it was a really bad one, because if it was they would have kept me in longer wouldn't they? And they're quite happy with me at the moment so... (14: 52-55)

Betty reasons that her heart attack was not as severe as others', because her period of hospitalisation was comparatively short. It is this type of observational work that enables patients to categorise the severity of their own cardiac event in some type of hierarchical way, and parallels can be drawn here with a recent study from Lawton and colleagues (2005). At a time when self-management is being increasingly emphasised in service delivery of diabetes care, they found that diabetic patients would "interpret non-referral to hospital as meaning their diabetes cannot be serious" (Lawton et al, 2005, 1432). This type of 'interpretive work' was prevalent among the cardiac patients of this study, who were also able to interpret their position in relation to others, who are perceived of as being worse off, such as John who draws upon his observations of those who have had bypass surgery, concluding that others have more of a reason to engage in behaviour change than him:

> Well yes, it was a warning yes, but ... it's different for me, but somebody who's had a bypass have got more motivation than me, they've got something visible, something tangible that I haven't got. It says yes, if you don't do this exercise, we can't do it again, we've gone as far as we can, there's not a lot else that can be done but strictly speaking in my case, there is the bypass. So I've got ... I'm only one step down the road – I'm not at the end of the road, but if you've had a bypass, you're up against it aren't you, it's that or the great blue yonder. In a way I've still got another three hundred yards to go before I get to that point. (10: 371-379)

Cowie (1976) noted a trend among the cardiac respondents of his study who attempted to normalise their heart attack through a process that he refers to as 'retrospective reconstruction':

> By engaging in such reconstructive work, patients attempt to make their heart attack intelligible, something that was not "really" unexpected, but which in retrospect was building up and thereby it is perceived as less threatening. Patients also compare themselves to other patients in the ward with reference to symptoms, age, number of attacks and perceived progress. Reconstructing the past and comparing oneself to fellow patients allows the cardiac patient to normalise his heart attack. (p.87)

In one sense, the biographical work of some of my own cardiac respondents appears to involve re-writing the past to fit the present. As Williams suggests: "From such a situation narrative may have to be given some radical surgery and reconstructed so as to account for present disruptions" (1984, p. 178). Following a disrupted biography, some sense must be made of the present situation and the patient's *reason* for being in that situation. If the patient's situation is one of reluctance to engage in the recommended behaviour change, there needs to be some personal explanatory reason for this. One way of reasoning is to interpret the heart attack as being insufficiently severe to warrant behaviour change – there is no threat, and so no *risk*. The other way is to interpret the health protective value of one's existing lifestyle, which leads me into the next section of this chapter.

From an understanding of severity flows a rationale that relates to lifestyle choices and individual responsibility for rehabilitation. We are able to reflexively 'create' a health value for existing behaviours, from information that we have been provided from, not least, health education messages. This third theme for discussion, appears to represent 'public accounts', and may suffer from the potential limitations of data collection methods used, specifically the fact that patients were discussing their health behaviours with someone perceived as a health professional. However, it does provide an insight into the ways that people are able to reconstruct a biographical explanation of 'lifestyle', from 'official' information. Not only are we able to take information and use it as an underlying principle for changing our behaviours, but we can also use it to justify *not* changing our behaviours.

## 4.4 REDEFINING THE HEALTH PROTECTIVE VALUE OF 'BEING BUSY'

One of the most common statements that we hear today, regarding 'expert' advice on how to lead a healthy life, and a sentiment that is echoed by many of my own respondents, is that "if you believed everything they tell you about food, you'd never eat anything" (25: 210). This attitude applies not only to food, but also to a whole range of health (and also non-health) behaviours that are being impressed upon us by health professionals via the media. Take the following genuine headlines that were reported in 2003: "Gardening is the ultimate danger sport" (Telegraph); "Short thighs carry higher diabetes risk" (Telegraph, New Scientist); "Nail biting damages IQ" (BBC); "Move away from that monitor or die" (BBC); "Electric kettles may damage your health, scientists warn" (Guardian); "Shaving habits linked to stroke" (BBC). The consequences of this type of health education are that people will either believe nothing or they will be selective about what they do believe.

Patients might feel that they are doing sufficient exercise because of the health promotion messages, which are often mixed and confusing. For example, the current guidelines for physical activity are that we should all attempt to accumulate thirty minutes of moderate intensity physical activity on most, but preferably all, days of the week. It is proposed that the incidence of heart disease, and other conditions related to inactivity and weight gain, can be reduced on a population level if the health promoters can encourage us all to engage in this minimum level of exercise. We are assured that we can effectively accumulate this physical activity by incorporating more manual activities, such as housework and walking, into our lifestyles. However, Lawlor and colleagues (2002) have found that housework actually holds no health protective value at all and that there is no significant difference in the incidence of heart disease between those who undertake high levels of housework and those who do not. This piece of research, as with most studies that appear to go against established medical knowledge, was widely reported among the tabloid press and made its way into the news bulletins on both national radio and television. Indeed, Professor Ebrahim, one of the authors is quoted as saying: "My advice would be for people to share the housework with their partner and then for both of them to go and do something more energetic".

So, on the one hand we have health professionals telling us that any activity is good activity, while on the other; eminent professors in the field of health research are telling us that it isn't. So who do we believe? I would suggest that we actually accept the message that best fits our own biography and, therefore, can be accommodated in our biographical work. For example, Betty describes the way that she dropped out of the structured exercise that she engaged in at the Leisure Centre, rationalizing that she gets enough exercise from her active lifestyle:

> "I came for a good few weeks, but I felt that I was getting plenty of exercise with my dressmaking and sewing and that, so I gradually came less and less … I do my house work and everything and I'm always on the go" (14: 117-119).

It is clear from this that Betty has incorporated the health promotion message recommended at Phase III, that sufficient physical activity can be gained from everyday activities. While I certainly wouldn't argue against the fact that physical activity can be incorporated into one's lifestyle, indeed this can often be accomplished very effectively, I would suggest that many people engage in a reconstruction of the facts regarding this issue, leading to an increased emphasis of health 'value' being placed upon their activity levels. Taking Betty's example, most people would be hard pushed to associate sewing with physical activity, certainly not at the level that confers any health benefit. However, this interpretation fits better within Betty's biography.

Others share a similar view of the health protective value of their physical activity and in many of these cases a physically active lifestyle is very possibly being undertaken. It is difficult to determine from an interview whether or not a person is actually 'physically active', indeed data collection from this type of self-report has long been noted as being unreliable because people tend to retrospectively overestimate their activity levels (Dishman, 1988). However, it is not the purpose of this study to ascertain the activity levels of cardiac patients with any level of accuracy, rather I am concerned with exploring their interpretations and perceptions of this health behaviour, within the context of their own biography. From this perspective, it is clear that many patients are of the opinion that a physically active lifestyle is not the sole domain of the fitness suite. When asked if he thought exercise was an important aspect of rehabilitation, Richard replied:

> Yes, but not necessarily exercise as such. I don't exercise now, not at the leisure centre or anything, but I get lots of exercise with the gardening and the odd jobs, sawing and that... (4: 116-119)

> Well, I know that you are interested in exercise and I think that it's really important to be fit, but you don't need to go to the leisure centre to do it. Just be active like I am, do your jobs around the house and that's enough. (4: 185-188)

Richard's "jobs around the house" quote brings us back to the earlier point about how health promotion messages are interpreted and, similar to Betty, Richard has interpreted this in a positive way. Richard is a sprightly looking eighty-one year-old who, if I hadn't been aware of the fact that he had experienced both a heart attack and bypass surgery as well as a "slight" stroke, I would have thought was in very good health – which he may well be. Richard holds a very functional interpretation of health and, for him, fitness relates to quality of life – the kind of 'fit-for-purpose' perception that is held many older people (Blaxter, 1990).

> Well, I'm over 80 now and I don't have to worry about getting fit and running round the course or anything any more, but it's about quality of life I think, getting quality of life. Well of course, I don't know how many times I went [to Phase IV sessions], but I was doing carpentry work and other things, sawing … and I gradually thought 'well I'm good enough to forget about that' so I just gradually stepped off it. (4: 69-73)

This is very similar to the way that Betty dropped out of the exercise, attending less and less as the realization developed that enough exercise was being performed from an active lifestyle. The justification for this is the health promotion messages that 'any activity is good activity'.

The confusion surrounding the mixed messages from 'official' epidemiological public health research also provides a legitimate basis upon which cardiac patients can justify their diet, their weight and, therefore, their health. In discussing the risk factors associated with his heart attack, John attempts to eliminate a poor diet from the cause of his own heart disease, but appears to be unsure himself:

> I haven't put that much weight on, although I've been up and down, I mean when I was in the Far East I was playing football in the afternoons and basketball at night and I got down to about twelve stone. It didn't stay that way though and I went up and sort of levelled off at around ... fifteen I suppose, although I've gone up to sixteen on occasions and sometimes more than that. But the way that I've looked at it over my experience of over forty years is that I'm <u>not</u> overweight, although if you look at the charts and take the weight with the height, they say <u>technically</u> I <u>am</u> overweight. (10: 95-101)

So "technically", from a medically 'official' perspective, John is overweight. However, he has redefined this fact, he has engaged in a 'reconstructed narrative' (Williams, 1984) such that the risk of developing heart disease through this factor is no longer relevant. Michael has a similarly mixed view of his dietary habits:

> I'm a bit sort of ... although I overeat, I'm conscious of what I eat and I don't eat vast quantities any more – at least I don't think so – but a dietician would come in and say "you don't need half of that", but it's not fatty food, I mean there's not acres on the plate. (22: 381-384)

Again, there is a contradiction in this account; in as much as he feels that he doesn't overeat, he also suggests that a medical professional – a dietician – would disagree. Both John and Michael have taken the 'meaning' that best fits their own biographies. It could be argued that they are attempting to normalise their diet by thinking something like: 'it may not be perfect, but it isn't so bad that it caused my heart attack'. Observing people around them who appear to consume a far worse diet than they do themselves can reinforce this view.

For some cardiac patients, the concept of 'rehabilitation' itself can be problematic because the term implies that one can be 'rehabilitated'. In other words, there is an end point to the rehabilitation process, at which point the patient can just get back to normal again with, apparently, nothing more to worry about. In Southampton, as with many other places, the Phase III rehabilitation programme unwittingly reinforces this notion by issuing a certificate of completion to all patients who finish the eight-week course. Richard mentions this twice in his interview when recalling his experiences at Phase III:

> That was very satisfactory and I got my passing-out certificate - never found any problems… (4:62)
>
> That sort of thing is important and we learned that at the rehabilitation. I mean, I got my certificate so that shows that I am alright now, but I still don't do all those things and I still exercise even though I've got my certificate. (4: 160-163)

The second statement, where he is referring to lifestyle behaviours such as drinking and smoking, appears to emphasise the 'rehabilitated' concept, as he implies that even though he possibly could do those things – because he no longer has anything to worry about – he chooses not to. In terms of risk, Richard does not think that the threat of heart disease remains.

Following a biographically disruptive event, then, some cardiac patients from this study are able to engage in biographical work that involves the redefining of symbols and the attachment of new significance to them. The immediate aftermath of their cardiac event proved disruptive, but their response was to maintain an identity that was, after all, satisfactory. Margaret provides an illustration of this in a telling passage from her interview:

> I mean when it comes to exercise and living a healthy life and everything, perhaps I don't want to admit defeat, you know ... this is the way that I live and maybe I don't want to admit that its wrong and that it could cause problems later in life. I just want to carry on, as before - be the person that I was before, because well I was all right. (Margaret, 16: 309-314)

Margaret demonstrates the pressure involved in taking responsibility for leading a healthy life, but isn't convinced that there was anything wrong with her previous lifestyle. Admitting defeat would be to admit that she was leading an unhealthy life and that this was a direct cause of her heart disease. As Bury (1982, p.173) has put it, "to do anything less is to accept fully the burden of responsibility". This, in turn, would justify the behaviour change recommended by health professionals, which Margaret is not only trying to reject, but is also searching for a justification of this rejection. Continuing her pre-heart attack lifestyle was a way of maintaining the identity that she was comfortable with.

## 4.5 HEART DISEASE AS NONDISRUPTIVE AND SOMETHING THAT SHOULD HAVE BEEN EXPECTED

Lawton (2003, p.27) has highlighted the importance of the age of a person and the stage in the life course at which a person develops a chronic illness, citing a few studies that have "sought to revisit and critically reappraise" the notion of biographical disruption. Bury (1982) had originally discussed the implications of timing, pointing out that the stereotype of arthritis (as being a disease of older people), provided one explanation of why his younger sample had experienced such severe disruption. Pound et al (1998, p.491) explored the idea that chronic illness could be experienced as more or less disruptive depending upon the age, and therefore the stage of life, in their study of older stroke patients. Paying particular attention to the ways in which age may mediate illness experience, they began with the view that:

> Bury's theory of biographical disruption may not be applicable to those who have prior experience of illness, or indeed those who have had any experiences which have led them to question the foundations and trajectories of their lives. Further, because the theory was developed within a study of relatively young people, we suggest that its applicability to those who are older is limited. (1998, p.491)

The authors conclude that it is "highly likely" that experiences of, and responses to, illness are mediated by age. This is actually something that Bury acknowledges himself in other work (Bury and Holme, 1991), when he suggests that chronic illness is met "with greater acceptance" in old age.

However, I would suggest that there is an initial period of disruption experienced by all of my respondents, regardless of their age. The difference lies in the biographical work that is undertaken during efforts at maintaining identity. Indeed, the respondents of the study undertaken by Pound and her colleagues were elderly East Enders who were living in relative poverty. I would suggest that this poverty was more of a mediator of illness experience than was age, and that the "hard earned lives" (Cornwell, 1984) aspect of the study had more of an effect upon the interpretation of the interviews. For example:

> Mr Victor, who had originally come from the Caribbean, was living in hunger and poverty. When asked about the effects of the stroke in his life, he simply replied, 'I'm starving'. (Pound et al, 1998, p.499)

Pound et al (1998, p.500) point out that the stroke often "paled into insignificance beside the societal and practical problems they had to face every day". This, then, is clearly not exclusive to age, but equally to social circumstance. As a person grows older, it is to be assumed that comorbid conditions would develop as a consequence and, in conjunction with these deprived social conditions, a negative life story is developed. Within such a life story, a stroke is viewed as "not extraordinary".

Williams (2000) has taken a similar perspective on Bury's implied notion that lives are taken for granted prior to the onset of disease and draws upon Giddens' notion of 'risk society' in making the point that 'biographical uncertainty' is an inherent feature of many people's lives. Giddens has highlighted the way that the fashioning of self-identity has become increasingly reflexive, involving "a never-ending cycle of biographical appraisals and re-appraisals, assessments and re-assessments" (Williams, 2000, p.57). My own study suggests that some cardiac patients engage in reflexive reassessment of the consequences of heart disease, over a period of time. Wiles (1998), drawing on Johnson (1991, p.1478) points out that cardiac patients engage in a "process of reflection in attempts to "make sense" of what has happened to them in order to regain a sense of control". Further, she suggests that this process can take up to two years and is achieved once the person feels able to "put the event behind them". Similarly, those of my own respondents who engage in biographical work in maintaining continuity, take a significant period of time in reflexively making sense of their new situation. For example, all respondents completed their Phase III rehabilitation programme and undertook a period of time exercising within the Active Options scheme. I would suggest that they experience the associated disruption of biography that a life-threatening event should typically induce, but because of the nature of heart attack, i.e. its contrary position to that of arthritis, patients are able to suggest to themselves that, yes, it was only to be expected. After this period of reflection, they are able to 'make sense' of their life story in such a way as the 'only to be expected at my age' hypothesis fits comfortably into their thinking.

Earlier, I used Phyllis as an example of the typical 'risk-factor understanding' of heart disease and how she experienced a severe disruption to her identity. Although Phyllis had described the cause of her heart disease in terms of a risk-factor aetiology, after she had had time to reflect, she tended to draw upon her observations of growing older, ultimately putting her illness down, in part, to the ageing process:

> The thing is, when you get into your sixties things can go wrong. I know that, everyone knows that don't they. Things go wrong and there's nothing that anyone can really do about it – you have to live with it, as much as you can anyway. Like I say, I went through all the hatred and jealousy stuff, but at the end of the day you just have to accept it '*que se ra*', so they say. It's part of growing old, so enjoy it while you can, and that's what I did! (23: 147-152)

Similar to Phyllis' story, Wiles (1998) found that perceptions of, and vulnerability toward, risk can change through time. Although, her cardiac respondents recalled "feelings of shock and disbelief that they had had a heart attack" (p. 1479), over a period of time, they began to draw increasingly on the 'lay epidemiology' (Davison, et al, 1991), which tends to contradict the medical evidence in supporting the random nature of heart disease. Understandings of 'only to be expected at my age' can be developed more readily once the initial shock, or biographical disruption, has been overcome. Further, expectations of recovery are an important factor and, very often, those who are older and may be experiencing a deterioration in general abilities, may be prepared to be more accepting of their condition.

Richard is an 82 year-old man who experienced two heart attacks at the age of 78 and underwent bypass surgery the following year. He accepts that illness can be a consequence of growing old and tolerates the various conditions as they emerge: "you're getting older and getting older, and I've had a slight stroke this year, which has affected my vision and I can't drive the car any more. But we get about on the bus and really, we have a good life, a normal life" (4: 79-81). We have already seen that, for Richard, health and fitness are related to both expectations and purpose. This 'fit for purpose' approach to life provides him with a certain level of bodily contentment, and reflects what Becker (1997, p.141) describes as, "cultural notions about what bodily losses are expected for a particular age group". Richard is able to come to terms with aspects of his life that he might otherwise view as abnormal. While he recognises the importance of exercise in both general health and in recovery from heart attack, he is able to put things into some perspective, and although I have used this passage elsewhere, it is worth repeating in this context:

> Well, I'm over 80 now and I don't have to worry about getting fit and running round the course or anything any more, but its about quality of life I think, getting quality of life. Well of course, I don't know how many times I went, but I was doing carpentry work and other things, sawing ... and I gradually thought 'well I'm good enough to forget about that' so I just gradually stepped

> of it and, I've done well really. Never dreamed that I'd ever get this far. (4: 69-74)

His final sentence demonstrates how satisfied he is with his recovery, which is actually more than he could have hoped for in the early stages post-event. He also has very definite views about rehabilitation. For him, it is very much a medical 'treatment' which appears to have a definite end-point: "That sort of thing [healthy lifestyles] is important and we learned that at the rehabilitation. I mean, I got my certificate so that shows that I am alright now, but I still don't do all those things and I still exercise even though I've got my certificate". Richard has received his certificate; he has a physical capacity that is reasonable for his age, "all things considered" and has achieved a good level of continuity: "Now though, I'm back to doing as much as I can, which is quite a lot considering I'm over 80 now".

The 'fit for purpose' approach to rehabilitation is echoed in the narrative of John, a 66 year-old who experienced a heart attack in 1998:

> I'm not top class or anything but I can go out and walk six miles and it wouldn't bother me, but I don't do it regularly ... I mean, I took my caravan to Shirley last week and I walked back to Bassett, because I had to, and I did the two odd miles in just over half an hour. I sort of pushed it to get a bit of exercise and I wasn't creased-up at the end of it. (10: 175-180)

John doesn't need to be "top class", in terms of fitness, for the everyday tasks that he undertakes, and even when he is required to push himself a little harder, he can manage without too much difficulty. To go out of his way to engage in a structured exercise programme is not required and may actually mean that he needs to admit that has a heart problem and, in turn, that he has failed to look after himself. In the first instance, John does not think of himself as a cardiac patient, suggesting that he actually feels a "fraud":

> Well I did (laughs). Yes I tend to think I'm a bit of a fraud really because I don't get any reaction to the heart attack. I mean, you go along to the doctor or to the nurse for the reviews and "do you get any pain?" and "what exercise do you take?" and you tell them ... and I don't get any pain. I told you I did that walk back from Shirley and I started to get a bit of a pain there in the top of the chest, and maybe ... I don't know, it's a case of doing it again and seeing, because it could have just been on the day. I don't get any other reaction to it, so I just think what's all the fuss about? (10: 324-331)

John appears reluctant to take on the identity of an ill person, someone who has heart disease and so needs to take particular care of himself. His heart attack was a surprise to him: "... so yes, I was quite surprised – a bit put out really – to think I'd had a heart attack", and he feels that his social identity, or the way that others view him, is similar: "there was some surprise among various people that I'd had the heart attack". This type of denial is not uncommon among the chronically ill. Adams et al (1997) have reported that asthmatic patients often feel that their identity has been threatened by the development of asthma. Their respondents differed in their readiness to accept the identity of asthma sufferer, which in turn, was related to the beliefs that were held regarding the meaning of the condition. The group that the authors refer to as "deniers" were keen to impress upon the interviewers that they did not actually have asthma and that there was no impact from their condition upon their daily lives. However, the researchers, by means of in-depth interviewing, were able to elicit the true extent, which was entirely different. As they rejected the term "asthmatic", so too do John and a number of others from the present study, reject the identity of cardiac patient. John describes himself as a "fraud" for being involved in the study:

"Well, as I say, I feel a bit of a fraud for talking to you because my heart attack wasn't that serious, you know". He cannot deny the fact that he had experienced a heart attack, but what he can do, as part of his biographical work, is to represent the heart attack as being something so inconsequential that he can distance himself from the identity of a cardiac patient. Further, he has diabetes which is actually much more disruptive than the heart disease demanding, as it does, a high level of monitoring and care. This was very common among the respondents who are represented in this chapter, and highlights the earlier discussion regarding the way that chronic illness can actually be viewed as a biographically anticipated event, rather than a disruptive one.

Early in her interview, Molly describes some of her health problems and how she manages to cope with them:

> The heart attack itself wasn't too much of a problem, but the angina is more of a problem for me really. I've got a slow working thyroid gland as well and I've recently been told that I have a bowel disease. Of course, I'm developing arthritis as well and, of course, I'm on medicine as well so it's all under control and I know how to lead my life. I mean some days I'm really exhausted, but I know then just to do the <u>necessary</u> housework and then I know not to push myself, which is very annoying because, I mean I like to go out and we have no social life as such. I do like to go out to the shops and do a little bit of shopping, but I'm afraid I just can't get out of the house where I'm so really tired. (19: 9-17)

Compared to the other health difficulties that Molly experiences, the heart attack appears now to be insignificant. The other illnesses that she experiences are disruptive to her life and require a strategy that allows her to deal with the practical consequences, whereas heart disease is not so disruptive. Molly implies that, at seventy-three years of age, "of course" she has got arthritis, but everything is under control because her conditions are medically managed. In the face of such expectations of growing old, the heart attack became, what Williams (2000) has described as a "biographically anticipated" event. The life threatening nature of the heart attack caused some initial anxiety for Molly, but once she had engaged in the medically led Phase III rehabilitation, and once she had had time to reflect on her situation, this disruption was put into the context of what she perceives as being ordinary, as opposed to extraordinary. In the development of understanding 'biographically anticipated' events, personal experience of ill health in old age, is supplemented by the observations of peers who experience similar problems. Doris provides a good example of this in her narrative:

> Well I'm quite old now, so you do expect these things at my age don't you? I mean, most of the people that I know – well those of my age anyway – they've all got something wrong with their hearts. If it's not heart attacks, it's high blood pressure or even stroke, so it's only to be expected really. (25: 15-19)

At the age of seventy-one, Doris has accumulated an abundance of experience related to the health related problems of ageing and she has a clear understanding of how old age should be lived. She accepts that with old age comes poor health and so when she experiences illness it becomes something that is to be expected.

In her discussion of the meaning of the term 'narrative', Becker (1997, p.28) provides an interesting way of looking at the stories that people have told her: "The stories in this book all have a beginning, a middle, and an end, although in many cases the imagined or hoped-for end is not yet in sight. That is, many of these stories do not have an end that is satisfactory to the storyteller". I would argue that the biographical work of those cardiac patients, who make attempts at continuity, is geared toward providing a satisfactory end to their illness story. To bring this particular chapter of illness to a satisfactory conclusion in as blameless a way as possible in allowing the storyteller to continue to lead the lifestyle that best fits their own life-story. For example, Richard has his certificate, which to him represents a medically endorsed 'end' of his rehabilitation and, with it, this particular chapter in his health biography.

## 4.6 CONCLUSION

As discussed in the introduction to this chapter, for my own purposes biography relates to identity – both self and social. Throughout the life course, one holds on to certain experiences, both lived and observed, which comprise the life story. These inform the person's identity, or more specifically, they contribute to the present identity as well as the identity that one may develop. In other words, the personal view that one holds and the person that one sees him/herself becoming. From the latter, the individual can anticipate future experiences and future social roles that they will perform. An understanding of the perception of how that person is viewed by others is also developed. From this understanding of biography, my cardiac respondents have reacted to disruption by reordering and redefining these experiences in a "process of reframing" (Becker, 1997, p.176). The experiences are used as a framework within which an understanding of cause, severity, lifestyle and situation can be created. These are reflected in the themes previously discussed.

So, what I am saying about biographical disruption is that it is, in itself, not the 'end of the story' from which new beginnings are formed. If stories have a beginning, a middle and an end, as Becker (1997) suggests, biographical disruption does not have to be the conclusion of one chapter, where the next chapter takes over. The biographical narratives of the respondents discussed above are all related to the maintenance of identity. Their biographical work relates to reducing the effect of the disruption as much as possible so that disruption is assimilated into the life story – more of a full stop than an exclamation mark. Another way of looking at biographical disruption is that, while it can have a significant effect upon the cardiac patient, this effect can be a transient one. It can be reinterpreted and redefined to fit the patient's life story. A biography can be disrupted, but then that very same biography (the patients life experiences) can be reworked in order to resolve the disruption.

It should be noted that this response to biographical disruption is specific to cardiac patients. It is a disruption that reduces in salience over time, whereas those with chronic physical conditions can experience an increased disruption. For example, the arthritis patient will experience an increased disruption to quality of life as the symptoms of the condition develop. For the cardiac patient, the opposite is true. Of the eleven cardiac respondents whose narratives comprise this chapter, only two felt that they were incapacitated by their condition. In this respect, the biographical work of these two involved attempts at impressing upon others the seriousness of their condition. This will be given fuller consideration in chapter seven, but for them, the invisible nature of heart disease was a source of frustration – it did not provide them with legitimacy. However, these two apart, I did not find any evidence of present disruption in the accounts of any of the 'non-adherent' respondents. There was no acknowledgement of the disruption of heart disease upon the daily lives of patients. Indeed, the desire to be viewed as normal and undisrupted was evident.

A further contrast between the disruption experienced by cardiac patients compared to their arthritic counterparts is in the way that the former are keen to disassociate themselves from blame. I would argue that arthritis patients do not exhibit this characteristic to such an extent, because arthritis is not considered to be a lifestyle disease in the same way as heart disease. While virtue has been explored among the chronically ill (for example in Williams's 1993 study) this relates more to the ways that people should respond to illness, which is different from being blamed for developing the illness. Where heart disease is concerned, individuals, in general, have a responsibility to behave in such a way as to avoid its development.

I should add here that a disruption, to some degree, occurred among all of my respondents. However, that is not to say that all cardiac patients experience a disruption to their biography. I have a purposive sample who have all participated in Phase III Cardiac Rehabilitation programme, whereas some cardiac patients may experience a heart attack but choose not to participate in this medically-led intervention – similar to the 485 cardiac patients in Southampton who chose not to take up their offer of a place on a Phase III programme in 2004 (personal correspondence from the Lead Cardiac Nurse, Southampton PCT). By this I mean that if a person has a heart attack but then either denies, or fails to accept that the heart attack as being a serious, life-threatening illness, then no disruption will have taken place. Perhaps this is biographical work in maintaining continuity at its most extreme. However, I have no data on these people and so should not continue to speculate.

Brian Turner (2001, p.3) in *Medical Power and Social Knowledge* has discussed the central issues of sociological theory, providing a useful toolbox from which to work. He suggests, "sociology is concerned to understand the meaning of social action, that is, the subjective perspective, emotions and feelings of human agents as social individuals". He continues that sociology is also concerned, "with the relationship between agency and structure. Sociology attempts to explore the relationship between human action and the structural determination of social relations by certain constraining elements which in general we can describe as power relations". I will attempt to address these issues, briefly in the following, but more fully in the final chapter.

Social structure relates to the way that the health promotion movement, strengthened by Government legislation, encourages a culture of individual responsibility. As discussed in the literature review, medical surveillance has become an increasingly important aspect of public health. From their metaphorical watchtowers, the guardians of the nation's health oversee, with a panoptic view, the behaviour of individuals. Further, a culture has been created whereby we self-regulate our health - the task of surveillance has been handed to the individual and, similar to the way that Foucault described the 'interiorizing' process, we have become responsible for our own health surveillance. The "health promoting self" (Nettleton and Bunton, 1995) has become the chief weapon in the 'fight' against lifestyle disease.

In the literature review, I asked the question: "if the panoptic gaze of medicine were as powerful as has been suggested, why are deaths from lifestyle disease, such as heart attack, still the biggest cause of mortality in western societies? Why do we not regulate our bodies as efficiently as we are advised to?" I would now say that the answers to this question lie in the accounts of the respondents in this chapter. While individual responsibility is, indeed, a powerful, structural influence, the social actor can biographically work around its effect. This biographical work can leave the structure intact (i.e. the concept of individual responsibility for health), while simultaneously creating the conditions within which individuals can legitimate their actions, even though they go against medical endorsement. Their resistance to medical power is not overtly confrontational; rather it is subtle and discreet. It is not about being outspoken in the views that challenge the power of medicine (in the way that some sociologists do, such as Ivan Illich, 1975), but being cautious and considerate of medical authority. Perhaps if this research were to be repeated in fifty years time, the twenty-somethings of today may be more outspoken in their opinions, but the sample from this study were brought up in an age of deference to the medical profession. However, this actually strengthens the case of human agency, that a group of people who may have respect for medical authority can still exercise their will over it.

The current uptake of cardiac rehabilitation services, certainly in Southampton, is quite low - only 40% (323) of eligible patients took up their offer of attending Phase III rehabilitation in 2004 (personal correspondence from the Lead Cardiac Nurse, Southampton PCT) - and health professionals are constantly engaged in attempts to develop strategies to improve this uptake. It would appear that the biographical narratives of these respondents could provide health professionals with some answers. When health professionals discuss the risk factor approach to encouraging cardiac patients to change their health behaviours, a greater understanding of the meaning of health behaviour to the individual might ensure that more people are not excluded from these services. Similarly, the psychological models of behaviour change, which have been criticised for treating individuals as "emotion-free actors" (Lupton, 1999) would do well to consider the strength of agency over determinism.

So, from the narratives of the eleven cardiac patients who have chosen not to engage in facility-based exercise rehabilitation I now have some understanding of the complex process of construction and reconstruction, interpretation and reinterpretation of the health-related symbols in their lives. These understandings are formulated in order that the patients can maintain continuity in their lives and choose *not* to 'do the right thing', while maintaining their 'moral authority', as Becker (1997) would call it. Ultimately, choosing to reject the recommended health behaviour of exercise provided the only way of 'getting back to normal' for these patients. However, I now need to understand why the other fourteen respondents *did* choose to adhere to their exercise-rehabilitation. As most of these cardiac patients were inactive prior to their cardiac event, why did they not also take the biographical 'line of least resistance' and engage in the reinterpretative biographical work that I have described here? The next two chapters, then, will provide an understanding of the motivations behind the actions of these respondents.

# CHAPTER 5: CARDIAC REHABILITATION AS A PROJECT

## 5.1 INTRODUCTION

As might be expected, the content of this chapter bears a contrasting relationship to that of the previous chapter. I have described the ways that cardiac patients are able to rationalise and give meaning to their inactive lifestyles, so it follows that the data that inform this chapter will read in a very different way. Whereas the cardiac patients of the previous chapter were able to engage in a creative form of biographical work that reinterpreted symbols in such a way as to fit the biography and, thus, absolve them from the blame of reacting the 'wrong' way to their rehabilitation, those from this chapter have no such problems. They are able to articulate, in a very morally superior manner, the way that they now 'do the right thing' in response to their heart disease. They have a control over their illness, and they can portray this in a descriptive way that those who do not engage in behaviour change cannot. However, I will endeavour not to present the data merely as a series of accounts from those who have engaged in a physically active lifestyle. Rather, and in keeping with the symbolic interactionist nature of the study, I will interpret the meaning of these actions from a perspective of the lived experience.

Social scientists often assign descriptive labels to the groups of respondents that they are studying in order to classify the specific orientation of different groups. I have two fundamental groups within this study, those who, following a heart attack, change their lifestyle in accordance with recommendations of health professionals, and those who do not. In keeping with this social scientific tradition, I will assign labels to these two core groups of cardiac patients, so that future reference will avoid the necessity of repetitive explanation. Those from the previous chapter engage in a type of biographical work that enables them to make amendments (through reinterpretation and redefinition of facts and events) to symbols that have salience to their lives. For this reason, I will call this work, 'biographical amendment'. However, this will not suffice as a label that describes the group members, because much of this biographical amendment has the distinct purpose of allowing these cardiac patients to adjust to new definitions that various roles within their identity assume for them. I have previously discussed the notion of identity as being comprised of a number of roles that people perform in their everyday lives. The performance of these roles is disrupted by the heart attack and, consequently, they must be played out in a very different way. This will be given a fuller consideration in the next chapter but, briefly, those from the previous chapter were able, through biographical amendment, to *adjust* to these new performances and place some value upon the new definitions that these roles take on. This is important if they are to maintain continuity of their biographies. I will, therefore, refer to this group as 'biographical adjusters'.

The cardiac patients whose narratives form the basis of the next two chapters are very different to those previously discussed. These are the patients who are 'doing the right thing' in response to heart disease by accepting the type of lifestyle that has been recommended by the medical profession. Similar to the way that legitimate access to the sick role demands that the patient seek medical advice and act accordingly, these patients are able to gain legitimacy in their lives by engaging actively in rehabilitation. In so doing, they appear to engage in, what I will term, a rehabilitation project. They undertake the task of rebuilding the roles that have been disrupted in an architectural manner that consist of distinct developmental components. I will, therefore, refer to this group as 'biographical architects'. In my introduction of the previous chapter, I remarked that, broadly speaking, the respondents of my study responded to biographical disruption in one of two ways:

- Those whose biographical work relates to creating the conditions for continuity, or for 'getting back to normal'.
- Those whose biographical work relates, in varying degrees, to the development of a regained, or sometimes new, identity in which new patterns of exercise adherence figure strongly.

I can now develop this by saying that these two responses to disruption are exemplified in the biographical work that they engage in, namely, biographical adjustment, or biographical architecture. In Chapter 6, I will discuss the ways in which the valued roles that are central to one's identity become disrupted, which can bring one's whole identity into question. Biographical work in response to this is key to my classification of the two categories described. Whereas one group of cardiac patients could adjust to the new definition of these roles – hence the term 'biographical adjuster' – the other group could not. This group of cardiac patients needed to rebuild their identities in a creative way. In looking for a suitable term to describe this, I drew from the discipline of sports psychology, which has the notion of 'cultural architects'. These are sports players who have the capacity to rebuild confidence in themselves and their teammates following defeat. They do this creatively by looking at where they are now, picturing where they want to be, and developing, cognitively, a plan of action that will restore their former confidence. They rebuild their sporting identity, but not from an imposed set of rules that are imposed from without – which would place them as 'builders', but by becoming the 'architects' of their own reconstruction.

The work of biographical architecture begins by accepting the blame for developing heart disease in a way that those from the previous chapter were not able to do. They accept that their previous lifestyles were unhealthy but, rather than provide explanations of why they had led this lifestyle, they can now leave this behind and construct new beginnings for themselves. In a way, this wipes the slate clean and lays the foundation upon which their biographical work can progress. These cardiac respondents talk of the value of a good work ethic and of the potency of hard work in addressing their future risk for heart disease. It is believed, by some patients, that even fate can be overcome through hard work and application. The second element of biographical architecture relates to risk. However, I will not approach this from the perspective of the *risk society,* which some sociologists have recently concerned themselves with (Beck, 1992). Rather, for these cardiac patients, the concept relates more to the 'factors' for risk that have been identified by medicine as significant in the development of heart disease. The risk society approach is concerned with the environmental and technical risk, over which we have no control, that can make us feel "overwhelmed by a sense of powerlessness" (Giddens, 1991, p.193). From this perspective, risk cannot be understood as something that is calculable (Lupton, 1999) or which can be favourably influenced by actions of the individual. However, biographical architects hold an understanding that the 'factors' of risk for heart disease *can* be influenced, and with it their risk of a secondary event. These cardiac patients are provided with that very sense of control that 'risk society' thinking rejects. As Shilling has said, "at a time when our health is threatened increasingly by *global* dangers, we are exhorted ever more to take *individual* responsibility for our bodies by engaging in strict self-care regimes" (2003, p.5, italics in original). The biographical architects were provided with the same epidemiological risk factor information as the biographical adjusters, but whereas the latter incorporated the non-modifiable factors into their biographies, the biographical architects found more use in the modifiable ones that could be 'worked at'. Thirdly, in order to construct an effective identity as an exerciser, the cardiac patient engages in a process that involves gaining expert knowledge in the fields of health and exercise. Not content with the standard lifestyle advice offered as a matter of course by health professionals involved in cardiac rehabilitation, these patients engage in what Giddens (1991) has termed 'reskilling'. As such they learn as much as they can and take a scientific approach to their rehabilitation. However, rather than accept with blind faith the explanations provided by medicine, they bring them into question by evaluating against personal experience. Finally, these patients adhere to a structural framework that relates to the 'virtue' of leading a healthy life. I have shown in the previous chapter that cardiac patients who choose not to engage in behaviour change work hard at demonstrating that they are not to blame for developing heart disease. They strive to maintain their moral authority in the face of a condemning society who would too readily blame them for their failure in self-care. However, the patients of this chapter demonstrate a moral superiority that would perpetuate this condemning environment, scathing as they are in their antipathy of those who respond the 'wrong' way to illness.

## 5.2 ACCEPTING THE BLAME AND WORKING TOWARD RISK REDUCTION

An interesting, and key, theme from the narratives of those who successfully altered their lifestyle following a cardiac event was a willingness to take responsibility for their illness condition. This is in stark contrast to the accounts of the 'biographical adjusters', whose biographical work had a primary aim of disassociating themselves from blame. For these cardiac patients, heart disease is "in the family", or was something that "should have been expected at my age". However, when the patient makes the recommended lifestyle changes, efforts at reconstructing and reinterpreting these symbols is not necessary and the patient can accept some blame for developing heart disease. In fact, it appears to be something of a prerequisite as there was only one from the fourteen respondents, whose narratives form the basis of this chapter, who did not view unhealthy behaviour as contributing to her condition. (This exception was a thirty-three year old who "inherited" high cholesterol.) The closest thing that I can relate this to is the alcoholic who stands up at the beginning of an AA meeting to state his/her name, followed by "and I am an alcoholic". This provides a starting point from which the person can begin to rebuild a life that had been disrupted by alcohol. I am not suggesting that to lead an unhealthy lifestyle, e.g. low activity levels, high-fat diet, smoking, etc, can be directly compared with being an alcoholic, but the life-threatening/disrupting consequences may be similar. Goffman's analysis of stigma (1970) suggests that we tend to perceive ourselves as if looking into a mirror, which reflects society's view of us. Goffman suggests that if people manage themselves in such a way as to be categorised by others as a 'failed' member of society, that label will be internalised and incorporated into what becomes a 'spoiled' self-identity. The acceptance of a spoiled identity acts as the bedrock upon which the ensuing biographical work, or 'project' can be developed.

When discussing cause, Arthur provides a response that is typically framed in terms of the classic risk-factor understanding of the aetiology of heart disease. Whereas the 'biographical adjusters' were keen to emphasise the blameless nature of their condition by emphasising an association with family history – the ultimate detachment from blame – Arthur appears to be at pains to stress that there is no such connection:

> *What do you think was the cause of the heart attack?*
>
> Stress and smoking, I can tell you that right away. Definitely, I had a very stressful job in the way that some one would phone and give you an amazingly difficult problem to solve, and the first thing that you did was grab a cigarette and think "well what am I going to do about this?" cold sweats in the middle of the night thinking "oh, I've got this and that to do tomorrow". There's absolutely no history in my family, I'm the only one in the family who

> have ever had a heart attack, and they've all gone on to seventy and eighty. (21: 250-258)

Arthur accepts that his previous lifestyle was "not good at all", which raises an interesting point of terminology. As a result of the widespread health education campaigns in the popular media, which have supported the government's emphasis upon the role of the individual in maintaining good health, we now have 'right' and 'wrong' ways of living, or 'good' and 'bad' lifestyles. To live a good life is to eat a healthy diet, drink only in moderation and take regular exercise. James describes the opposite extreme to this:

> I had a very bad lifestyle, I was very stressed, very overworked ... I smoked like a trooper as well, certainly my normal was twenty a day, but that went up to thirty a day (20: 152-154).

A bad lifestyle, then, involves doing all of the things that we are generally advised not to do, such as "smoking like a trooper". Diets can be made up of "good or bad food" (Puran, 5: 152) and ill health can be caused by a "bad diet" (David, 6: 137) or by generally leading a "bad life" (Ahmed, 1: 132). Cornwell (1984, p.128), in her discussion of the concept of health and illness, provides an explanation:

> "... good health is also said to be the reward for a good life, meaning a life of moderation and virtue, cleanliness and decency, and above all, a life of hard work. In other words, just as one's place in the hierarchy has to be achieved by 'making the most of oneself', so too one's health has to be 'earned'."

Some of the biographical architects take the literal view that good health can be 'earned' from hard work. Working for health is a notion that these cardiac patients are familiar with and forms an important component of their biographical work. Ahmed, a 68-year-old man who had experienced both a heart attack and bypass surgery, employs the metaphor of work in relation to the way that health can be earned:

> I used to be in a regular job, you know, I worked as inspector for Royal Mail and my duties were mostly shift work - six o'clock and two o'clock and then at night, ten o'clock, you know, so now every morning I've got my alarm, you know, quarter to six … and I'm here at seven o'clock and I'm on the treadmill. It's just like going to work. I used to earn money - you can earn money, and you can earn health. You know, by coming here I know I'm getting more value for my life than money because if you've got that, you've got everything - if you haven't got that you've got nothing. (1: 181-189) … you know I feel like I am going to work - there I was getting money and here I am getting health, which you cant buy. (1: 198-200)

This passage from Ahmed's narrative reveals a strong association with the Protestant ethic, something which all of the adherent cardiac patients appeared to endorse. I would say that health is now viewed as an 'attribute' over which people have control, a notion that results in a person being held accountable when things go wrong – a moral transgression. To take responsibility for this transgression, then, should be something to avoid, but that is not the case with these particular cardiac patients, who often admit that they led a 'bad' life. However, as they are now doing the morally correct thing, they can avoid the stigma of this transgression by blaming their former selves. As mentioned previously, this provides a starting point from which their new identity, or certainly the new role of exerciser, can begin. In the same way as (it is said) ex-smokers often become the biggest advocates of smoking cessation, so too do those cardiac patients who lived a 'bad' life appear to fervently endorse exercise participation. Accepting blame and examining the "things that I did wrong" are all part of the biographical work that helps to inform the way that patients act toward their rehabilitation and provides a foundation upon which the subsequent biographical work is undertaken.

To work hard at something is to make things happen – as in the old sporting saying, "the harder I work, the luckier I get". This is analogous to the way that these cardiac patients approach their rehabilitation, with the thinking that hard work has its own rewards. Take Arthur for example, a 66-year old who had a heart attack in 1990 and who feels that his participation in exercise will help him to defy fate:

> *So do you feel at risk from another heart attack?*
>
> I feel that I will get another one, yes.
>
> *So what's your motivation to carry on exercising then?*
>
> To stop it!
>
> *But do you feel that it's inevitable?*
>
> Well, it's funny because we were only talking about this the other day, and I was talking to a guy who was in the Force at the same time as I was in the national service, we were in the Middle East together. I said, "did you ever get the driver instructions out there" and he said "what, if you run somebody over to make sure that you kill them, because you can't afford to keep them going?", "yes that's the one". Well out there they've got the attitude, and I can't remember the actual word, but it means 'God willing', it means that if you're going to walk across the road then you take the risk ... they work on the theory that somewhere there is a book written that somewhere on some day at a certain time, you will die. I think for a long time I had that attitude, and you have that attitude when you're younger, "there's nothing I can do about it, I can smoke, I can do whatever I like, because on a certain day at a certain time it's written that I'm going to die". But I think that as you older and life becomes more precious, you come to think, "oh I'm going to take out a mortgage for 25 years", well I couldn't take out a mortgage for 25 years because I haven't got 25 years left and I'm starting to think "have I got 5 years left, have I got 10 years left, have I got no time left" I don't know.
>
> *So have you lost that fatalistic view of life?*

> I have lost it yes, I think well I'm going to fight against it, if it's written in the book, I'm going to go out and get a bloody great rubber and rub it out and change the date, I'm desperately trying to change the date. (21: 476-508)

Arthur is taking on the challenge of rewriting his own destiny in the same way as he is 'taking on' heart disease. His approach is something of a head on challenge and he is accepting it with enthusiasm by giving up smoking, eating a sensible diet and engaging in an exercise programme, three of the classic risk factors for heart disease. He anticipates that this lifestyle change will act as the "bloody great rubber" that will help him to put right what had previously gone wrong. By doing this he can erase all of the damage that had been done by his previous unhealthy lifestyle habits and, therefore, reduce the risk of heart disease becoming the predicted destiny that is "written in the book".

Various authors have suggested that the term 'risk' no longer relates to the 'probability calculations' (Douglas, 1992) or 'calculable probability' (Lupton, 1999) that characterized the term in earlier times. These were times when, "risk, in its purely technical meaning, came to rely upon conditions in which the probability estimates of an event [were] able to be known or knowable" (Lupton, p.7). Rather, today's risk society takes a "high-consequence" perspective, which considers threats, such as that of nuclear war, which are seen as inescapable (Giddens, 1991, p.4). However, the rejection of risk calculation by these authors appears in direct opposition to my own data, which suggest that cardiac patients actually balance their risk factors (and therefore their risk of a second heart attack) in a very calculable way.

This is typified by David, a fifty five year old man who experienced a heart attack three years prior to his interview, in his response to being asked what he thought was the cause of his own heart attack:

> "As I say, smoking must have been a big part of it because I smoked twenty a day for over thirty years … must have had a hell of a lot to do with it. Lack of real exercise, because I was busy and I was running around like a blue-arsed fly, but it wasn't real exercise - it wasn't a beneficial way of doing things. Probably diet as well, you know, I'd eat little or nothing during the day, pig out when I got home in the evening … sure that must have had some bearing on it as well." (6: 107-122)

He then describes the way he has balanced out the risk of a secondary event by modifying these risk behaviours:

> *Do you think that this stress could cause another heart attack at all?*
>
> "I don't think so because I'm managing things better now - I don't smoke, so that's got to help because I've stopped smoking for almost three years now … I don't work so late, I stop for lunch, I eat better…" (6: 126-129)
>
> "But personally I think … the way that I look at it is the most important thing is exercise. I really felt so good when I was doing the exercise by comparison to how I felt before." (6: 138-140)

So it would appear that David feels that he is reducing his risk of heart disease by cutting out the factors that he feels were responsible for his heart attack, i.e. smoking, inappropriate exercise and poor diet, he is now, as he puts it, 'managing things better'. This may appear simplistic, but it does demonstrate the way that cardiac patients view 'risk' as being something that can be balanced and worked at.

That risk can be calculated and balanced is an important consideration in understanding the biographical work of these patients. From this understanding flows the rationale behind the basic element of the rehabilitation project, a notion that Giddens (1991) refers to as 'reskilling'. If the cardiac patient is to act in such a way toward risk that it is possible to 'rub out', as Arthur would put it, the (predetermined) risk of heart disease, it is necessary to gain the skill required to do the job to best effect. Reskilling relates to the biographical work of acquiring knowledge and skills that will be required in order to address the negative effects of biographical disruption. As Giddens puts it, "individuals are likely to reskill themselves in greater depth where consequential transitions in their lives are concerned or fateful decisions are to be made" (1991, p. 7). There can be fewer more fateful decisions than how to lead one's life after the life-threatening event of a heart attack.

## 5.3 RESKILLING

Before discussing the ways that cardiac patients engage in 'reskilling', as part of their rehabilitation project, it should be noted that a small caveat might exist in the study. Of the fourteen cardiac patients who adhered to their exercise rehabilitation programmes, and who therefore may be potentially engaging in a rehabilitation 'project', only three were women. It could be assumed, then, that men are more likely to engage in this type of biographical work than their female counterparts, but this is not something that I have given specific consideration to.

Typical of the 'reskilling' approach is James, who sought re-assurance from a medical evaluation, which gave him the opportunity to learn more about heart disease as a medical condition and about the extent to which he had been affected by it:

> I paid privately for a very fine hospice, they took x-rays and did tests on me and … well this I really appreciated and you can't get it on the health service – I think in those days it cost about a fifty quid – but they spent the whole hour with me and said well this is this and that is that, and they explained everything to me. They said that if I lived sensibly and if nothing has happened within two years you could just forget about that heart attack. (20: 109-114)

Even though James was provided with the basic lifestyle information at his Phase III cardiac rehabilitation sessions he felt that he needed to know more about what had happened to his body, which Giddens suggests is not unusual following such a 'critical moment' as a heart attack:

> At such moments, when life has to be seen anew, it is not surprising that endeavours at reskilling are likely to be particularly important and intensely pursued. Where consequential decisions are concerned, individuals are often stimulated to devote the time and energy necessary to generate increased mastery of the circumstances they confront. (1991, 143)

The cardiac patients for whom basic lifestyle information, such as the type provided at Phase III is not sufficient, typify this "increased mastery". The patient is motivated to learn as much about their condition, and the ways that exercise can impact upon it, as possible. As Giddens suggests, in today's risk society: "empowerment is routinely available to laypeople as part of the reflexivity of modernity" (1991, p.141).

Edward, a seventy-seven year old man who had experienced a heart attack six years prior to being interviewed, gained the identity of 'marathon man' within his community, because he had completed the London marathon four times, raising thousands of pounds for charity, even though he had never exercised previous to his heart attack. The new identity that Edward had gained from becoming an exerciser was achieved, in part, through a process of reskilling. Edward constructed an identity both through exercise and education, reading textbooks about cardiac rehabilitation and absorbing facts and figures from many sources:

> … and I've read quite a bit about it as well. It's been proven that a very large percentage of your health will be better, maybe up to sixty per cent from just exercising, and you don't have to do anything fantastic, but just exercise in your limits. That can stop you from having strokes and heart attacks, it strengthens your heart and your lungs … and really, I'm living proof of it because when you have a mini stroke – I've read quite a bit about it – it's a warning that you could have a major stroke (17: 74-79).

Edward, who had also experienced a 'mini stroke' (transient ischaemic attack), has done his research on the subject and has found evidence, that can be quoted at will, to support the worth of his actions. He takes a very technical attitude to his rehabilitation in suggesting that health can be improved by "up to sixty per cent", an interesting way of thinking about a concept that is very hard to measure. For example, what would one hundred per cent health be? Edward needs to think in these quantitative terms though, because it fits in with the way that he understands his rehabilitation project. A similarly technical view is taken by Jim, a seventy five year old man who underwent bypass surgery two years prior to his interview:

> Well look, I've had this check since I started a year ago and all the tests show that, well my blood pressure went down from 170 to 140 and that's only because of the exercise. That convinced me of how important it is, and my pulse rate, my resting pulse rate went down from 85 to 80, so my heart is working more efficiently than it has been before. (18: 83-87)

This demonstrates a typically quantitative approach to health that can be measured and improved upon, in terms of grades and ratings, that views health from a functional, body-as-machine, perspective. Engaging in an exercise programme is being seen, increasingly, as a way of controlling one's body and people are now inclined to feel "that the body is *their* machine which can be maintained and fine tuned through diet, regular exercise and health check-ups" (Shilling, 2003, p.33). Similarly, the cardiac respondents of this study share this functional, 'man-as-machine' perspective and view healthy people as being those who engage in these traditionally healthful behaviours. In describing a healthy friend, David epitomizes the components of health that are directly related to fitness:

> "He exercises a lot, his skin tone is good, very clear eyes, his breathing is exceptionally good, he is able to do fair distances of walking or running without getting breathless, his body is very supple ... and he really is superbly in tone you know, his muscle tone is very good.
>
> *So you seem to associate health with fitness and physical function.*
>
> Oh very much so, yes. I've always looked - well the fitter you are the healthier you are." (6: 188-196)

David has encapsulated most of the principles of fitness within this definition, including strength – articulated as good muscle tone – flexibility and endurance. This has been achieved by virtue of the fact that this person exercises a lot. Jane, an eighty-year-old lady who experienced a heart attack two years prior to being interviewed, provides a similarly functional definition, by reference to a friend:

> "Well, she seems to be able to *do* things so much, and enjoy doing them, it's not an effort for her to do it, and she does exercise ... very fond of the outdoor life and exercise. Not what you would call a couch potato - I don't think that's good." (8: 90-94).

Jane, and most of the other respondents, describes health as being much more than simply the absence of illness:

> "Oh you can [still be healthy even though you have arthritis], yes, you can put up with things - often I think if you know what it is that's wrong with you, you can put up with it, and often you worry about things that you think might be wrong with you, you know, you might feel certain things. But if you know what's wrong with you, even if you know that you'll not get better from it - physical things like arthritis and rheumatism and all these things - you know you'll not get better, but if there's anything you can do maybe to help it a bit so that it won't get any worse for a while, at least you can live with it. I mean I can live with quite a good pain - what do you call it - threshold? yes I can live with and put up with pain if I know what it is." (8: 104-110)

This notion that the presence of illness does not reflect health and the perception that illness can be overcome is important for these cardiac patients. To have the perception of health as being more than just the absence of disease holds the promise that it is not too late to 'do the right thing'. The cardiac patients from this study perceive a strong relationship between health and fitness, with exercise being the vehicle through which fitness is delivered. As Matthew puts it, "You've got to do it right ... you've got to do the right things" and the right thing to do following a cardiac event is to exercise, but more than this, it needs to be the right sort of exercise.

Whereas the 'biographical adjusters' were able to place a health protective value on everyday activities, those who take on the rehabilitation project need to be doing the right type of exercise. Robert expands on the point when talking about the walks in the country that he enjoys:

> *Do you think that that kind of unstructured physical activity is as beneficial as the exercise that you do in the gym?*
>
> No definitely not. Although it gets you out in the fresh air and it gives you exercise, because they say if you walk an hour a day or something ... but what it doesn't do is increase your heart rate as such. Not unless you start marching

> or walking very fast, for example, but if you have a reasonably quick walk around, you're not going to raise it as you do on the treadmill or the exercise bike or something. (13: 191-195)

So, engaging in the rehabilitation project is the right way to respond to a cardiac event, but does this mean that these respondents have become the health promoting selves that the medical profession are trying to encourage? Are the guards in their metaphorical watchtowers overseeing the health of cardiac patients by way of Foucault's panoptic gaze? From the surface of things it would appear so. The prison model of the panopticon left the prisoner subject to observation at any time by possible viewers and it was assumed that this surveillance would prevent those being watched from doing anything "wrong." It would appear, similarly, that these cardiac patients, in their efforts to avoid being caught doing anything wrong, are embracing the rehabilitation project and, in doing this, are succumbing to the structural power (or, what Foucault (1995) referred to as 'disciplinary power') of individual responsibility.

However, I will argue that, in fact, these cardiac patients do not engage in this project blindly and automatically, as the panoptic model would have us believe. The health promoting selves, to which Foucault alludes, would be acting under a punitive threat of an unforgiving society that would frown upon their intransigence. I will argue that these cardiac patients are creatively empowering themselves to transform disruption into order. The cardiac rehabilitation project is undertaken to various levels and in varying degrees by all of the 'biographical architects', but to suggest that they do this automatically in a self-surveillant manner would be to do them a great disservice.

The rehabilitation project is distinctive to the individual and to the individual's biographical circumstances. To simply 'do the right thing' in an automatic manner would end at the Phase III level of rehabilitation. This phase of rehabilitation has the purpose of equipping cardiac patients with the knowledge and the health-related education sufficient for someone to become a 'health-promoting self ', but these patients have, mostly, gone beyond this level. They question the advice provided by health professionals and they undertake an almost scientific approach to garnering more and more information about their condition. Consider Arthur's questioning of the cholesterol-lowering medication that has been prescribed:

> I kept going to the doctor and saying, "these tablets are no good", "well they're working, your cholesterol is down", but I said "my weight's up, so surely one's defeating the other" (21: 100-103)
>
> It took eight or nine years, because they said you've got to take them, that's it and all about it, then I found out that it could affect your liver, so I was very, very against them then, and I demanded that I had various tests done and they said yes your liver function is perfectly OK, but yes it does affect it, and I said that I don't mind taking these tablets but not if it's going to ruin the rest of my body. (21: 114-120)

Arthur went on to explain that, subsequent to this, he persuaded the doctor to change his medication to one that he, himself felt was more appropriate for him. He took such an active role in his rehabilitation project that he managed to get his medical treatment adjusted. When Jim is asked about the effectiveness of walking, compared to exercising in a fitness suite, he takes a very technical approach to framing his response:

> Well I don't have any comparison, no scientific comparison on that so I don't know.

> *Is that important then?*
>
> Well it is yes, that's the way that I look at things, if you've no evidence … it's all very well guessing, but you've got to have evidence. (18: 133-137)

He is not blindly taking the health promotional message that attaches a strong a health protective value to walking for thirty minute per day on a regular basis, because he doesn't have any evidence to support it. On the other hand, he cannot say that structured exercise is any more effective than that type of unstructured physical activity; again he doesn't have any evidence. What he does know, though, is what has been effective for him. He has evidence of its efficacy and, so, he will continue with this in his rehabilitation project.

## 5.4 THE MORAL IMPERATIVE OF CARDIAC REHABILITATION

In the last chapter, I discussed the ways that 'biographical adjusters' were able to avoid engaging in an exercise programme but, at the same time, maintain a degree of moral authority, in the way that they live their lives following a cardiac event. As discussed, this is difficult in the individualist society of today. With individual responsibility comes a moral responsibility and this is a theme that runs through the accounts of both groups of respondents. The difference, however, is in the way that the 'biographical architects' negotiate this moral responsibility, and this is addressed in this section. Durkheim has stated that "If it is not good, it is bad; if it is not moral, it is immoral" (Durkheim, 1964, p.52) and that certainly holds true when it comes to recovering from a cardiac event. Durkheim has suggested that we are obliged to be morally responsible for our actions and it is incumbent upon us all to know how to act in such morally responsible ways: "... but everyone is now forced not to be ignorant. This obligation is, indeed, so strongly entrenched that, in certain societies, it is sanctioned not only by public opinion, but by law." (1964, p. 51). Although Durkheim, in this instance was referring to science as being the only element of civilization that presented a moral character, this holds true for health in modern times. Regarding our health, we are all forced not to be ignorant and although we have not yet gone so far as to outlaw unhealthy behaviours, such as smoking (although it is banned in many public places), modern governments have drawn up White Papers that instruct the medical profession to 'encourage' healthy behaviours.

In discussing the 'moral character of civilization', Durkheim observes that, "very often moralists have no objective criterion to distinguish moral facts from those not moral. We fall into the habit of qualifying as moral everything that has a certain nobility and some value, everything that is an object of elevated aspirations." (p. 52). Cardiac patients are faced with a similar problem of distinguishing between healthy and unhealthy, good from bad and therefore, as Durkheim states, moral from immoral. The problem is that the very lifestyle that led to a cardiac event must now be categorised by the cardiac patient as being 'bad' and, consequently, immoral. The following comments are testament to an unhealthy lifestyle:

> "I had smoked since I was a kid – think how much damage I must have done, how much *bad* has been done to me in all that time" (Arthur, 21: 619)
>
> "I had a very bad lifestyle, I was very stressed and overworked" (Matthew, 12: 288)

> “it was summed up by another professor at the hospital he said "your lifestyle has got to change because all it is at the moment is the three Ws - work, women and wine". He was right of course and he said "no wonder I'm going to have to take your pancreas" ... and my gall bladder and my spleen.” (William, 15: 31-34)

Key to the biographical work of the ‘biographical architects’ is the maintenance of a morally superior position, particularly in relation to other cardiac patients (or patients of any other kind, really) who have not been as successful in their health care. They have not been successful in taking responsibility for their own health and, as such, are to be thought of as morally inferior. The main approach to maintaining a morally superior position employed by these cardiac patients was to emphasise the ‘successes’ of behaviour change, particularly when others are not so successful, epitomised in William’s account:

> ... one is laziness, that’s the main thing, they just can’t be bothered. I think they get into a rut, well certainly the ones that I know, and all they do is moan and “poor me” and stuff like that, instead of getting off their ... I have to make an effort, I kick myself and force myself. The first time I came down here [the gym] I had to have a couple of diazepam because I’m very wary, very nervous ... that’s the way I am, but they have got into such a rut and they expect everyone to do it all for them and everything else, well that’s not me. I’ve got to do it myself if I can – I know its going to take me twice as long – but I have to have a go, and I will do it myself, but they ... it’s just laziness with them, it really is, they want somebody else to do it all the time. (15: 226-235)

Although this reads as something of an outburst or the ranting of a dogmatic and judgemental “health fascist”, it actually came from an intelligent man and delivered in a calm and measured manner. Further, it isn’t a one-off, but is actually a very commonly held outlook. Arthur, when reflecting upon his own experiences of rehabilitation and the difficulties that he faced (and overcame), demonstrates a similar attitude to someone who appeared to have ‘given in’:

> A lot of people accept … "oh well, that's it I've had my heart attack now and that's me finished" you know "I shall never be able to do this again". I've got a brother in law, he had a perforated aorta and he nearly died with it, but they managed to save him, but he came out and said "well that's it" I said "what do you mean", "well that's me finished" he said "I wont be able to play golf again and I wont be able to do this and that" and he's lived on the fact that he can't do it, and he does *absolutely nothing* ever since. He won't decorate he won't … he wants to be an invalid, he likes sitting down watching the television and having a drink, why should he go out and cut the grass. If his daughter comes in and says "don't worry dad, I'll do the decorating" he sits back and lets the decorating be done. He's a parasite as far as I'm concerned, that's my attitude, but that's the difference between two people, some people will use the sickness as a passport to an easy life, other people will resign themselves … like I've lost a leg and it's either hop or never walk again, I can't be bothered to hop so I'll never walk again. So I can only answer the question from my point of view, but when you get to my age you get the chance to see lots of different ways of dealing with sickness. I can give you a completely opposite view now, a guy that I play golf with – I've played golf with him twice this week – January he was in Spain, he got a stroke, he lost the sight in one eye he lost his voice he lost all the feeling down one side of the body, he was in hospital in Spain for about ten days, they flew him home and we're playing golf now. There's no way he's giving in "I'm not giving in" he said, and he's got a tennis ball and all the time he's doing that (demonstrates squeezing with hand) "I can't hit the ball as far because I can't get the grip back, but all the time I keep doing this, there's a chance", and he thinks the same way as I do. All the time he's squeezing that tennis ball, he's not going to give in.

This is a lengthy passage of narrative, but I've used it in its entirety because it demonstrates the two opposite responses of dealing with illness and Arthur flows from one to the other in a seamless style. He demonstrates the 'giving in' to illness, and the feelings of contempt that he feels are associated with this, and he also demonstrates the stoical response, which is to be admired and revered. Goffman's (1961) notion of the moral career of the asylum inpatient, which he suggests, can be paralleled with other moral careers, becomes pertinent when examining the sentiments of both William and Arthur. To recap, Goffman sums up the concept:

> "If the person can manage to present a view of his current situation which shows the operation of favourable personal qualities in the past and a favourable destiny awaiting him, it may be called a success story. If the facts of a person's past and present are extremely dismal, then about the best he can do is to show that he is not responsible for what has become of him, and the term sad tale is appropriate." (1961, p.150)

Both William and Arthur (and others) are keen to present themselves as someone who has successfully negotiated, what Harré (1993, p.206) refers to as an "occasion of hazard". The cardiac event, such as a heart attack or bypass surgery, is as an occasion of hazard (discussed in chapter 2), from which respect can be gained from a successful negotiation. Placing heart disease within the established framework of the 'sick' role is problematic (Parsons, 1951, Freidson, 1970), but one of the characteristics of the notion is that the sick person has a responsibility to both want to recover and to seek help in recovery. The fact that a cardiac patient believes that recovery from heart disease is possible, provides a legitimate place for heart disease within the sick role, and this belief is endorsed by Jane. A *moral imperative* emerged from the narratives of the adherent exercisers, in that rehabilitation became a necessary intention:

> I mean, perhaps some people need, or enjoy rather, the sympathy of others ... like having a cold I suppose, some people want to be nursed and some people want to be left alone. Maybe those who don't want to exercise enjoy being nursed after the heart attack, but not me. I suppose it comes down to your past life and your own mentality, I mean I've got a friend who had a heart attack, ... but he had a heart attack and he used it very much to his own ends. He was very much "oh well, I can't take any stress now", you know, and he *wanted* that and he *used* that very much to his own ends. (8: 342-349)

Both Blaxter (1995) and Cornwell (1984) have demonstrated the *virtue* associated with health. As covered in the literature review, in her biographical approach to understanding the meanings of health among women from the North East of Scotland, Blaxter found not only a strong emphasis upon individual responsibility for health, but she also found a strong influence of poor health over identity. To these women, 'giving in' to illness demonstrated a weakness of character, the guilt of which would lead to a re-examination of 'who they were'. This "moral identity" as Blaxter (1995, p.206) describes it, relates not to the *fact* of illness, but to the way that a person deals with it, therefore to 'soldier on' in the face of adverse health is credible, whereas to give in, demonstrates moral weakness.

The 'biographical architects' of this chapter were similarly keen to emphasise the virtue of their health behaviours and the way that they deal with their rehabilitation. Cornwell (1984) in her study of a working class community in the East End of London, found that responding in the 'wrong' way to the experience of chronic illness can "threaten not only the practical basis of their lives but also their moral reputation" (p. 127). I have discussed the importance of working hard at the rehabilitation project, and Cornwell, similarly, found that people were very cautious not to depict themselves as being lazy, another morally irresponsible attribute to possess, and this is evident among my own cardiac patients in this study who have changed their lifestyle:

> "Oh yes, yes I was because I was getting out and I was always good work-wise, I was never a lazy man. So I was always gardening and things like that, always busy with decorating and everything else, never worried about working." (12 [Matthew]: 32-34)

This judgemental attitude extends across all of the cardiac patients who have embraced the role of exerciser, even to Edward, a religious man who tries not to disapprove of other's behaviour, but observes:

> "I've seen them in my Senior Citizens Club. Very nice people, no problem but letting themselves go to pot ... somebody had to walk up a little hill to get to the Senior Citizens Club and they've given up coming now, they said "oh it's too much walking up the hill" and, you know, I would like to advise them that they should walk up that hill. Different if they had a heart problem but they don't, it's just overweight and lazy really, they can't be bothered."
>
> *Do you think that laziness is a factor then?*
>
> "I would say that laziness comes into it, yes that comes into it, there's a lot of people who just can't be bothered to exercise and they think it's going to hurt them, but it's not going to hurt them." (17: 305-317)

Those who fail to negotiate the 'hazard' of ill health, therefore, are to be 'blamed' for being in that position, as Les observes:

> Well they've only got themselves to blame ... I mean, if someone's got asthma or something like that, it cant be helped because that's out of their control, but I'm talking about general health where people just let themselves go. I think they've got nobody to blame but themselves ... that's my opinion. Its like these claims that people are making because they've got damage through smoking – nobody made them smoke – they did it off their own back. (7: 244-249)

This moral stance in the face of chronic illness is nothing that we are not already aware of in sociology. I highlight the notion within this study both because it is such a strong theme, which should not be overlooked, but also because of the way that it is used, in an almost confrontational manner, as an influence over the actions of these cardiac patients. As such, it appears to be employed as a motivational tool in the rehabilitation project. Maintaining moral authority and disassociating oneself from blame has been a significant theme that has run through the accounts of both types of biographical work. A comparison between the two ways that it is negotiated in the biographical work of both types is interesting. For the 'biographical adjusters', it was important to construct an image of moral approbation if the detachment both from blame (in developing heart disease in the first place) and individual responsibility (for failing to accept the recommended lifestyle changes) is to be achieved. The onus of detachment is not relevant to the 'biographical architects', however, because they are doing the right thing, they are taking responsibility for their own rehabilitation and they are taking control of their future health by engaging in an exercise programme. So why, then, is it not just enough to accept that they are doing the morally correct thing? Why is it important to emphasise that others do not take such good care of themselves and, further, why does this take such a vitriolic form in some cases?

It would appear that there is a sense of frustration that rises to the surface in the accounts of some of these respondents. When Puran, a sixty-four year old Asian man who experienced both a heart attack and bypass surgery talks of the difficulties that he has overcome in his rehabilitation, he is clearly bothered by the fact that others are not so willing to put themselves out:

> *So, you have done really well in your recovery, but why do you think it is that some people don't manage to recover as well?*
>
> Like I say before – bloody lazy, that's what they are, that's it. If they knew what I had to go through! You have to say, "Alright, I'm going to bloody fight it!" Even my doctor - she looked after me very well - she said to my brother "that's the kind of man that you need to be if you are going to get over this sort of thing - never seen a man so strong as him" he say ... you have to fight! My brother say, "he walk here" - "he what!" my brother say "he walk here - he wont let anybody help him". If you give in, you will die - I won't give in. But they do, they give in.

> *When you say, "give in" do you mean that they don't change the way that they live?*
>
> You have to change though, you have to! Do they think I wanted to have to do all this? Exercise for me… well, bloody hell, I've had to learn how to do it all again. It's hard work, hard work, you know. They know! They know it's hard work, that's why they won't do it! But I have to do it, so why don't they? Don't feel sorry for them – I don't. It's their fault! Fight it! (5: 422-439)

Puran took on the fight and is not afraid to let everyone know about it. His opinion of those who will not act in a similar way is typically judgemental, but more than this, he uses his own experience of how he has had to put himself out and of how hard it has been for him. Although it is not apparent from this passage that it has been used as motivation, Les is more specific:

> *Do you think that it has been easier for you to stick with the rehab, because of the fact that you have always been active, than it is for others?*
>
> Well in a way, probably yes, but I'm sure that I would have done it anyway. It's about the type of person that you are and I would do it whatever. I mean, I see these other people – never put themselves out for anyone, let alone themselves, you know. I often think to myself – in fact I said to the wife the other day actually – if I were ever to be like that, shoot me! You know because, well, it hasn't been easy for me – when I was young fine, I was always running round back then, but I have to push myself now. But that helps me, in a way.
>
> *How do you mean?*
>
> Seeing those lazy so-and-sos. It helps me to carry on, because no way do I want to end up like that. I don't want anyone thinking that I can't be bothered to put myself out. I've never been like that and I'm not going to start now, no matter how ill I am. (7: 323-347)

The moral component of health goes hand in hand with the concept of individual responsibility for maintaining health and in recovering from illness. As such, it is a structural social force that exerts its influence over us in many ways. However, I would argue that these patients are not simply falling in line with society's idea of how illness should be met, e.g. in a stoic manner that preserves the moral authority of an individual. This social structure is used, to varying levels, in a creative manner in motivating the cardiac patient to maintain the recommended health behaviour change of physical activity.

## 5.5 CONCLUSION

One of the aims of this study is to explore the concept of agency and structure in relation to the lifestyle choices of cardiac patients. Williams (2003) has highlighted the fact that, although the concept of social structure is "one of the building blocks of the social sciences", it appears to lack "any precise technical definition within general sociological theory" (p. 131). From this perspective, then, social structure can encompass both the tangible, such as material disadvantage, as well as the ideological, such as that of individualism. Whereas Williams was concerned with the social structures that reproduce health inequalities, my own study relates to the cultural influence of a society that perpetuates the notion of individual responsibility for health. My working definition of structure, then, is related more to the 'cultural constructs' of, for example healthism, rather than the more traditional ones of social class and poverty. I will return to this presently, but first of all, I will tackle Williams' concerns, as it is the type of problem that needs to be addressed in a study of this nature.

In his paper, published in the Silver Anniversary Issue of *The Sociology of Health and Illness* (2003), Gareth Williams investigates the social structures of inequalities in health, such as poverty and unemployment, and the harsh living conditions that accompany them. Through some very powerful narratives of people who have lived in these conditions, Williams argues that the "risk factor epidemiology tends to assume a freedom to make healthy choices that is out of line with what many people experience as real possibilities in their everyday lives" (2003, p.147). The epidemiological risks to health – smoking, diet, alcohol, lack of exercise – "were part of social conditions that they could do little to change". As Williams continues, "one of the routes through which material disadvantage affects behaviour and health is through people's ability to construct a sense of identity and purpose under very difficult social and economical conditions". Considering that I have reported the way that the biographical architects of this chapter are able to engage with these epidemiological risk factors as part of the rehabilitation project, which in turn has an influence upon identity, it should follow that I give consideration to this concern.

My initial response was to check the files of my respondents so that I could assess, at least at some superficial level, the socio-economic status of these cardiac patients. As Williams had emphasised the need to contextualise risk within the "wider material and environmental conditions in which the risks are embedded" (2003, p.147), so maybe the respondents of this chapter were more well off, better educated and, therefore, better able to make healthy choices in their lifestyles? Maybe those from the previous chapter were less well off, and so, really had little practical choice in the matter? To compare the groups, I used 'Leisure Card' usage as an indicator of socio-economic status. This is a card issued to those residents of Southampton who are either unemployed or on low incomes. Leisure Card usage was slightly higher among the 'biographical adjusters', compared to the 'biographical architects', but there was only a difference of one person. The fact that around three quarters of all of my respondents were using Leisure Card, suggested that lower socio-economic status was well represented. I then explored the types of jobs that these respondents were either doing, or had done previously (many were retired), but there were no obvious differences. I then compared the areas (council wards) that they lived in, and compared this against the 'Index of Multiple Deprivation' information, which was made available to me by the City Council. Again, there were no obvious differences.

I went back to my data and re-read the transcripts of the biographical architects in their entirety, looking for references related to social class, a key concept in understanding the relationship between social structure and health (Williams, 2003). I found nothing, but maybe the reason for this is that this was not something that I had, in my interview schedule, been intending explicitly to investigate. Neither did it develop throughout the data collection process and, considering the iterative nature of grounded theory, it would have had the chance to do so. Clearly, if one asks questions directly related to social class and health inequalities, which, after all, were what the studies cited by Williams, had done, then the data will bear some relationship to that. This will be discussed more fully in the final chapter. The guiding structural influence that developed through the narratives of these cardiac patients was related to individual responsibility and the moral responsibility that accompanies it.

Regarding social class, however, it will be useful to highlight the way that Edward has forged an identity as an exerciser within his local community. Edward makes reference to his deprived neighbourhood and the pride that local people feel for him:

> I am the marathon man, that's who I am ... where I live, and I live in a deprived part of Thornhill, been there for forty-five years and people around there have never had a marathon man. (17: 115-117)
>
> I know we've been singled out as a community – given money to make things better, and all that – but nobody is as bad as they try to make out you know. Older people are scared to go out in the evenings and there is a lot of vandalism and the like, but underneath, they are mostly good people. They think the world of me there, they really do. (17: 460-463)

At the risk of sounding contradictory to Williams's observation that people are affected by their material disadvantage in their ability to construct a sense of identity under difficult social and economic conditions (which they undoubtedly are), Edward demonstrates that behaviour change can be achieved. Edward lives in an area of Southampton that is rated among the lowest in the country, according to the Index of Multiple Deprivation. As such, it has attracted millions of pounds of Government money under the New Deal for Communities initiative, and there is a great deal of regeneration work under way in the area. Many of my respondents, representing both types of biographical work, live in this area. As a consequence, all that I can say, with any confidence, is that social class does not *appear* to be a significant issue in my study. However, this is not to deny the relationship between low socio-economic status and poor health. There are probably many variables to be explored in gaining a full understanding of this, but to do so would fall outside of the remit of this study. Rather, I will continue to be informed by my data in exploring the social processes of the 'healthist' society that we live in today.

I have mentioned that my data suggest a dynamic relationship between social structure and human action, in as much as an individual is influenced *by*, but also has an influence *over*, guiding social structures. Given that the social structure to have emerged from my study is that of the 'healthist' overemphasis of 'individual responsibility for health', we appear to be living in a society that judges us by how well we look after ourselves (at least the respondents of this study are of that opinion). Efforts at disassociation from blame, which might be attributed to our state of health, are at the fore in almost all of the accounts given in this study. It is, therefore, clearly apparent that the ideology of individualism is a powerful social structure that exerts a persuasive influence over the behaviour of these cardiac patients. However, it might reasonably be expected that the cardiac patients who make the recommended lifestyle changes following their heart attack would be sensitive to this. It might be assumed that they would demonstrate an understanding nature toward those who may feel that they are being viewed as, what Goffman would call, a 'sad tale'. Rather, what they actually do is give strength to the healthist pressures that their fellow cardiac patients are subject to, by vilifying them and their inertia toward exercise participation. This has some resonance with Giddens's concept of 'structuration theory'.

Structuration theory is often linked to what Giddens calls the 'duality of structure', which "means that social structures are both constituted by human agency and yet at the same time are the very medium of this constitution" (1976, p.121). As Craib (1992, p.112) observes "He [Giddens] argues that sociology usually sees structure as a constraining or determining feature of social life, but in fact it is also enabling". Craib continues, "Structures are, as it were, 'enveloped' in action: they exist only in and through action, which produces, reproduces and changes them" (1992, p. 112). I would argue that the biographical architects not only use structure to inform their work, but reinforce this structure as a consequence of their work.

However, they do not act blindly in their biographical work, following the schemes of behaviour set out for them in the panoptic way that one might assume, and as discussed earlier. I would argue that these cardiac patients demonstrate choice and agency in the way that they work biographically at their rehabilitation project. For example, rather than working from the health education provided at Phase III rehabilitation, they go beyond this in gaining a quantitative understanding of the best method in 'beating' heart disease and 'rubbing out" the risk of further complications. They bring into question the advice provided by the medical profession, if it does not fit with their own biography, and this is an important fact. To understand the response to illness it is, as Turner (2001, p.5) suggests, important "to locate the patient in a social and personal environment". This brings me on to the ways that patients respond to the disruption caused to the roles that are a component of their identity. Before this though, my concluding observation, made through my data, is that although social class can have an undeniable effect on the behavioural choices of cardiac patients, and upon individuals in general, the agency of the social actor is a potent influence. It can help to account for the marked variations that can be identified *between* individuals, including between individuals in apparently similar structural situations.

# CHAPTER 6: IDENTITY: ROLES DISRUPTED AND REGAINED

## 6.1 INTRODUCTION

In this chapter, I use the concept of 'role' as an analytical tool in understanding the biographical work of cardiac patients who adhere to a physically active lifestyle. To reiterate something that I have discussed previously, the working definition of identity that I use for this study is that a person is made up of the roles that are performed in living one's daily life. While some are more valued than others, people will always relate to us in the ways that we perform these roles, and this will be explored in more detail. Before I continue to give expression to my data and develop the discussion of biographical work of the cardiac patients who actively engage with the lifestyle advice offered by health professionals, it will be useful to explore a sociological understanding of role and, therefore, the part that it plays in this study.

In sociology, the notion that a person's identity is strongly influenced by the roles that are bound up within that identity is nothing new. As far back as 1968, David Mechanic described role theory as "a major conceptual tool in medical sociology" (p.76) that not only influenced individual identity but also acts as a link between "social structure, social process and social character" (p.76). Similar to Goffman's notion of identity being a bundle of roles, Mechanic describes "role bundles" and "bundles of behaviour [that] are learned by people as they assume new social positions and … are reciprocally related to other roles and thus these links serve as the backbone of social organisation" (1968, p.77). However, it was supposed that role theory had a deterministic influence over the individual and assumed that people acted as "social robots" (Mechanic, 1968, p.77) that were destined to play out the role as it had been developed by society. Goffman (1961), however, brought human agency into the concept with his notions of role embracement, role distance and role sets, all of which will be discussed more fully in the following chapter. Goffman developed the idea that different people occupying the same roles were able to act and react differently according to the situations in which the roles were acted out. He also proposed that roles could be tailored to these situations, by borrowing material from other roles that are bound up within our identity.

The notion of biographical disruption is central to this study and I will argue that there exists a strong association between the disruption of a person's biography and the disruption of roles that are bound up within a person's identity. Bury (1982) states that "there is the disruption of taken-for-granted assumptions and behaviours" at the outset of illness development, leading to a re-examination of "the expectations and plans that individuals hold for the future" (p.169). I will argue that fundamental to these future plans are the expectations that a person holds for the development of roles, both old and new. As we grow older, we may expect to gain a new role of, for example, grandparent and we have certain expectations of how that role should be performed. Similarly, the role of parent has some very definite characteristics that give it value – it is a supportive undertaking and one that thrives on the dependence of the child. To feel un-needed as a mother or father can be a devastating development in the parent role. Further, to be viewed by others as a bad parent can be taken as an insult to one's identity as a whole.

The respondents of Bury's study were arthritis patients and he uses an example of one woman who thought that she had chipped the bone of her finger, whereas she had actually developed the condition in her hands. The disruption of not being able to use her hands in the way that she was always able to had implications for the way that she lived her life. In turn, the roles that she performed on a daily basis were disrupted. The role of wife for many elderly women, will have central to it the tasks of washing cooking, shopping, etc, which all rely on the ability to use one's hands to good effect. To lose the ability to perform these tasks is to disrupt the anticipated trajectory of the role. The research of Charmaz (1983) suggests that it is also to experience a loss of self.

Charmaz found that leading a restricted life, and the associated loss of control over the life course, typically resulted in a loss of self. Again, this notion has an inextricable association with the concept of role disruption. As Charmaz observes:

> These chronically ill persons become aware that they cannot do the things they valued and enjoyed in the past, or if they are fortunate enough to be able to participate on some level, that level is apt to be much diminished from that of the past. (1983, p.172).

These things that were "valued and enjoyed in the past", it later transpires, are all associated with the roles that most people will perform on a daily basis, those of mother, sister and friend. I will argue, then, that biographical disruption and loss of self, two notions that have dominated the medical sociology literature for the last two decades, are inherently associated with role disruption. To disrupt ones biography is to disrupt the roles that are central to that biography. To experience loss of self is to experience a loss of value that a role holds for the individual.

This is an important point to make at the beginning of this chapter, because I will be using a definition of 'identity' that is understood as an amalgamation of the roles that an individual performs. Researchers in the social sciences have used definitions of identity and self in many ways, often failing to agree on even the most basic characteristics of the terms (Leary and Tangney, 2003). In this chapter's introduction, then, I have not attempted to align myself with anyone else's definition, but simply to make clear my own.

So how do the biographical adjusters fit in with this understanding of identity and role disruption? Charmaz (1983) highlights the way that the chronically ill respond to illness, and while a consideration of this is important to a general sociological understanding of illness, it actually becomes a vital understanding of my own study. She describes the way that "maintaining a 'normal' life or returning to one becomes the symbol of a valued self. Under these conditions, chronically ill persons not only view dependency as negative, but also often blame themselves for it" (p. 169). I have shown previously that the type of biographical work that some cardiac patients engage in allows for a process of redefinition and reinterpretation of certain symbols. Through a practice of reworking previous understandings, this biographical work provides a socially legitimate basis for their reluctance to engage in the health behaviour of exercise participation. They have returned to a 'normal' life and have established a level of continuity congruent with their expectations of how their lives should develop and be lived out. This can be understood through a symbolic interactionist perspective, which understands the self as being fundamentally social in nature. As such, the self is developed and maintained through social relations. Charmaz uses symbolic interactionism as a theoretical framework to "examine how illness as an experience shapes situations in which the person learns new definitions of self and often relinquishes old ones" (p.170). Similarly, I am exploring the illness experience of heart disease as a precursor to the development of new definitions of roles. Those from the previous chapter were able to reinterpret certain symbols within their biographies and, as such, were able to adjust to the new definitions that were held for these roles. In other words, they were able to adapt to the new form that the role took for them. This passage from Richard's interview illustrates the point:

> *So, you are in your 80's and you feel healthy, what would you say the secret is?*
>
> Family life, as I said before you've got to have your family around you and you all have to get on, don't fall out over silly things, because life's too short. When you get to my age you have a lot of experience and I see people falling out for no reason and it's such a waste. Your family is the most important thing in life. I actually feel quite bad about the fact that ... well, I can't do as much for them as I'd like really. I'd like to help them out a lot more, but I just can't get to them. They live so far away now. It's usually always the case of them visiting me, and they always want to make sure that I'm OK – fussing around me. I should be looking after them though really, shouldn't I? I feel quite bad about it, quite guilty. And it's not that I <u>couldn't</u> help them either. I'm capable enough in that respect because, as I say, I'm always doing things for people, the neighbours and that. But I can't <u>get to them</u> (points). They're

> up in the midlands and I won't drive that far. Anyway, they like to feel like they're helping the old man, you know (laughs). (4: 179-193).

Clearly, Richard values his family as being the most important thing in his life. It is also apparent that he is dissatisfied with the new definition of the role that parent and grandfather now hold for him. However, rather than make any attempt to regain the roles in their former status, he accepts that these roles must now be performed in a different way. From looking at this short passage of his interview, it could be argued that it is difficult for an eighty-one year-old man to get to the midlands and rather than choosing to accept the new definition, it has actually been forced upon him. However, Richard attended his interview at the leisure centre with his grandson, who sat in on the interview, and prior to switching on the tape recorder we had been talking about his family. He said that he only had an hour to spare as he was taking his grandson back up to Coventry that afternoon on the train. He also said that he visits them regularly by train, which is why, when the passage that I have used above came up, I wondered what he meant. I chose not to pursue the matter, because to do so might have looked as if I was contradicting his message, but I made a note of it in my field notes. So my interpretation of this is that, yes, he is fundamentally dissatisfied with the new definition of his parent and grandparent roles, but his biographical work allows the capacity for adjustment to these new roles. He appears to have taken a much more passive role and partly justifies this by saying that his family enjoy helping him. As we shall see, the cardiac patients of the present chapter make strenuous efforts to resist this acceptance and hold very judgemental attitudes toward ill people who are happy to sit back and let others do things for them.

As the ‘biographical adjusters’ provide a convincing account of the way that a disruptive health threat can be normalised, the question to be answered in this chapter is, why don’t all cardiac patients engage in the same type of biographical work, discussed previously? As those from the present chapter were not, on the whole, ‘exercisers’ previous to their cardiac event, it might reasonably be assumed that they would ‘take the line of least resistance’ and also engage in this re-interpretative biographical work.

The answers to this lie in the way that roles have been disrupted for them and in the value that they place on the new definition that these roles now hold. I will discuss the way that these cardiac patients are unable to adapt to the disrupted roles in a similar way to the ‘biographical adjusters’, primarily because they place a different value upon the main aspects of the roles. They anticipate their role-trajectories in different ways. Whereas the ‘biographical adjusters’ were able to say, ‘I should have expected this at my age’, the ‘biographical architects’ were not able, or not prepared, to do this, for various reasons that will be discussed. They hold, what Charmaz refers to as “a heightened self-concern about the person they see themselves becoming and about valued self-images from the past which they have lost” (1983, p.190). This concern is the impetus for change. Charmaz (1987) has accepted that loss of self is not necessarily a permanent feature and illustrates ways that people can move beyond this stage in creating new ‘reconstituted identities’. She also emphasizes that those whose condition improves “were more likely to see their earlier suffering as a path to knowledge and self-discovery” (1983, p.191), ultimately coming out the other end of illness as a better person. This is a concept that is also apparent among my respondents and is something that I will discuss more fully. As they 'recover' from their heart disease, many reflect on their previous identity and conclude that they have actually become a better person for their experience.

## 6.2 ROLE DISRUPTION

I will begin this section by discussing the story of Louise, who at the age of thirty-three is by far the youngest of the respondents in this study. Her story reflects very well the notion of role-disruption brought about by her experience of her heart attack. Louise had suffered a heart attack the previous year in 2000, just two months after giving birth to her baby daughter. Her situation is particularly unusual because not only was she too young to be traditionally associated as someone who would be likely to have a heart attack, but she was also an aerobics instructor. As such, she was probably the last person that anyone would associate with having a heart attack and this, in itself, was particularly problematic for her. Here she talks about her early phase of recovery:

> *Was it a big disruption at the time?*
> I suppose it was, more so for my partner than for me, because of having Lilly I had time off work anyway and I was on maternity leave ... although he was on maternity leave as well, it meant that he had to do everything. Had to tend to Lilly constantly, to come to hospital – I mean for me, I was just in hospital and that was that, and when I got out of hospital I suppose that was the hardest bit. My mum and my sister coming around, doing all my housework – which is nice but I do like to be independent, and I lost that. I wasn't allowed to do anything like go out for a walk or anything, and I had a new baby and I just thought that I just want to go and show her off and do this that and the other (11: 305-314).

Clearly, Louise had anticipated the role of mother in a very different way to the one that was provided for her following her heart attack. She depended on her husband to look after the baby and on her mum and sister to look after the house. Whereas she had anticipated taking her baby out and showing her off to friends and family, as would be expected of a young mother, she was unable to do any of this. Louise's response to this was to get back to the physically active lifestyle that she had always led:

> I was quite naughty with the things that I did, but I thought that my body could take it so … I thought, well when they write these booklets they write them for people who are probably fifty plus, you know and they are unhealthy, whereas I regard myself as being not that bad. So I thought that I could just push it a bit, so I suppose after about four weeks I was back to doing what I did before, although obviously taking things a little bit slower (11: 318-323).

This helped her family to see that she wasn't as helpless as they possibly thought she was and that she was capable of doing things for herself. One might expect that this would happen in time anyway, given the young age of Louise, but she was keen that this should happen sooner rather than later and so got back into exercise following the birth of her daughter quicker than she might have done if she had not had the heart attack. For Louise, the disruption to the mother and wife roles was just one aspect of her feelings of lost identity. This was compounded by the way that her friends treated her:

> A lot of people shun you actually … I know that one of my friends hasn't been in contact with me at all. I haven't heard from her in over a year, which is the whole time that I've been ill. So I haven't heard from her at all.
>
> *Are you sure that she knows that you've had a heart attack?*

> Well her other half knows because he's been doing some work on our house ... so I just think it's not worth it because if you don't have your friends around when you need them most, what's the point. Then sometimes I think, don't let it bother you (11: 401-414).

It may well be that people reacted to her in this way because of the age that she was when she had her heart attack. However, for Louise, this simply makes the disruption that much greater. Although she tries to put on a brave face by suggesting that she isn't bothered about losing her friend, this isn't an isolated incident and is clearly affecting her more deeply than she lets on. While pursuing the issue of a disrupted identity during the interview, I ask Louise if she feels that people see her differently since the heart attack:

> I suppose a lot of people wouldn't say really – either too frightened or just don't know what to say. Perhaps they don't want to upset you, because that's another thing I've noticed, when I'd had the heart attack, I wasn't in touch with a lot of people – I was at home most of the time – so ... and I had a phone call from my netball coach. This was a few weeks after and she didn't know that anything had happened and she was thinking that I must have had my baby by now let's see if she wants to come to the Christmas 'do'. So I was speaking to her I could tell that she hadn't heard and I was thinking 'do you know what's happened', but she didn't and then when I'd explained to her and she was like, oh god, you know. A couple of days later I had this massive bouquet from the netball team, but then I go on the Christmas 'do' and it's like nobody wants to talk to me. I had thought, 'oh this is something to talk about', and I didn't see it as a sympathy thing, but yes this is something to talk about, but nobody wanted to talk to me. It was weird, and I just thought that perhaps they no longer see me as being healthy and fit and ... must be getting old and decrepit, sort of thing (11: 421-436).

This reaction by her friends appears to have been a common reaction to Louise following her heart attack and proved to be a big disruption to the way that she thought of herself at this time. The role of 'friend' that she had played in a very specific way was disrupted and the only way that it could be regained was to try to get back to normal as soon as possible and this meant getting back into her exercise habit.

Goffman's notion of identity supposes that each of us is a 'bundle of roles', and each individual role, as I have suggested, contributes to one's biography. To experience disruption to a valued role, is to disrupt one's identity, and is to create a severe disruption to one's biography. I have discussed, in the introduction, the way that Richard was able to adjust to the new definition of the grandad role – even though he was not entirely happy with it, he accepted that it had to be performed in a different manner. However, the 'biographical architects' would typically resist this acceptance and would work toward regaining it in its former status. This is demonstrated particularly well in the narrative of Jim, a seventy-five year-old man who had a heart attack in 1989, when aged 62, and experienced bypass surgery the following year. In this passage, he describes the way that, even though his own attempts at maintaining the role of grandad were actually successful and were accepted by his grandchildren, the reality was that it was a role that he was unable to 'pull off':

> I think people can be, I mean it's over a year ago since my operation, and they treated me rather carefully, but if I give you one example of the attitudes - I've a crowd of grandchildren who live on the Wirral, the oldest being 19 at the time, four of them, three girls and one boy. The lad is a very tall lad and I have a very good relationship with them all, and at Easter, a couple of months after my operation their parents had said go easy on grandad, you know, he's had a nasty operation, kind of thing. We went out to Hythe for the afternoon, this was the day after they came down here and I was behaving as I normally did, which sort of changed the attitude of the girls from thinking "oh we've got to look after the old boy" to "well he's near enough back to normal". I know this because, not what they said but because, my granddaughter who was about 17 at the time, she's a good runner so she's quite light, but we came in and I sat down to watch the telly and she came in the door and without so

> much as a word, she decided to sit on my knee. I just put my arm around her and she leant back on my arm, but I knew that I wasn't going to take any strain because of the operation, so I let her go back and she went down with a bang. So what I'm saying is that they had relaxed and were treating me as they normally would, but ... (18: 218-234).

Jim tried to "behave as I normally did" with the grandchildren, in his attempts to perform the role of grandad, but everyone soon realised that, from their perspective, the role would need to be performed in a very different way. However, Jim was not simply going to accept the new definition of this role and so, for him, exercise rehabilitation was important in regaining the functional ability that was required for this. When Jim's grandchild fell off his lap because he was too weak to hold her when she leaned back, he actually *couldn't* hold her weight. It wasn't a case of misunderstandings in perceptions of functional ability – he simply wasn't strong enough. Exercise accelerated his functional recovery and allowed him a speedy return to the role, and the status that the role held that was valuable to him. From this understanding, it is little wonder that Jim should hold exercise rehabilitation in such high esteem.

When Bury (1982) talks of the uncertain trajectory of a disrupted biography, I would argue that he is referring more to the roles that are lost completely to the individual's identity. One role that underpins the identity of a person is that of mother, the nature of which is a helping and supportive one. To lose this responsibility is to lose more than the role itself, but also the ways that others regard you. This is demonstrated in the account of Win, a 67 year-old woman who had a heart attack in 1999:

> Well I suffered. Not really physically, but I had a hard time of things ... I felt like I was letting people down. I mean, don't get me wrong, my husband and children were great, they wanted me to take things easy all the time, but that's not my way, you see. And they wouldn't let me do anything, so I ended up going mad. I felt like an invalid ... I'd gone from being a healthy, fit and active person to someone who couldn't be trusted to make the beds.
>
> *So do you feel that your identity changed then?*
>
> I was a completely different person after the heart attack and it's silly because ... I think it's the shock to others really - the rest of the family, you know - they just thought, "well mum's had a heart attack, so we've got to look after her now", but I didn't want that. For three months, I just felt useless. (24: 51-66)

In one fell swoop Win had lost the roles of mother and wife, the two roles that had a huge influence on her identity as a whole. Just prior to this, in Win's interview, she had been talking about how her mother had taught her to behave stoically in the face of illness. However, this was an illness that she was unable to be stoic about because her family would not let her. This situation did not change for Win until she began her exercise rehabilitation programme and her family were able to see for themselves exactly what her physical capabilities were, as she continues:

> *What happened after three months?*
>
> Well, I started the rehab' over at Oaklands and that made me realise that I could do things, because up until then, I was believing them - what they were all saying.
>
> *What do you mean, your family?*
>
> Yes, because they were saying that I couldn't keep going up and down the stairs all day, and that sort of thing. When I started exercising I realised that I could do all of these things. And the important thing was that my husband used to come over to the rehab' with me, so he saw the exercise that I was doing. That's when things changed for me really - that's when things got back to normal for me. I mean, perhaps they would have anyway after a time, you know, these things wear off after a while don't they, but the exercise brought it forward for me.

> *So once you'd finished the rehab', what happened then?*
>
> Well I was a bit worried at that point, because I really wanted to keep going with it. I mentioned this to the rehab' nurse and she told me about the work that you do - that it's a carry on from the rehab, so I asked her to sort it out for me and she did. I've been exercising here ever since and it's not often that I miss, you know. (24: 68-91).

It was not until her husband saw for himself that her level of competence in carrying out physical tasks was much higher than he had initially understood it to be, that "things got back to normal for me". Exercise, for Win, provided a way of regaining a valued role and everything that goes with it, particularly the fact that she no longer needed to be "wrapped in cotton wool". From this point of view, exercise proved to be something of a saviour to Win and, as such, informed the way that she went about her biographical work.

Phase III cardiac rehabilitation programmes actively encourage husbands and wives to attend sessions. As a cardiac nurse from Southampton General Hospital explained to me, it is hoped that the health education message will be reinforced by providing information to a couple rather than the patient alone. Also, the partner will be aware of the intricacies involved in leading a healthy life and can, therefore, "keep an eye on them for us". It, therefore, appears to be about policing, constantly reinforcing messages, and ensuring that patients do not "fall off the wagon". She also pointed out to me that social support has been found to be an important factor in exercise adherence: "all the research supports it", she rightly reminds me. However, what I am finding in this study, demonstrated by the accounts discussed above, is that by encouraging partners to attend rehabilitation sessions provides the cardiac patient with the opportunity to demonstrate that they are capable of 'doing'. They do not need to be wrapped in cotton wool and kept away from activities, such has housework and gardening, which have defined the roles that they play out every day. They can, once again, allow others to be dependent upon them in the way that they had always anticipated things to be. Moreover, exercise provided improvements in strength and functional ability, which allowed for improved performance of roles, and Jim provided a good example of this earlier.

## 6.3 IDENTITY DISRUPTION

There are many examples of 'role-disruption' experiences in the narratives of my respondents and they demonstrate the fragile nature of the cardiac patient's identity. What is less common, although not unique, is the, apparently, total break in one's identity. James, a 67 year-old who experienced a heart attack in 1979, went through a particularly significant loss of self-identity during the early part of his rehabilitation. Here he provides a graphic illustration of how he was affected:

> I think it just is a shock, that's it really. It's just like a cut, like that (chopping action with hand) or, do you know these things … I think they're called ha-ha's … but they divide fields in the same way as a fence, but it's a ditch. They're ditches in between fields, but to look across you wouldn't know they were there, so on the outside you wouldn't know that they were there, on the outside things look exactly the same. A heart attack is not unlike that, it's like a ditch is there between you and your past, and that's something that I can never get back to, that's done, that's past. It's like a cut in your self, your self-awareness.
>
> *So would you say it was a case of two separate identities for you?*
>
> I would say it's like that, yes the before and after, and it took me a long time to get used to the after, and it's taking me a long time to get used to the old age as well. That's a very similar thing, one minute you are young and you

> can do things, then all of a sudden things change for you. One has to accept that though. (20: 287-312).

James's identity was irrevocably damaged by his heart attack and he was conscious not only that his previous identity had been lost, but that it could never be regained. Exercise helped James to construct a new identity for himself, but this did not happen overnight: "It did take a while to get used to my new identity, yes it did". For James, exercise took on a new dimension, which he did not fully understand:

> That was the thing, yes ... the bicycle after the heart attack was so important to me, but I would cycle – I could be anywhere really – but I would be cycling and I would re-live parts of my life. I've never discussed this before, but I remember it well, suddenly I would be back at school and I'd be re-living the whole thing, like going through to another world, which was past me. It was very curious and it only happened when I was cycling. (20: 307-316)

The fragile state of James's existence is apparent in this extract. It is interesting that the practice of exercise, the thing that might prevent another heart attack, induced a "re-living" of past experiences, as if exercise had acted as a saviour to him. His identity was then built up around, not just cycling, but exercise in general, as he later continued to exercise in a leisure centre gym. In simple terms, James's biographical work involved, what Bury would refer to as "the mobilisation of resources, in facing an altered situation" (Bury, 1982, p. 170), the resource being exercise participation.

It would appear that, for James, it wasn't the case of losing certain roles that provided the disruption (although this may have been the case also), but actually losing his *identity* and he actually uses this terminology himself. An intelligent man (he had been a University Dean before he retired) he was able to articulate his feelings very well, and his main feeling was of a lost identity. He felt that he had become a different person and this must be something that is extremely difficult to negotiate. A new identity was developed as he relied increasingly on exercise to "see me through". Building an identity around exercise is common among 'biographical architects', none more so than in the case of Edward, a 77 year-old who experienced a heart attack and found an identity as "marathon man":

> I mean one day four little boys came up to me, about six years old they were, and one of them said to me "Mr marathon man", that's what they called me "are you running the marathon this year?" and another boy said "who's he, is he a king or something!" well he showed me a lot of respect he did, he said "would you be quiet" he said "I'm talking to the marathon man". As true as I'm sitting here, I've got children waving to me ... there's a young girl, when she's delivering her papers – I don't even know her name – when she sees me "hello marathon man". I am the marathon man, that's who I am ... where I live, and I live in a deprived part of Thornhill, been there for forty-five years and people around there have never had a marathon man (17: 144-157).

For someone who had never exercised before, gaining a title such as "marathon man" must have signalled a significant shift in Edward's identity. This can be explored by using Goffman's notion of dramaturgy, as Edward had taken on a 'role' that was previously alien to him. Goffman (1961, p.85) suggests that the "individual's role enactment occurs largely through a cycle of face-to-face social situations with *role others*, that is, relevant audiences" (italics in original). Throughout Edward's interview, examples of face-to-face interaction with others in his closely-knit community, served to reinforce his identity as someone who exercises. Edward recounted various 'scenes' (similar to the one above) word-for-word that demonstrated the ways that 'relevant audiences' reinforced a "marathon man" identity. As his audience grew in both size and enthusiasm, Edward adopted an almost missionary zeal, always keen to spread the word, to 'convert' people to exercise.

> I'll be quite honest, I like people to talk to me about their problems and you'd be surprised how many people come and tell me their problems, and I just listen to them. I don't know why they do it, but I want them to do it and I'm able to explain to them about my training and my running (17: 399-403).

This type of role enactment will be covered in greater detail in the next chapter, but I felt it important to introduce the concept here, because it is such an important part of the biographical work that adherent cardiac patients engage in. The research literature in the field of disability studies, particularly that which looks at the lived experience of disability, has been revealing with regard to the way that disabled people can sometimes view disability in a positive light. I mentioned in the introduction the way that Charmaz emphasizes that those whose condition improves "were more likely to see their earlier suffering as a path to knowledge and self-discovery" (1983, p.191), ultimately coming out the other end of illness as a better person. Edward provides a perfect example of this, and articulates the notion very well:

> *So you've almost become a completely different person then really?*
>
> "Oh absolutely, and my son actually said to me [if the heart attack hadn't happened] I would never have done the things that I'm doing now, he said I would still be sat on my bum watching television and, with mum being a good cook, I'd have got fat. But like he said, life has changed for me, so it's almost as if some good has come out of it" (17: 224-229)

Some good coming from a potentially disastrous situation mirrors one of the conclusions in Johnson's (1991) research into adjustment following a heart attack. Johnson found that some of her respondents were actually "grateful" to the heart attack, because it had forced them to make changes in their lives that transformed their identity to more positive ones. I feel that this was certainly the case for Edward whose 'biographical disruption' was severe and he had to engage in the type of biographical work that would provide him with, not only a morally acceptable identity, but also a sense of purpose to his life. Jim, who had successfully regained his role of grandad, concisely sums up the way that he has improved from exercise, when asked if he feels that he is now back to normal: "No, I'm better than that to be honest, I'm better than before..."

So, in respect to disrupted roles, what are my respondents telling me? They are saying that the heart attack was a disruptive event that brought into question their ability to perform valued roles and disrupted the trajectory that they had anticipated for their performance of these roles. However, this disruption had to be accepted in a way that 'biographical adjusters' were unable to do. From this acceptance of a phase of life coming to an end, biographical work can begin to reclaim these roles and, therefore, re-establish continuity.

## 6.4 CONCLUSION

I have said previously that all of the cardiac patients in this study experience biographical disruption to varying degrees and that the difference between those who engage in lifestyle change and those who do not is demonstrated in the type of biographical work that they engage in. I have also said that those who do not engage in lifestyle change experience their biographical disruption as more of a full stop than an exclamation mark in their life story. I would like to develop that notion a little further, to suggest that the biographical work that is undertaken actually *transforms* the biographical disruption *into* a full stop, something that was not actually as bad as it was initially interpreted and, actually, "should have been expected at my age" anyway. Similarly, 'biographical architects' interpreted the disruption of their biography very much as an exclamation mark and, in some cases, the end of a chapter from which new beginnings can be made. Valued roles are lost and they cannot be regained any other way than to initiate behaviour change, particularly exercise, which brings with it indications of physical capability, control and good health.

Although the two types of biographical work are very different, I will argue that the ultimate objective is a common one. That objective is continuity in the 'core', or substantive, self. I have shown previously that the continuity work of those who choose not to engage in an exercise programme involves a reordering and redefining certain experiences in a "process of reframing" (Becker, 1997, p.176). From this endeavour, continuity is achieved through a process that involves the establishment of minimum disruption. For the 'biographical architects', however, maximum disruption needs to be established before lost roles can be regained and the trajectory of life can be realigned. Through very different processes, both types of biographical work are able to put lives back on track. Win's account of her exercise classes at Phase III rehabilitation and the way that it provided the opportunity to demonstrate her physical ability to her husband was the point where "things really changed for me really – that's when things got back to normal for me". The paradox was, that things needed to change before they could get back to normal. Getting back to normal is the ultimate goal of continuity. Similarly, Jim got back to normal once he had regained his role of grandad:

> *So you don't feel at risk from heart disease then?*
>
> Oh no, no I do what I like, throw the grandchildren up in the air and all the rest of it.
>
> *You just get on with leading a normal life then?*
>
> That's what I'm concentrating on doing, yes just getting on with it like normal. Like I was before. (18: 64-72)

Through a process of change, involving an altered lifestyle in response to the disruption of a cardiac event, the biographical architects were able to achieve continuity in their lives. They were able to get back to normal through their engagement in an exercise programme, something that was, after all, quite alien to them. Reflexively, the experience of heart disease was reinterpreted as a disruptive event that necessitated new beginnings, which is something of a paradox, in as much as things need to change in order to, ultimately, stay the same.

I have, then, shown how the roles that are integral to a person's biography can be either adjusted and adapted to, or reconstructed in the biographical work of cardiac patients. I will now examine the ways that the new role of 'exerciser' is performed by the biographical architects, and the ways that the biographical adjusters are able to rationalise not making such performances. I will also examine the influence of the exercise environment upon these performances.

# CHAPTER 7: SELF-PRESENTATIONAL CONCERNS

## 7.1 INTRODUCTION

Goffman used metaphors from the stage to describe the ways that people give ‘performances’, create ‘scripts’ and move through ‘scenes’ that comprise their lives. Referred to as a dramaturgical approach, it is aligned with the symbolic interactionist school of Mead, which argues that we are able, as active and creative individuals, to manipulate social situations by the selection of appropriate roles. Goffman states that the role is the basic unit of socialization, and expands upon this by suggesting that the individual usually performs more than one role, depending upon the audience and the setting. As discussed previously, the notion of ‘role’ is central to this study’s investigation of the ways that cardiac patients engage in an exercise rehabilitation programme. It is, therefore, appropriate to examine the ways that cardiac patients are able to perform the role of ‘exerciser’, as well as the factors that inhibit performance.

In Goffman’s terms, we can either embrace a role or keep our distance from it and this is best understood by using Goffman’s own example. In his book on *Encounters* (1961a), Goffman uses the example of the ‘role’ of the merry-go-round rider to demonstrate the way that the small child embraces the role:

> The rider throws himself into the role in a serious way, playing at it with verve and an admitted engagement of all his faculties. Passing his parents at each turn, the rider carefully lets go of one of his hands and grimly waves a smile or a kiss ... here, then, doing is being, and what was designated as a “playing at” is stamped with serious realization (p. 106).

However, as the child grows older, certain irreverence is attached to the role. Older children appear to stamp their own character upon the role by demonstrating the ease of the challenge. For example, older children will be seen standing on the saddle, taking hands away from the pole or holding on with one hand and leaning back, looking at the sky. The adult has another approach, often acting "completely stiff, affectless and preoccupied" (p. 110) when riding with his or her child.

From this example, we can distinguish the youngster who *embraces* the role, from the older child and adult, who maintain *role-distance*. Role-embracement versus role-distance provides an interesting framework in which to examine cardiac patients who negotiate the role of 'exerciser'.

When a cardiac patient takes part in an exercise rehabilitation programme, he or she takes on a role – that of an exerciser – and, as a consequence, is required to give a performance. In Phase III rehabilitation, cardiac patients are able to carry off this role because it is seen as being part of their treatment, so their main role remains that of a cardiac patient. In effect then, they are 'exercising cardiac patients', rather than 'exercisers' *per se*. They can perform the exercise because there are no undue expectations of them from the audience, which is made up of fellow patients and rehabilitation professionals. However, in Phase IV their exercise participation moves to a different setting, that of the fitness suite, and is played out in front of a different audience. The new audience is made up of individuals who the cardiac patients might view as 'real' exercisers – people who have *embraced* the role, who wear *role-*

*appropriate clothing*, and in front of whom, the cardiac patients will feel less confident in their ability to carry-off the role successfully.

As discussed previously, both Charmaz (1983) and Bury (1982) suggest that the apparent demise of positive self- identity is not an inevitably permanent feature of biographical disruption. In a later paper, Charmaz (1987) discusses the ways that the chronically ill are able to create new 'reconstituted identities' as they "participated actively in creating their lives and, moreover, *themselves*" (p.318 emphasis in original). Similarly, Bury describes the way people respond to biographical disruption through a process involving "the mobilization of resources" (1982, p.170) in adjusting to their new identity.

Charmaz has employed symbolic interactionism as a framework within which to examine the meaning of chronic illness and it could be argued that the findings of the other authors, particularly Cowie (1976) and Wiles (1998), share a similar perspective. Symbolic interactionism posits that by viewing ourselves from the standpoint of others, we come to see ourselves as others do (Blumer, 1962), because the self is essentially social in nature. Symbolic interactionism, then, could be seen as the explaining factor in the studies of Cowie and of Wiles. Blumer suggested that people do not react to others' actions without first interpreting and defining those actions. Further, the fact that the individual has a 'self' means that s/he can make himself the object of her/his own actions, or act toward her/himself in the same way as he acts towards others. Charmaz describes, through a symbolic interactionist perspective, the way that those with chronic illness are able to bring previous social experiences to their reconstructed definition of self.

> "The ill individual draws upon past social experiences, cultural meanings and knowledge to engage in a mental dialogue about the meanings of present physical and social existence, specifically, the emergent indications of identity elicited by illness." (Charmaz, 1983, p.170.)

Charmaz's respondents were able to create their 'reconstituted identities' through this process. Erving Goffman, a student of Blumer (who is credited with coining the term 'symbolic interactionism') at the University of Chicago, is noted for his books and essays that proposed a dramaturgical view of the world. In The *Presentation of Self in Everyday Life* (1959), Goffman outlined his sociological perspective of social life:

> "I shall consider the way in which the individual in ordinary work situations presents himself and his activity to others, the ways in which he guides and controls the impression they form of him, and the kinds of things he may and may not do while sustaining his performance before them" (p.9).

Goffman found that there were few social situations where people could disregard the self-presentational implications of their behaviour. He has also stated that the 'role' is the basic unit of the self and that individuals perform more than one role depending on circumstances, situations and audiences. In reconstituting an identity disrupted by chronic illness, a valuable role to be adopted – one that is medically endorsed and congruent with general perceptions of health and self-control (Blaxter, 1990) - is that of the exerciser. The self-presentational concerns of cardiac patients toward exercise formed one of the main themes of my research.

## 7.2 EMBRACING THE EXERCISER ROLE

An examination of the ways that people present themselves to others necessarily demands that the interactions are observed. While much can be gained from listening to what people say about the ways that they feel others view them, and the ways that they want to be viewed, a complete picture cannot be provided through interviews alone. The ethnographic nature of the study allowed me to make the most of my work that, during the period of data collection, involved me spending lengthy exercise sessions instructing cardiac patients in a fitness suite. Themes that were beginning to emerge from my interview data could be explored and further developed by observing and talking to patients in the exercise environment. Obviously, this means that the data that were collected by this method related more closely to the adherent exercisers, or the biographical architects, than the non-adherents. One aspect that lends itself well to observational study, is the ways that cardiac patients engage in their exercise sessions, or in other words, how they perform the role of exerciser.

Goffman (1968) has suggested that effective body management is essential to the smooth flow of encounters and to the acceptance of a person as a full member of the interaction order. I would suggest that managing one's body is particularly important in a fitness suite not least because of the perceptions that people hold of such places. As Shilling (2003, p.66) points out, "here, the body assumes the status of a resource, which can be managed in a number of ways in order to construct a particular version of the self". To the new exerciser, particularly one who has never been into a fitness facility before and who has no previous experience of sport or exercise, such places are often viewed with trepidation. Many times in the course of my work, I have been told that actually coming to the Leisure Centre has been the hardest thing, regarding their health, that many people have done. Plucking up the courage to come through the doors has been seen as being harder than undertaking the exercise itself and, from my evaluations of the scheme, is one of the main reasons given for not attending initial appointments. They feel that they might be let down by their bodies in an arena where bodily control is perceived as being under the microscope.

Those who are able to embrace the role of exerciser appear to be successful in managing their bodily appearance in the exercise setting. The following extract from my field notes, taken while exercising in a Gym that is not a part of the Active Options Scheme, but operates in a neighbouring town for the same purpose, demonstrates that to embrace the role of exerciser is to have a certain level of confidence in one's own ability to perform in the exercise arena:

> One of these adherent exercisers sat on the cycle next to me and immediately struck up a conversation with me. Following a few brief one-liners, the gentleman (who I have called Colin) proceeded to impress upon me his present level of fitness, the conversation going along the lines of (but not exactly):
>
> *Colin:* *What level are you on there then? (Intensity level of the cycle)*
>
> *Me:* *Level 5, I think, but I tend to go more by how hard it feels rather than what number the counter is on.*
>
> *Colin:* *Yes I know what you mean, but I need something to measure myself against. Wasn't so long ago that I could only do level 1 – arthritis in my knees – but when I was your age ... I could do level 5 and some more (laughs).*
>
> *Me:* *Fit then, were you?*

> *Colin:* *Well, I was fit, yes, but I loved cycling, that's what I mean. I used to cycle everywhere.*
>
> *Me:* *Are you a GP referral, same as the others?*
>
> *Colin:* *Used to be, yes. Got a lot of arthritis – well, I was sent here because of the blood pressure after cardiac rehab, but that's all right now.*
>
> *Conversation came to an end as an elderly looking lady got on to the adjacent cycle and my new friend seemed to be more intent on impressing her than he was on impressing me. I overheard him tell her "don't worry darling, you'll soon be fit" – strange thing to say! On a more serious note though, this man was probably trying to lend some support to someone who was clearly new to exercise, but I wondered if this was negative or positive – I would have taken many of his comments as patronising, but I'm not an elderly lady trying to learn a new activity in an intimidating environment.*

Obviously Colin was a confident and outgoing person generally and it would be quite wrong to put his confidence down simply to exercise. However, his self-assured attitude toward exercise struck me at the time as being unusual for someone who had been referred for exercise by his GP. From speaking to the scheme co-ordinator at the end of the session, I found out that he had been exercising there for more than a year and that he had been much more quiet when he first started attending, which is quite typical of newly referred exercisers. He had, then, been able to embrace the role of exerciser in the period of around one year, *becoming* an exerciser who can interact on level terms with other exercisers (such as me) and provide advice and support (as he saw it) to the less confident exercisers.

On a subsequent visit to the fitness suite I explained to Colin that I was undertaking a study of cardiac patients and the way that they respond to exercise, and I asked him if he would mind being involved in a short interview with me. The whole thing was very informal, taking place in the cafeteria following the exercise session, and although I didn't tape record it, I made detailed notes during the interview. His comments were such that he certainly viewed himself as an exerciser who "had to learn how to do things properly because I didn't like the way that the others in the gym thought of me – like I was a special case or something". He even felt that, because he had actually experienced the heart attack himself and then learned as much as he could about how to lead a healthy lifestyle, he was in a better position than the fitness instructors to help the newly referred patients – something that I would certainly not argue with. From my own experience as a fitness instructor, I have found that this type of empathy is certainly well received by newly referred cardiac patients.

The way that he managed to 'carry' himself in the fitness suite reflected very well the way that he *self-classified* himself. Goffman's work on stigma (1968) suggests that we self-classify by perceiving ourselves as if looking into a mirror, which offers a reflection framed in terms of society's views and perceptions. Colin felt, rightly or wrongly, that a 'spoiled' identity was the image that others (certainly other exercisers) held of him, so his body management needed to be such that others would view him more positively.

What struck me from the interview with Colin, also, was that the defined role that he performed as an exerciser did not appear to extend beyond the physical boundaries of the fitness suite. Although, as with other embracers of the exerciser identity, he was pleased with the positive image that exercise provided for him following a cardiac event, he was concerned mainly with his image within the exercise environment. This appears in direct contradiction to Edward's identity as "marathon man" which is performed before the wider local community, with the defining difference being in the type of exercise being performed. For Edward, running around the streets provided the opportunity to be seen by others, thereby reinforcing the role and his identity, whereas Colin did not value this type of exercise in the same way. This paralleled a minor theme that I had found in my interview research, which has been articulated by Les, a seventy-three year old heart bypass patient:

> "I think it's great [the exercise rehabilitation], I mean only talking from my point of view because after I had that operation, what would I have done? All I could have done was walked, but now I can get on machines and things and they are great. I mean, you get on that rowing machine and you are working your chest and all, whereas the walking is just the legs really, you know."
>
> *Do you prefer using the machines to walking out in the open?*
>
> "I do because it's a different feeling from walking; I think you feel much better for it – better than you would from just walking." (7:255-266).

Les has embraced the role of exerciser but he has also embraced the *type* of exercise that is performed in the fitness suite, placing a much higher value upon it compared to "just walking", a term that Jane, an eighty year old cardiac patient uses. David, a fifty five year old patient who was a keen martial artist in his youth, echoes this:

> "For me ... I need to be somewhere using an apparatus of some kind to feel fit - or to be with an opponent, and I don't mean that in an adversive way, but a competitor if you like."
>
> *So you say that you were doing physical activity, your walking, but by coming into a gym and using a machine, that was different somehow?*

> "I think using a machine gives it … exercise value, if you like. The walking itself - although I've realised that it's good for me - it doesn't give me the mental … presence, of exercising - I mean, I have exercised today, in as much as I've been for a walk this morning - but I don't feel as if I've *exercised*." (6: 359-369).

Exercise value is something that is very important in the role of exerciser and the exercise *mode* is integral to the exerciser image, and this echoes something that was discussed previously in the rehabilitation project. In her ethnographic analysis of gym culture, Roberta Sassatelli (1999) describes the gym as being "a place which has its own rules and where a vast array of meanings and identities are negotiated" (p. 228). Drawing on Goffman's notion of the interaction order, Sassatelli's portrayal of the gym is of a place where participants carefully manage their behaviour and interactions and where certain rules must be observed. This 'cultural competence' is not something that a newcomer to the gym will immediately be aware of but is something that will be developed, as it has been with Colin, over a period of time.

Returning to the observation component of my research, one of the main differences between the *embracer* of the exerciser role compared to that of the exerciser who maintains role-distance, is the acceptance of role-appropriate clothing. Sassatelli explores this concept by examining the actions and interactions that occur in the changing rooms of the gym:

> "To change from everyday costumes for a purpose-made, gym specific outfit is, for example, not simply a material requirement of training. It is also a fundamental symbol of having entered the gym, of tuning in, of being in the right spirit to work out, recognizing the specificity of the work on the body that is to be done" (1999, p. 231).

One of Sassatelli's respondents, a middle-aged male surgeon, described the way that casting off his everyday clothes allows him to escape the external world, providing an alternative identity that fits well with the exercise session to follow. Similarly, a female middle-aged clerk felt that getting changed in preparation for exercise allowed her to get into the right frame of mind and "enter the spirit of the gym" (p. 231). Sassatelli concludes that the changing room allows the individual to switch to the exercise realm, to its rules and meanings, far from the external definitions with which the individual entered. So it is then, that the exerciser role is produced and defined, in part, by the clothes that the role demands and this is no less relevant to the cardiac patients of this study. The newly referred cardiac patient does not very often come to their initial visits to the fitness suite dressed in clothing typical of an experienced gym user, such as track-suit bottoms, 'proper' training shoes, etc. This is because his or her most recent experience of exercise participation would have been at the Phase III sessions, where patients are generally dressed in casual, comfortable, but 'normal' clothing. Typically, trousers and soft outdoor shoes are the order of the day. Those who progress to embracement of the exerciser role will, over time, adopt the clothing that reflects their 'cultural competence'.

So the fitness suite, being a 'world in itself' (Sassatelli, 1999) demands a very specific application to the role of exerciser, which is a major shift from the most recent role of my cardiac respondents – that of patient. To move from being a patient, with the associated, possibly negative, connotations that this carries, to being an exerciser, with the associated positive image that this portrays, is a significant change in identity and one that some cardiac patients are unwilling to accept.

## 7.3 ROLE DISTANCE

Many cardiac patients are able to maintain long-term adherence to an exercise programme, and perform that exercise within a fitness suite environment, while at the same time being keen *not* to be viewed as an exerciser. This, again, can be understood through the 'dramaturgical' approach of Goffman. Harre (1993) explored the ontology of dramaturgy, suggesting that the most important distinction to be understood is that between the actor and the actor's 'parts'. Whereas the theatre actor has an identity that is distinct from the part that he or she is playing (i.e. once they have finished performing, they come off stage and revert to their 'own' identity), the real life actor finds the ontological relationship reversed. People *are* the parts they play and Harre suggests that to detach oneself from this part "may induce a stultifying self-consciousness, inhibiting convincing performance" (p. 171). He continues by discussing the distinctions between personal and social identities, which allows for the detachment of the actor from the part. Harre suggests that this detachment allows for the possibility of control over the role.

From the earlier example from Goffman, of the youngster who *embraces* the role, compared to the older child and adult, who maintains *role-distance* - detachment from the role allows for control over it. Similarly, the cardiac patient who maintains detachment from the role of exerciser is able to maintain control over both self and public identity. The two ways that these cardiac patients appear to control their image, and therefore maintain distance from the role are, firstly, to avoid looking like the typical exerciser and, secondly, which I will come to, to hold a cynical opinion about exercisers.

The scornful comments from the cardiac patients, although not evident in the transcribed interviews, were intended to leave no doubt as to their true feelings about those who appear to be "living it" as Arthur (interviewee number 21) put it. The following passage is from my field notes, which were noted immediately following the conversation, but which obviously cannot be verbatim:

> "They think of nothing else, these people, they eat it, drink it and sleep it – exercise is all they live for and for what, to look like that?" At this point he nods toward two very slim women dressed in tight gym wear, "If I had a wife like that I'd get a good meal inside of her!"

It is worth pointing out (which possibly demonstrates either the strength of feeling or the importance of being seen to be holding the views that he has) that these comments were made, quite firmly, in the fitness suite and no more than five or six metres from the women that he was talking about. This type of comment, although not always bordering on the insulting like this one did, was nonetheless very common. Another cardiac patient who had been exercising for around eight months made a point of explaining to me: "I'm not one of that lot you know", referring to the 'exercisers' in the fitness suite. He then pointed out to me, as he thought that I was a new instructor, that he had been referred to the Leisure Centre by his doctor and that he was "here for the rehab exercises". It is very important to such respondents that this differentiation between general exercise and 'rehab' exercise is clearly made. Another man made a point of explaining to me that exercise had been “the best medicine for me, honestly it has”. This ‘medical model’ type of attitude toward exercise appears to be an extension of the perceptions that are formulated at the Phase III rehabilitation programme. Robert’s account of his experiences with Phase III is typical:

> “I think it [exercise] still protects you from that sort of thing. I mean the heart’s a muscle and muscles need work, so the more exercise you do the stronger it becomes … it’s a very good group that they have up there, and the information that they give you is very good indeed - diet is important and stress is another one. The information they give up there is very good … the treatment as well, you know.” (13: 131-135).

The lifestyle advice provided at Phase III is viewed as being medical advice, because cardiac rehabilitation nurses have imparted it, which translates it into treatment, as Robert has pointed out.

A further aspect of the ways that cardiac patients express cynical opinions in maintaining role-distance is directed toward the exercise itself, rather than other exercisers. A chance comment from a lady who has been attending the fitness suite for around three years provides a typical example when asked, quite simply, how are you” “I’ll be better in fifty minutes” (referring to how long it will take to complete her exercise session). To emphasise how common this type of remark is, I have included some comments from my field notes that are related to this theme:

> “I wish I were you!” (Comment made by a man entering the fitness suite to another who was leaving).
>
> “Why do we put ourselves through this torture!” (Comment from one man talking to another on stationary cycles).

> "Right, that's me done then – I'm off now!" (Comment from a man who entered the fitness suite, made a mocking effort to touch his toes, before turning toward the door).

It is interesting that these comments were not made by new exercisers, but by people who had been attending their exercise sessions regularly for more than a year. Their need to express the fact that they do not enjoy the exercise experience, for the exercise itself, had become no less significant over time. This suggests that these cardiac patients do not begin their exercise 'lifestyle' in a defensive way before embracing the role as they become increasingly confident with their ability to perform the role of the exerciser. Rather, they continue their whole physically active lifestyle by disassociating from any portrayal of enjoyment of the exercise experience.

Goffman (1961) has suggested that many of the actions that we take are done so with a view to defending ourselves from the opinions of others who may be better placed, either socially or otherwise, to judge us. Goffman describes some "general facts about role distance" (p. 111) by recounting his own observations of a group of girls who were clearly novice horse riders, who had decided to "do" horse riding on one of the mornings of their holiday.

> The six I observed came in clothing patently not designed as a consolidation of the horsewoman role: pedal pushers, cotton leotards, ballet-type flats, frilly blouses. One girl, having been allotted the tallest horse, made a mock scene of declining to get on because of the height, demanding to be allowed to go home. Another girl leaned over the neck of her horse and shouted racing cries, again while the horse was locked in a walking file of other horses. (p. 111)
>
> In the presence of age-peers elegantly attired for riding and skilled at it, the girls I observed might falter in displaying role distance, feeling hostile, resentful, and unconfident. Whatever their showing, they avoid having to be

> humbled before those who are socially placed to make a much better showing. (p. 112)

From my discussion so far, the parallels from this passage are clear. While the cardiac patients of this study do not engage in the type of overacting that Goffman observed, they do employ actions, such as expressions of cynicism, which disassociate them from the more cultured endeavors of the 'experts'. These actions leave them in control of the situation, because they appear to have made it clear that they have no serious claim to the role. The above passage also brings me on to the second characteristic that has emerged from my observational studies, which is the rejection of role-appropriate clothing.

One aspect of role embracement that Goffman (1961) provides us with is the concept of role appropriate clothing. Individuals who take on a role as part of their identity are more likely to accept role appropriate clothing, whereas those who are distanced from the role may be more likely to wear deviations from expected role attire. The expected attire of the exerciser is well accepted, indeed a whole industry has been developed around the type of leisure wear worn by exercisers – even non-exercisers wear the clothes of the exerciser, appearing to adopt the 'role', but without the participation.

My observational work would suggest that, while many adherent exercisers (i.e. those who embrace the role) are keen to wear the clothing traditionally associated with the role, equally there are those who attend exercise regularly in their 'normal' clothes. Some elderly gentlemen even prefer to exercise in a shirt and tie, which would be their usual dress, because they feel more comfortable this way. This suggests that, although the role appears to have been accepted, in as much as the person is an adherent exerciser, some distance must be maintained in order to preserve the identity that they have developed.

A typical illustration of this non-acceptance of role appropriate clothing can be seen from the example of a man who had bought himself some new clothes in which to exercise. This followed a conversation with myself the previous week when I pointed out to him that the shoes that he was wearing were quite heavy and cumbersome and that the low back pains that he had been experiencing following some exercise sessions might partly have been because of this. I explained to him that he need not spend a great deal of money on brand name training shoes, but he would need a new pair if he were to continue exercising safely. When I commented on the fact that he had a new pair of soft outdoor shoes on he replied: "Well you've got to look the part haven't you!" with tongue firmly in cheek. Clearly, he was making the point that, actually, you *don't* have to look the part and he has no intention of doing so. Obviously there are practical considerations for his choice of shoes, not least the fact that the pair that he bought can also be worn in his everyday life outside of the fitness suite. It does, however, contrast sharply to those who embrace the role of exerciser and who would never wear a pair of everyday shoes into the fitness suite. My observations suggest that cardiac patients from similar social groupings choose quite different ways of engaging in exercise and this extends to the choice of clothing that they wear.

## 7.4 SELF-PRESENTATION OF BIOGRAPHICAL ADJUSTERS

The self-presentational concerns of the cardiac patients described so far have been related to participation in exercise, either through embracement of the role of exerciser or by maintaining role-distance from the identity. By participating in exercise they are able to portray themselves as being in control of their health and rehabilitation, a pre-requisite of legitimate access to the sick role. However, it would appear that for some cardiac patients, being seen as a fit and healthy person is an unwelcome impression that has been imposed upon them by others. This can lead to potential demands that are out of keeping with the way that some cardiac patients perceive themselves, as with the case of Steven who is frustrated at not being acknowledged by 'the system' as being a person with a disability, which is how he sees himself:

> Trouble is, in the system you're not allowed to do that, the system wants … really the system's saying 'we can help you, and we want to help you, but you've got to be sat in your room dying'. Sit in that chair and don't move. I can go out and cut my hedge, but then be so tired that I have to sit down for two weeks to get over it, but that doesn't matter because all people see is me cutting my hedge – so I'm OK. That's one of the things that need shaking up. (3: 233-244)

Steven is actually too ill to exercise and is keen to maintain an impression of himself that supports that fact, as demonstrated when asked how he thinks things might change if he were capable of engaging in exercise:

> Well, it would make me happier in myself. If I could do things and didn't have people on my back saying 'you can do this so you can't have that benefit now' and 'we won't give you this money because you can do that'. It's a whole vicious circle, you know you are going to get jumped on so why do it then?

> *Do you think that's a reason not to exercise then?*
>
> Yes, it is. The fitter I am … well the less chance I have of getting help. (3: 212-218)

Although he appears keen to present an image of himself as being unable to perform many tasks, and so is motivated not to exercise in case he is viewed as 'able' and therefore not eligible for benefits, Steven has actually attempted to exercise. This turned out to be a negative experience for him:

> I tried to go swimming at Applemoor (Leisure Centre) late at night with my wife, but if I've sort of had asthma, I'd get in there and I'd do half a length and there's only one way I can go, you know you've got to go length swimming and I'd go half way along and think, you know, I'm a bit tired here. That's when I need to hold on to the side, but I feel like people are watching me, they're thinking 'look at a big bloke like that and he's doing that', so I think 'Oh, I've got to get out of there', so I get out of there because I feel embarrassed. I never felt that way before, but I do feel that way now. (3: 256-263)

Drawing on Goffman, Shilling (2003, p.75) emphasizes the importance of body management in the smooth flow of encounters, "the acting out of roles and, more generally, to a person's acceptance as a full member of the interaction order". This acceptance is integral to ones self-identity, in order that one can think of oneself as socially acceptable. Shilling suggests that this is because "the vocabularies of body idiom used by people to classify others are also used for the purposes of *self-classification*" (2003, p.75, italics in original). This is because, as Goffman suggests, we perceive of our bodies as if looking into a mirror, seeing a reflection of society's views and prejudices. Steven's self-identity has been informed by the way that he perceives that others view him and he possesses, what Goffman has termed, as 'spoiled identity'. Goffman's analysis of stigma (1970) provides specific examples of how the relationship between self-identity and social identity is mediated. When a person displays inconsistencies in their character, or in other words "when they fail to enact their social roles with poise" (Shilling, 2003, p.75) they cause themselves *embarrassment.* Steven's body, which is central to the smooth flow of interaction, has, in his own view, failed him. This is particularly disruptive for Steven, because he also feels that the first impression that others have of him is that he is a "big bloke" who should actually be capable of physical activity. There are various examples of this from Steven's narrative:

> I've always been involved in football teams and that, which I still do but not in the same way. That's because someone will say, 'Oh you're the manager of a football team? You must be fit!', you know. Then someone will say 'Oh, you can run the line and you can go training with them…' but they don't realise that I can do most of it from home, I can phone 'round and let the blokes know where we are playing and that.
>
> *So do you think that other people see you differently since your bypass?*
>
> Well, I can't help people out like I used to before. But people are asking me to do the same things now as before, but I can't do that now. I don't like to say that I can't do it, so I say 'yes OK'. I'm helping a boxing club out now, but it's not physical because I know quite a few people for sponsorship and things like that, so I can talk to people and get that. That's what I try to do for these young kids. (3: 234-252)

This demonstrates a clear frustration with the invisible nature of Steven's disability. To others he looks fit and healthy, he is tall and not particularly overweight and he has tanned skin, which people tend to associate with good health. His own perception of his health is diametrically opposed to this, however, and is something that he can not easily come to terms with.

Leary, Tchividjian and Kraxberger (1994, p.466) suggest that "there are certain people who need and want to exercise but do not do so because of concerns with the impressions they make while exercising" and the account from Steven regarding his efforts at swimming highlights this concern in relation to his public identity. The impression that he made while exercising appeared to be at odds with the impression that he thinks others might hold of him, resulting in embarrassment. Martin, Leary and Rejeski (2000) observe that some people who experience a medical condition can feel that their public images of competence are undermined, leading people to go to great lengths in maintaining impressions of physical competence. They use the example of patients with urinary incompetence to demonstrate the use of impression management tactics, such as organizing daily routines so that they can remain near toilets thus reducing the risk of public 'accidents'. However, others appear to react to the condition by withdrawing from society in an attempt to avoid the self-presentational consequences of embarrassment associated with the condition. Steven has reacted in a similar way by avoiding any situations that might place him in a potentially embarrassing situation, which is understandable according to Martin, Leary and Rejeski (2000, p. 175):

> People who perceive that they are incapable of sustaining a positive social identity ... may pursue an alternative identity as one who is ill, infirm, and in need of others' care. Self-presentations of illness and infirmity allow people to receive attention and support, albeit at the expense of making potentially unfavourable impressions. Although people are generally reluctant to project unfavourable impressions of themselves, they sometimes do so if such impressions will benefit them. In short, illness behaviour may be reinforced by the secondary gains that the person receives (Mechanic, 1968), some of which may be self-presentational.

Often, the "alternative identity" can be one that fits better with the patient's needs and circumstances, as in the case with Susan who, when asked quite directly if the cardiac surgery that she underwent affected her identity, responds:

> Yes, I do think so actually. I'm more reliant on other people now and whereas before I was organising and running things, I can't now so in many ways I am a different person, I cant do as much. It's made a big difference because I've just gone back to being at home now.
>
> *Do you think that other people view you differently?*
>
> They know that I've got my own way - that I don't go to work any more, because I'd wanted to give up work for a long time. I thought well that's it, I don't want no more hassle of work, so I'm not under stress any more, I'm quite relaxed now and I do what I want. I do the gardening and I really enjoy it. So my identity has probably gone back to what it was before I went to work. (2: 112-122)

For Susan, the secondary gain that Martin and colleagues cite from Mechanic is, evidently, a welcome return to her previous identity – an identity that was without the stress brought about by her job. Mechanic (1968, p. 153) has suggested that the "meanings people give to symptoms are the product, in some measure, of their life-situation" and an understanding of Susan's life situation is integral in understanding her response to illness. Susan worked as a civil servant and, as such, was desk bound for most of the time. Her job was a source of great stress to her, as partly evidenced by the way she points out that she has "gone back to being at home now", which means that her identity has probably gone back to what it was before she went to work.

I interviewed Susan in the August of 2001, which was two years after her bypass surgery, at which time she was still too ill to exercise or to return to work. I tried to explore the reasons behind her inability to exercise, but most of the reasons given appeared to relate more to a dissatisfaction with the practice of exercise itself, rather than any lack of ability:

> I just didn't feel well enough. I had done the hospital rehabilitation ... the exercise and everything, but I couldn't carry on afterwards. The hospital exercise was OK because there's a lot of you doing it and your all in the same boat. But it's certainly not something I'd do ... I find exercise boring (laughs) I bought myself a treadmill after I stopped going to the leisure centre, I thought well at least I can do something, but even that I find so boring. I know I need to exercise, but to go for a walk outside ... I don't like doing that either. You need to get someone to do it with you, just to wander around on your own is a bit pointless! (2:34-42)

Without appearing overly judgmental of Susan, it should be highlighted that she had completed the Phase III Cardiac Rehabilitation programme, begun Phase IV Cardiac Rehabilitation at the leisure centre and then bought herself a treadmill so that she could exercise at home, while the image that she presents of herself is one of inability. This fits with her life situation, whereby she has more to gain from being too ill to exercise or return to work.

As mentioned, Martin, Leary and Rejeski (2000) suggest that: "people who perceive that they are incapable of sustaining a positive social identity ... may pursue an alternative identity as one who is ill, infirm, and in need of others' care". For Steven, the maintenance of a positive social identity, one that was in keeping with the way he was perceived by others, was impossible. He was too ill to do the things expected of him, such as run the line at football matches, or engage in exercise in front of, what he perceived as a hostile audience of fellow exercisers, so presenting himself as being ill and infirm was preferable. However, Susan pursued an "ill" identity, not because she was incapable of sustaining a positive social identity, but because her identity was unsatisfactory at the time.

This may seem a harsh judgement, but the ethnographic nature of the study allowed me to take an unexpected opportunity of following up on Susan's story when I happened to bump into her at the leisure centre some eighteen months following our interview, which was three and a half years after her bypass surgery. She had been swimming with her grandchildren and had got out of the pool ahead of them for "a peaceful cup of tea", so I sat with her for twenty minutes while she kept an eye on the children from the cafeteria. I made notes of our conversation which, as she was well aware of my research, Susan had no objection to. I asked if she was more active now that she had had more time to recover from her bypass surgery and I was quite surprised to learn that she had joined a private health club and was exercising regularly with her daughter. A telling comment was: "I should have done it years ago really", which immediately struck me as running contrary to her account at the time of being too ill to exercise, which I pointed out to her. Her response was that she "couldn't get her head around it" at the time, but that her life was more in order recently. Six months ago she had started working part-time at a local corner-shop, which she was enjoying mainly because it had no stress associated with it, unlike her previous job. At the age of fifty-three, she felt that she always knew that she would need to go back to work at some point following her heart attack, but was determined not to return to "the old place". As I was running out of time (one of the children was crying!) I took the direct route of asking if she felt that she was physically capable of continuing with her exercise at the leisure centre, or were there other reasons for dropping out. Her response was that her previous job was the most significant thing in her life at the time – she was in the process of being "disabled out" and couldn't think beyond that. Although she "probably could have carried on", she didn't feel that it was the highest of her priorities at the time, and so it "fell by the wayside". In other words, it did not fit with her biography at that moment in time.

Looking at Susan's comments from a self-presentational perspective, the identity that she wanted to present was one of being too ill to exercise or return to work, and this may have been motivated by the fact that she was awaiting the outcome of an employment hearing that was deciding whether or not she was fit to return to work. This may appear to be a cynical representation of the situation from myself, but Susan in fact supported it. As Martin and colleagues (2000, p.175) have pointed out: "Self-presentations of illness and infirmity allow people to receive attention and support, albeit at the expense of making potentially unfavourable impressions" and this appears to be relevant and appropriate for Susan.

What this shows, more than anything else, is that people's life situations can influence the ways that we employ self-presentational techniques. In Susan's first interview, her reasons for not exercising – apart from being too ill – were:

> I just find exercise very boring in doing exercise for its own sake. If it comes as a part of something else it will be ... do you know what I mean - if you're sort of doing something and exercise happens to be part of it, then that's fine. But to actually go to the gym ... it's just monotonous. I don't know how you can make it not monotonous.

*So the health benefits of exercise weren't enough to motivate you?*

No. (2: 142-147)

This was at a time when, although she was well aware of the benefits of exercise, Susan was not sufficiently motivated to engage in exercise herself, rather, she was more motivated *not* to engage in exercise. Eighteen months later, her life situation had changed and she was now regularly attending a private health club. Presumably, she does not now find "doing exercise for its own sake" to be boring.

In opening this chapter I emphasised that most self-presentational behaviours are not intentionally deceptive and, in spite of the discussion around Susan's self-presentational techniques, I would reiterate this in drawing the chapter to a close. Leary, Tchividjian and Kraxberger, (1994, p.461) suggest that "people tactically control the inferences that others draw of them by selectively presenting sides of themselves that will result in the outcomes they desire" and this appears to apply to both Susan and Steven. Their illness condition, i.e. heart disease, is one that is not visibly apparent to others, as it might be in the case of stroke or Multiple Sclerosis or even arthritis. Invisible symptoms cannot be 'presented' and, because we can only form impressions of others from what we see, cardiac patients can feel frustrated by the discrepancy between self-identity and public identity. As we have seen, this can impact upon their participation in cardiac rehabilitation, underlining the importance of appreciating the patient's life situation in the self-presentational concerns of recovery from heart disease.

## 7.5 CONCLUSION

When the Phase III cardiac rehabilitation nurse refers a patient on to Phase IV, which invariably takes place in a leisure centre, that nurse is assuming that the patient can move seamlessly between two distinct and opposing identities; those of patient and exerciser. The identity of a patient is one of dependence and support, whereas that of an exerciser is closely bound up with connotations of health and control. To 'become' an exerciser, particularly within the microscopic environment of the fitness suite, involves a difficult process of adjustment and confidence building. For some cardiac patients, the only way that they could maintain their exercise rehabilitation within this environment was to disassociate oneself with the exerciser identity, thus remaining a 'patient' in this environment indefinitely.

From the data collected during this study, I have formulated a typology of self-presentation in long-term exercise cardiac rehabilitation. This represents the ways that people 'do' their exercise:

i. The cardiac patient can adhere to exercise by *embracing* the role. They seek endorsement from the audience – the fellow exercisers who are present during the performance. *Role-appropriate clothing* will be accepted and patients will have the confidence to progress from the Phase IV rehab sessions to general public sessions. These are **unqualified biographical architects.**

ii. The cardiac patient can adhere to exercise, but maintain *role distance* from it. Endorsement from family is more valuable than that of the immediate audience and the role of 'patient' is carried over from Phase III, evidenced by a refusal to accept *role-appropriate clothing,* and a strong dependence upon the fitness instructors. These are **qualified biographical architects**.

iii. The role of exerciser can be completely disregarded by the cardiac patient in an effort to maintain previous identity. The exerciser role is not welcomed and the 'sick role' is maintained. Participation in Phase III exercise rehabilitation was viewed as treatment. These are **biographical adjusters**.

I should emphasise at this point that although the reader might assume that I have taken an overly judgemental approach to analysing my data, particularly in relation to those who drop out from exercise programmes because they are a 'problem' for service providers, I have, in fact, tried to be as objective as possible in my analysis and any bias toward those who exercise is something that I have consciously tried to avoid. There are two reasons why my approach is not judgemental: first in the terminology used, with both terms (architects and adjusters) being seen as positive by the researcher, and secondly because both patterns of behaviour are associated with academic 'problems'; that is, *why do some people continue to exercise* is just as much a problem that requires explanation as the question of why some people drop out. Having said this, I am aware that, given my professional background and my own belief in the benefit of exercise, complete impartiality is difficult to achieve.

# CHAPTER 8: DISCUSSION

## 8.1 INTRODUCTION

This study set out to gain an understanding of why so many cardiac rehabilitation patients fail to adhere to a medically endorsed rehabilitation programme. My findings indicate that those cardiac patients who 'drop out' of formal cardiac rehabilitation programmes engage in a complex process of construction and reconstruction, interpretation and reinterpretation of the health-related symbols in their lives. These understandings are formulated in order that they can maintain continuity in their lives. Ultimately, choosing to reject the recommended health behaviour of exercise provided the only way of 'getting back to normal' for these patients. Once I had understood this, the next puzzle became one of explaining why so many cardiac patients *did* adhere to exercise rehabilitation. In effect, my study came half circle. I started by asking why so many cardiac patients fail to adhere to exercise rehabilitation but, once I had gained an understanding of the need to maintain continuity, the next question became, why don't all cardiac patients take this re-interpretative 'line of least resistance'? The interesting finding regarding this question was that, although their biographical work appeared to be diametrically opposed to their more sedentary counterparts, the biographical architects were actually working toward the same end – that of maintaining continuity in their lives. For these patients it was necessary to change in order to remain the same and the key issue here was the significance of the roles that comprise one's identity. Whereas the biographical adjusters were able to accept the new definitions that roles held for them, the biographical architects needed to regain the previous meanings of the roles. The way that these cardiac patients 'lived out' their illness and rehabilitation is interesting. As Turner (2001, p.205) has said: "sickness is something we do rather than simply something we have" and, as I have shown, this can be 'done' in a number of ways.

In the literature review I described Turner's (2001) three levels of analysis that he suggests are required in order to develop a sociological analysis which, I proposed, provided a good starting point in a discussion of the literature related to my own study. My research can be understood through the same three levels and so this chapter is arranged similarly. Turner's first level related to understanding the experience of illness from the perspective of the individual and, in accordance with this, I will discuss the ways that cardiac patients 'do', or 'live', their cardiac rehabilitation. Secondly, Turner was concerned that medical sociology should focus on the social construction of disease categories and, accordingly, I will consider the effect of social structures that inform the ways that patients are able to engage in rehabilitation. Turner's third level of analysis was concerned with the societal organisation of health-care systems and their relationship to the state and the economy. I will, therefore, discuss the implications of my research in terms of the ways that it might inform the way that cardiac rehabilitation is delivered, the way that health education in general is delivered and the benefit that a sociological understanding can offer the traditional research methods into behaviour change. At a time when conditions of chronic illness dominate health care provision, cost-effectiveness is probably the most important issue to be addressed by the government.

However, whereas in the literature review I started from the societal perspective of health policy, then worked backward toward the individual, for this chapter, it will be useful to take things in Turner's original order, starting with the individual's perspective, or the 'lived experience' of cardiac rehabilitation. This will lead me, in a more seamless way, toward recommendations for policy.

In this chapter, acknowledging that a cardiac event represents both a crisis point as well as a reference point in these respondents' lives, I will discuss the sociological implications of the various responses to heart disease as demonstrated in the ways that these patients "do" their cardiac rehabilitation. I will argue that living with heart disease, and therefore the 'doing' of rehabilitation, is a reflexive undertaking that patients are impelled to engage with. I describe the cardiac event as a 'reference point' because the reflexive biographical work that develops must begin from a retrospective interpretation of what the cardiac event came to represent in terms of biographical disruption. Subsequently, the patient must steer a path through the wealth of lifestyle advice that is available at every turn – because information, as Giddens (1991) argues, is a key part of the reflexivity of the late modern age. However, in developing their biographical work, these cardiac patients were required to work within the social context of a culture that gives particular emphasis to individualism. This, I have argued, is the structural influence of 'healthism', which I would describe as the overemphasis of individual responsibility for health and recovery from illness that carries its own moral obligation. I will argue that the social actor, however, is able, through the reflexive interpretation of symbols (things that have symbolic value, such as the severity of the heart attack), to negotiate their way around this structure. Further, they are able to do this while maintaining the integrity of this social structure. It would appear that the industries, both commercial and medical, that produce the abundance of lifestyle advice from which we should choose, have generated an ambiguity in health education. These scientifically endorsed mixed messages actually provide the creative social actor with the material required for both types of biographical work. Those who choose (although I don't really think that it is a choice, more something that patients are impelled toward as a consequence of their biographical position- e.g. the ways that they respond to disrupted roles, discussed in earlier chapters) to engage in exercise rehabilitation are able to this in two main ways. They can embrace the exerciser role or they can maintain role distance, by emphasising the rehabilitative nature of the participation – this is in line with Turner's (2001) observation that we "do" rather than "have" illness, and my own development of this theme, which argues that we also "do" exercise rehabilitation.

## 8.2 INDIVIDUAL LEVEL

A basic premise of my study is the Symbolic Interactionist notion that supposes that the social actor has the agency to create the circumstances within which we can live our lives. As I have shown, cardiac patients are able to engage in a creative form of biographical work that reinterprets symbols in such a way as to fit the biography and, thus, absolve them from the blame of reacting in the 'wrong' way to their rehabilitation. This creates the conditions in which they can live out their cardiac rehabilitation. I will argue that this biographical work is undertaken in a reflexive manner and that it is only through considering one's present biography (what is happening in life), what has happened to lead them to be in that biographical 'place', and where one would prefer to be, do we create the conditions that enable this to happen. Therefore, one of the key points that I would argue is that living with heart disease is a reflexive undertaking.

For Giddens (1991), reflexivity is an inescapable feature of the late modern age. We no longer think and behave as past generations have been able to do and this may be because we are constantly obliged to live our lives in the 'best' way possible. Giddens argues that the 'individual' did not exist in traditional cultures and that individuality was not prized as it is today. Further, not only is it prized, but it is inescapable – the only measures are the degrees of success that are achieved when we undertake the reflexive, project-like formation of self identity. He uses the example of the modern day phenomenon of the therapeutic 'guides to living', which are aimed at helping us to help ourselves, but it extends far beyond this. If we suffer from stress, we can buy a book to help us to manage the condition, if we lose our jobs or go through a divorce, we can learn how to rebuild our lives through the self-management manuals that fill the shelves of bookshops. This is a characteristic feature of the individualist culture in which we live. The field of health and well-being, in particular, is dominated by the self-help culture. Newspapers and magazines are full of advice on how we can "beat the bulge" or "add years to your life", by following their expert advice and television programmes such as *Fat Club* and *Celebrity Fit*

*Club* allow us to share the experiences of others who endeavour to change their image by losing weight. That weight loss is something to be worked at reinforces the notion that to be slim is to be active and healthy, whereas to be overweight is to be lazy (Shilling, 2003). Providing advice for us to lead our lives is a multi-million pound industry, and this is an important point to make. It is important because the people who market these products bring all of their expertise to bear and the message becomes a very powerful one. Ultimately, not only do we have the, rather bland, health advice that is imparted by the medical profession, but we also have the powerful 'marketeers', or the "institutions of surveillance" (Giddens, 1991, p.15), who wrap their advice up in glossy images and soundbites. We are guided powerfully toward the choices that we 'should' make and, quite often, going against this advice is the hardest choice to make. However, making choices of any kind is a reflexive undertaking.

A significant feature of lifestyle advice is that it is always scientifically endorsed. As a consequence, we are able to reject at least one expert endorsed choice, because whatever choice we ultimately make we are able to rationalise why we made it and we are able to give it some authority due to the fact that there are other experts who support it. The fact that experts themselves are disagreeing over the best way to, for example, lose weight, makes it, at the same time, both easier and more difficult to make a decision. It is more difficult to make a decision because there are so many authoritative choices from which to choose, but it is also easier because our final choice will be a 'legitimate' one. In making our everyday choices we must choose between the rival claims of science and scientists. As Giddens (1991, p.3) puts it, "the self ... has to be reflexively made ... [and] this task has to be accomplished amid a puzzling diversity of options and possibilities". In constructing a self-identity following a cardiac event the cardiac patient must steer a path through a similarly "puzzling diversity of options and possibilities".

The guiding principle of the biographical work of all of the cardiac patients in this study is the need to be seen to be 'doing the right thing'. The problem for the medical professional, however, is that there are so many ways of doing the right thing. In the case of exercise, the cardiac patient can create a self-identity, complete with the moral authority required for living with chronic illness, either by becoming an exerciser or by choosing not to exercise. The current health education guideline, which is endorsed by the government, is that health protective benefits of physical activity can be gained from engaging in thirty minutes of physical activity on most days of the week. The message is that physical activity does not have to be strenuous and emphasises that "moderate" levels of activity are sufficient in maintaining good health. Further, this activity does not need to be undertaken in one thirty minute session, rather it can be accumulated throughout the day, so somebody could take a ten minute walk in the morning, another at lunchtime and then another in the evening (or it could be accumulated in five minute sessions, six times each day). Consequently, health promotion specialists are emphasising that activity such as housework can be included in this calculation. I would argue that only the most extremely sedentary of those amongst us would fail to meet these guidelines.

Consequently, not only can people convince others that they are doing enough exercise, they can also convince themselves. When my respondents tell me that they are "always busy", as most of them did, they are able to believe that they are engaging in physical activity that will protect them from another heart attack. When Betty assured me that she was getting plenty of exercise from her dressmaking and sewing, in her own mind this is what she believed - her account stands up to scrutiny. However, health researchers have examined this area and in their report, *Is housework good for health?* (Lawlor et al. 2002) concluded that housework provided no protection from heart disease at all. This report did receive some attention in the media, but this only served to perpetuate the idea that science and scientific information is in constant conflict with itself. In this example, the cardiac patient can either decide to believe the Government endorsed message or the health researchers of Bristol University but, most importantly, there is no 'wrong' answer. Giddens (1991, p.76) argues that, "reflexivity of the self is continuous, as well as all pervasive" and that the individual is constantly forced to "conduct a self-interrogation" when coming to decisions.

So, Giddens's understanding of the reflexive self relates to the requirement to constantly ask questions of oneself: "We are, not what we are, but what we make of ourselves" (Giddens, 1991, p.75) and there is a wealth of information available from which we can find answers to our questions. Similarly, the cardiac patient must ask questions related to the way that they should respond to illness. The way that these cardiac patients 'lived out' their illness and rehabilitation is interesting and Turner's

(2001, p.205) view that "sickness is something we do rather than simply something we have" is relevant here. As I have shown in previous chapters, illness and rehabilitation can be 'done' in a number of ways. The questions that cardiac patients ask of themselves appear to relate to the legitimacy of the ways that they live with their heart disease, and this can be understood by looking at the things that my respondents have said to me, which can be summed up:

Biographical Adjusters

- My heart attack was not particularly severe and not disruptive to my life (I didn't even know I'd had one).
- I am 'rehabilitated' – I've completed my medical rehabilitation (and have the certificate to prove it)
- My heart disease was beyond my control, so I was not to blame.
- My lifestyle prior to my heart attack was not unhealthy.
- I still lead a healthy life – I'm not lazy and I'm always busy.
- I don't feel at risk from heart disease.
- If I am at risk, it is beyond my control.
- When you get old, you expect poor health.
- I am too ill to exercise

Biographical Architects

- My heart attack was a life-changing event.
- I was probably to blame for my heart attack, but I have since altered my lifestyle.

- I am in control of my rehabilitation and my health.
- I am willing to work hard at regaining my identity
- I don't feel at risk from heart disease.
- I have a low moral opinion of those who fail to look after their health.
- I am either an 'exerciser' or an 'exercise rehabilitation patient'.
- I am pleased with the view that others hold of me.

In order to understand the meaning behind what the respondents of this study are saying, it is necessary to consider the timing of their interviews. A prerequisite for inclusion into the study was that cardiac patients should be at least one year post-event. This was necessary because the study was aimed at understanding long-term adherence to cardiac rehabilitation programmes, but what it also did was to allow the cardiac patient time to put things into perspective in a reflective manner. My interpretations of what I have been told by these respondents appear as retrospective conclusions. I am sure that if I had interviewed these people immediately after their cardiac event I would have received a different perspective, but this is the point that I am making – given time, people are able to 'make sense' of their situation. The process of making sense, then, becomes a reflexive project that is defined by the type of biographical work that is undertaken.

I have argued previously that all of the cardiac patients in this study experienced a biographical disruption. In part, this is signified by the fact that they all completed their Phase III Cardiac Rehabilitation programmes – it could reasonably be assumed that they were sufficiently concerned about their health to complete the programme. However, at the end of this phase of recovery, the question: "should I continue with exercise rehabilitation or not?" needed to be answered. It is important to understand the way that biographical disruption is reflexively organised, because this is an important aspect of the way that these respondents are able to create the conditions for their subsequent lifestyle choices. It, therefore, becomes a reference point in their biographical work. Giddens (1991, p. 75) has argued that "[t]he self forms a trajectory of development from the past to the anticipated future. The individual appropriates his past by sifting through it in the light of what is anticipated for an (organised) future" (brackets in original). The cardiac patients of this study have an anticipated trajectory of life and from this flows the biographical work that is designed to create the conditions within which this trajectory can be met. As I have discussed in chapter six the biographical adjusters, who chose not to engage in long-term exercise rehabilitation, needed to reflexively understand their cardiac event as something that was undisruptive. This created the conditions within which they could make their lifestyle choices without being viewed as someone who has failed to negotiate what Harré (1993, p.206) refers to as their "occasion of hazard". In other words, they were able transform it into something that was *not* an occasion of hazard at all. However, the biographical architects have, by virtue of their more positive life choices, been seen to successfully negotiate their occasion of hazard and so can view the cardiac event as the threat to life that it was. This is a very good example of the reflexive nature of the biographical work that was undertaken.

An important question for the cardiac patients, when ‘living out’ their heart disease and cardiac rehabilitation, is how to legitimate both the illness and the individual’s response to illness – their rehabilitation. Viewing sickness as “something we do rather than simply something we have” (Turner, 2001, p.205) – something that we have to respond to, and be seen to be responding to, in the right way – makes impression management all the more important. This links two of my main themes from this study, those of ‘health as virtue’ and ‘self-presentation’. The virtue of being in control of one’s rehabilitation has great symbolic value and it is important to present ourselves in this symbolic way in order to maintain what Becker (1997) would refer to as our ‘moral authority’. However, when it comes to ‘doing’ exercise, this is done in one of two ways – the cardiac patient can embrace the role or maintain role distance from it. For some, it is important in maintaining continuity that they do not alter their identity in too radical a way, which becoming an exerciser and accepting everything associated with that identity (possibly viewing exercisers as obsessive and narcissistic) would impose. Others are able to incorporate the role of exerciser into their self-identity in a way that makes them feel that they are now “better than I was before” – the cardiac event apparently shaking them out of their complacency and compelling them to change their lifestyle. This raises an important consideration for the way that cardiac rehabilitation is delivered, but I will come to this later.

## 8.3 THE SOCIAL LEVEL

The social structure of 'individualism' relates to the way that the health promotion movement, strengthened by Government legislation, encourages a culture of individual responsibility for health. As discussed in Chapter Two, medical surveillance has become an increasingly important aspect of public health. From their metaphorical watchtowers, the guardians of the nation's health oversee, with a panoptic view, the behaviour of individuals. Further, a culture has been created whereby we self-regulate our health - the task of surveillance has been handed to the individual and, similar to the way that Foucault described the 'interiorizing' process, we have become responsible for our own health surveillance. The "health promoting self" (Nettleton and Bunton, 1995) has become the chief weapon in the 'fight' against lifestyle disease. I have shown in this study that the structural influence of individualism is an influential guiding structure in the lives of cardiac patients. However, I have also shown that cardiac patients are able to use this cultural norm to their advantage in their biographical work. Clearly, these two observations do not sit easily alongside each other. On the one hand my data suggest that individualism, as a social structure, guides the behavioural choices of cardiac patients, but on the other, my respondents are able to use this structural influence in biographical work that is characterised by a degree of agency and free will. At the end of Chapter Four, I argued that the identity work of the biographical adjusters allowed them to lead a life that left the structure intact (i.e. the concept of individual responsibility for health), while simultaneously creating the conditions within which they could legitimate their actions, even though they went against medical endorsement. I argued that their resistance to medical power was not overtly confrontational; rather it was subtle and discreet. It was not about being outspoken in the views that challenge the power of medicine, but about being cautious and considerate of medical authority. I argued that this actually strengthens the case of human agency, that a group of people who may have respect for medical authority can still exercise their agency over it. However, in successfully absolving themselves of blame for their heart disease, they are, unwittingly, perpetuating the social structure. For example, by suggesting 'I'm not lazy – my heart attack was not caused by my own moral laxity', the notion that 'lazy people have heart attacks' is strengthened. In Chapter Five, I drew out, from the narratives of biographical architects, the condemning attitudes that they hold toward those who fail to look after their own health. I argued, again, that this strengthened the social structure of 'individualism'. In understanding the reciprocal nature of structure and agency that I have found in the narratives of these cardiac patients, it is useful to draw on Giddens' (1984) 'Structuration Theory'.

Giddens' theory provides a 'middle way' between theories that promote either too much agency and not enough structure or too much structure and not enough agency. As such, it fits well with my data. An extreme structuralist account might suggest that all of these respondents would appear to fall in line in a fatalistic manner, placing their trust entirely in the scientific medical advice. Similarly, an extreme interpretive/action analysis might suggest that all of these respondents would act in a voluntaristic manner, paying little attention to the influences of moral responsibility.

So, the cardiac patients of this study have engaged creatively with biographical symbols and have reflexively exploited the ambiguity that prevails in health education in order that they can engage in the biographical work that best suits their situation. The obvious question, then, is why do some patients become biographical adjusters, while others become biographical architects? I posed this question in Chapter Five and observed that the biographical adjusters were impelled to take the exercise participation route because of the dissatisfaction that they held toward the way that roles had been disrupted. I would develop this by suggesting that exercise participation can act as a resource that can be utilised at times of uncertainty, as I will explain.

The period of data collection for this study was approximately one year. While observations were being undertaken throughout this period, the interviews represent a cross-section of time in the lives of twenty-five cardiac patients. As such I can only bring my interpretations to narratives of people who were in a particular point in their lives, and in their rehabilitation process. Giddens (1991) suggests that lives are in constant flux, changing and adapting as we 'live and learn', as it were. The lives of cardiac patients are also evolving and it would be naïve to imagine that the people that I have written of in this study will remain static for any significant time period. In five years time, will the exercisers still be exercising and will the non-exercisers have taken up exercise? I can, partially, provide an answer to this. Three years have now passed since I undertook my first interview for this study, so I have time to observe the comings and goings of these participants. Some exercisers, who I would have been convinced would not give up their exercise habit, have not attended the leisure centre for more than two years. Others, such as Susan whom I spoke of previously in Chapter Seven, and who I did not think that I would ever see in the leisure centre again, are now regular exercisers. Who would have thought that Arthur, the man who said that non-exercisers use their illness "as a passport to an easy life" would have given up exercise? I use the example of Arthur because some of the people who have stopped attending sessions have done so for very practical reasons (moved out of the area, taken on caring work for a partner, etc), which they had told me of before leaving the scheme. However, I actually bumped into Arthur in town, some time after our interview and, as I had come to know him quite well, I had a joke with him about reasons why I had not seem him for a while. Arthur felt that he had been (and I paraphrase) "kidding myself going to the gym for all these years" and that he had never really felt like "it was me". I had categorised Arthur as a 'Role Distance' exerciser, one who had not embraced the role of exerciser, but who was exercising distinctly for rehabilitation purposes, so this should not have been a complete surprise to me. I asked if he was staying active and his responses were framed in the biographical work of the 'adjusters' – he walks to the snooker hall, and around the tables once a week, he is busy with the grandchildren and he helps his wife do the shopping – which at the time I found fascinating. His interpretations of exercise, of doing the right thing and of what being active actually meant to him had changed and his self-presentational biographical work had changed accordingly. Looking back at Arthur's narrative, it was clear that cardiac rehabilitation had provided him with the opportunity to demonstrate that he was not "useless" and should not be treated with kid gloves. It was used as a resource that had, apparently, served its purpose.

Susan also used exercise participation as a resource, or as material in her biographical work, although she used it in a reverse manner to Arthur. For Susan, an inability to perform physical activity provided a base upon which her self-identity could be constructed and this identity was, necessarily, one of a disabled person. In Chapter Seven I discussed Susan's change in circumstances, which influenced her biographical work. This was influenced by the fact that she was awaiting the outcome of an employment hearing that was deciding whether or not she was fit to return to work and once this had been resolved she engaged in a physically active lifestyle. This may appear to be a cynical representation of the situation from myself, but Susan in fact supported it. She subsequently engaged with exercise participation at a time in her life when she needed to remove herself from the role of disabled person. Susan needed to prove her ability to care for her grandchildren, which was an important role that had been lost to her. She had "never been able to do much with the kids (grandchildren)" immediately following her heart attack, but she had never been happy with the situation. Once her employment hearing had established her inability to return to her previous job, she was able to move on in her life, and that meant regaining the roles that had been lost to her. The constant flux of reflexivity, then, enables cardiac patients to move in and out of the sick role and in and out of the exerciser role, according to the current biographical situation.

Notwithstanding the case of Susan, for all other cardiac respondents of this study the type of biographical work that was engaged in had the ultimate aim of continuity: the biographical adjusters do this by not changing their lifestyles, whereas the biographical architects need to change in order to stay the same. Even Susan came to the understanding that she would need to alter her lifestyle if she were to maintain continuity in her life, with regard to the roles that she valued. Although it appeared that the biographical architects were constructing a new identity for the purpose of a 'necessary change' – either change or have another heart attack – what was actually happening was that they were changing in order to stay the same – to maintain continuity in their lives.

## 8.4 POLICY IMPLICATIONS

### 8.4.1 Cardiac Rehabilitation

Most of the respondents of this study had 'graduated' (a term that rehabilitation nurses use) from the Phase III programme run by Southampton City Primary Care Trusts. However, this phase of rehabilitation is standardised across the country so my observations can be generalised to cardiac rehabilitation in general. I have noted at various points throughout this study that cardiac patients view Phase III Cardiac Rehabilitation, and the exercise component within it, as medical treatment, even though medical professionals do their best to 'de-medicalise' it. There are three main reasons for this. The fact that medical professionals oversee this phase of rehabilitation is the first and most obvious reason. Secondly, cardiac patients are recommended to attend this programme by their own GP, who emphasises the medical reasons for their participation. Thirdly, this phase occurs approximately four to six weeks following their cardiac event, so the patient is very aware of the importance of such medical interventions, as they are still under close medical care. The fact that cardiac respondents of this study view their Phase III participation very much from the medical perspective is the cause of some concern to the rehabilitation professionals who run the programmes. Their aim is to 'de-medicalise' rehabilitation as much as possible so that patients can move more seamlessly into long-term exercise participation – they aim to turn the patients into exercisers early on in the rehabilitation process. If they represent it as a community exercise programme, the thinking goes, patients can become accustomed to exercise in the environments that they will be required to continue their new lifestyle habit. In line with this thinking, Phase III Cardiac Rehabilitation programmes typically operate out of Leisure Centres and Community Schools.

However, I will argue that the de-medicalisation of cardiac rehabilitation is not, for a large percentage of patients, the most effective way of encouraging long-term adherence. In support of this, I refer to the way that the 'role-distance' exercisers "do" their exercise rehabilitation. For them, it was important not to be seen as an 'exerciser' and everything that, in their perception, accompanies it – being skinny, wearing lycra or similar, and generally being "obsessed" with their body shape. To move from 'patient' to 'exerciser' is a difficult transformation of identity – both self and social – which is inherently problematic, so it is no surprise that most patients who drop out of Phase IV rehabilitation programmes do so after only one or two sessions. Those patients who maintain long term exercise rehabilitation are either capable of incorporating the role of exerciser into their own self-identity, or they have been able, in their own minds, to interpret their participation in terms of 'treatment'. However, it could be reasonably assumed that there will be patients who have dropped out because they were unable to make this interpretation for themselves. They felt, in line with what was being recommended, that they had to *become* exercisers and, I would argue, that a more explicitly medical mode of delivery would have assisted in long-term rehabilitation. In effect, it would provide patients with the opportunity to engage in exercise from a 'role distance' position.

The fact that patients view Phase III as treatment is also, though, problematic. This is because most people will think of treatment as having an end point – a time when treatment is complete and the patient has become rehabilitated. The fact that a patient receives a certificate on 'graduation' of their programme reinforces one perception that the patient may have regarding the completion of their treatment. Although they are advised to continue with exercise, this advice can blend in with the abundant lifestyle advice about how we 'should' lead a healthy life. Once rehabilitated, the patient can act toward this medical advice in the same way as they acted toward the general lifestyle advice prior to their heart attack – they can convince themselves that they already do enough 'health-maintenance' exercise. For long-term adherence to rehabilitation to be encouraged it should be impressed upon patients that their 'treatment' is ongoing – they then gain an understanding of the chronicity of their condition in the same way as arthritis or diabetes patients do. My point, made above, regarding the medicalisation of *long-term* rehabilitation will, for some patients, prove the most effective way of addressing adherence, as this will de-emphasise the notion of being successfully and completely 'rehabilitated'.

The aspect of current Phase III provision that works very well is in encouraging husbands and wives to accompany patients to the sessions. However, while the health professional's understanding of this is that the partner will be able to reinforce the lifestyle messages that are delivered during the sessions, for the patient it is about demonstrating that they are physically able to regain the roles that were disrupted immediately following the cardiac event. The cardiac nurse who told me that husbands and wives can "keep an eye on them for us" had her own agenda – a health surveillance one – whereas I have found that patients use this opportunity to demonstrate that they do not need to be wrapped in cotton wool from activities, such has housework, gardening and "throwing the kids up in the air", which have defined the roles that they play out every day. They can, once again, allow others to be dependent upon them in the way that they had always anticipated things to be. This reinforces the notion of exercise as a resource, something that can be used in times of biographical uncertainty.

I would argue that the lived experience of illness, and the associated themes discussed in this study, will need to be given increasing consideration to exercise adherence in GP Referral Schemes, such as the Active Options programme from where these respondents were recruited. It is not the purpose of qualitative research to provide conclusions that can be generalised to wider populations but, I would argue, the issues raised in this study can be transferred to the burgeoning field of 'exercise medicine' currently characterised by GP Referral Schemes. As long-term exercise participation is being acknowledged as vital in the management of a range of illnesses of chronicity, GP Referral Schemes will gain increasing importance in health care provision and the issues discussed in this study will become pertinent. For example, arthritis patients are encouraged to engage in regular moderate exercise programmes in order to maintain strength and flexibility in affected joints and to encourage social interaction and the "feel good factor", but going from 'patient' to 'exerciser', as I have shown, is problematic. However, it must also be considered that the medical profession appears keen to discharge their responsibilities toward treating those with conditions of chronic illness. They are, after all, an increasing burden on their budgets, but they have conditions that cannot be cured. The answer would appear to lie in the medicalisation of exercise programmes such as GP Referral Schemes, from where the respondents of this study were drawn. It would, therefore, be appropriate for distinctions to be drawn, at the Phase III stage, between those who view exercise as ongoing rehabilitation and those who view exercise as a general lifestyle issue. The former would then gain from the structure of a 'medical model' rehabilitation programme, while the latter should be encouraged into mainstream activities as early as possible. The planned delivery of Healthy Living Centres across the country (in which the Government are investing heavily) would be an ideal location for the 'medical model' rehabilitation, while community programmes will be more appropriate for others.

### 8.4.2 Health Promotion

I have discussed the ways that cardiac patients are able reflexively to negotiate a path through the wealth of lifestyle advice that appears to permeate our lives in the late modern age. The ambiguity that comes from scientific claims contradicting other scientific claims has developed a culture of “if you believed everything they tell you, you wouldn’t eat anything”, while simultaneously devaluing the credibility of ‘scientific’ recommendations. This is the biggest problem that medico-scientific health education faces in today’s world, but I would argue that it is something that it does nothing to address. In fact, it appears to perpetuate the problem, as is the case with physical activity messages.

The specific physical activity guideline (thirty minutes of moderate intensity physical activity on most days of the week) derives from North America and was determined by work undertaken by the American College of Sports Medicine and the Centre for Disease Control, and has been taken on by our own government. The rationale was that it was better to send achievable messages, which everyone should be able to manage, rather than unrealistic ones that people will simply say “I can never do that much exercise” and give up before they had even begun. I think that there are two main concerns in using this message. Firstly, the United States is far less active, with higher levels of obesity, than our own population. What is unachievable for most Americans may not be unachievable for most Britons who have a higher baseline level of activity (although, I do accept that this is changing as we become more

'Americanised' – the proliferation of drive-in McDonalds being an example). Therefore, guidelines that suit their population should not simply be transferred to our own. Secondly, a guideline that is so widely open to interpretation does nobody any good. As discussed earlier in this chapter, the message that this activity can be accumulated throughout the day allows people to believe that they are sufficiently physically active to benefit their health. Research from this country (Lawlor et al. 2002) disputes this message, stating that physical activity of the type gained from housework has no health protective benefit at all. Research undertaken in the early 1990s (Allied Dunbar, 1994), which health professionals still refer to today, endorse this by reporting that although seventy percent of the population are physically inactive, eighty per cent of the population actually think that they lead an active life. The challenge, then, lies in convincing people that they are actually not sufficiently physically active. The ambiguous nature of the current recommendations merely reinforces people's erroneous understandings. Tougher messages will, in the long run, be more beneficial from a public health perspective. Although the philosophy of public health is that small changes among many can have a greater population-level impact compared to great changes among a few, the current message cannot even address the former of these with any effectiveness.

However, although people need to understand the real meaning of exercise, it has to be accepted that, realistically, this is not unproblematic. This study has demonstrated that we, as active and creative social agents, are able to bring our own definitions to health messages so it would be reasonable to assume that even the more direct and basic message is liable to be redefined and given new interpretation in order to fit individual biographies. Nevertheless, a clear and consistent message would go some way toward minimising the available information from which to draw.

In the first chapter I reported the milestones that were set out in the National Service Framework for Coronary Heart Disease (Department of Health, 2000) related to partnership working, but they also set challenging targets in the reduction of deaths from heart disease. Their major method of achieving this is through the preventative work undertaken by health promotion services throughout the country. Health education is a major component of this work and, as such, has a heavy investment of government money. I would argue that unless they alter the way that they deliver their health education, for example by being more consistent with one common message, they are simply going to continue to allow people to interpret their own understandings from these messages and continue to believe that they are sufficiently physically active to benefit their health. For the general public, who are not exercising for rehabilitation, and therefore will not be able to maintain role-distance from their exercise, more physical activity options need to be available. This is already happening in many towns and cities that have forward thinking authorities, for example Southampton has been funded by government money to provide 'Health Walks' for residents. People who are unable to accept the 'exerciser' role are able to engage in physical activity that might be perceived as being less intimidating than going to a fitness suite. Green Gyms, whereby people can engage in countryside activities such as fence building and digging, are beginning to develop throughout the

UK (Southampton also has one) and are a further alternative for people who want to exercise but are unable to do so at the leisure centre. However, regarding the physical activity message, the same applies – even given the strength of agency that this study has demonstrated, people need to understand the meaning of exercise and this should be endorsed through the health education campaigns by one sufficient and consistent message.

I should note that the irony of my recommendations above is not lost on me. I have been critical of the health promotion movement that assumes that everyone should *want* to become more physically active and that their role is to help them to achieve this. I have also discussed their central issues of power and control in treating the potential for illness, rather than illness itself, from which the health promotion movement contribute to a culture of victim blaming. On the other hand I have, seemingly, made suggestions for how they can achieve this to better effect. It is, however, incumbent upon me to put my research findings into some kind of useful context, particularly with consideration to the fact that I work on a day-to-day basis with people who want to exercise because they believe that it will help them to avoid a second heart attack. Also, as I have highlighted, there are those cardiac patients for whom exercise has been beneficial in regaining roles and rebuilding identities that were disrupted following their heart attack. It is these people that I would like this research to benefit, not necessarily the general public as a whole, who the health promotion movement see as fair game in their quest to make sure that everyone leads a healthy lifestyle, whether they want to or not.

## 8.5 RESEARCH

This research study is, in part, a response to the quantitative methodologies that are predominantly used by health researchers in understanding health behaviour, particularly regarding exercise participation and adherence. In light of the findings from this study, these psychological 'model' approaches to research would benefit from a sociological perspective. In demonstrating this, I will use the most commonly employed of the models, the Health Belief Model. This model, as with all of the others, makes assumptions about the adaptive potentialities of the social actor's behaviour in a deterministic manner that assumes an underlying pattern to behaviour that can be explained on the basis of cognitive variables. The Health Belief Model takes as its starting point the "factor" of *threat perception* - an understanding that the cardiac patient will perceive heart disease as a personal threat and one that will be perceived as life-threatening. However, this deterministic standpoint does not allow for the creative agency of the social actors in interpreting their situation to their own end, thus fitting their biography at that moment in time. In the reflexive late modern age that the social actor inhabits, a process of interpretation and reinterpretation allows the cardiac patient the capacity to understand heart disease in a number of ways: something that is to be expected at my age, something that is not as severe as other people's conditions, or something that I can overcome through the existing lifestyle (which, in turn, is being redefined), for example. The point that I am making is that we do not automatically respond to the threat of illness in a standard and predictable way. The second factor is the notion of *behavioural evaluation* and is comprised of two further beliefs (a) the perceived benefits of a recommended behaviour and (b) and the cost of performance of the behaviour. The recommended behaviour of this study is exercise and, as discussed above, social actors are able to bring to bear their own definitions of what constitutes 'exercise' from the plethora of lifestyle advice available. Further, the medico-scientific advice is such that its ambiguity can easily be interpreted to suit whatever biographical situation one requires it to. As regards the cost of exercise, we are supposed to weigh this up against the benefits that it brings and come to a rational decision. However, if we have already interpreted the health education message in a way that best fits our biography, this becomes unnecessary.

To be fair to the health/sports psychologists who undertake their research with the Health Belief Model, they do accept its limitations and they also accept that its predictability rate (that people will adopt a physically active lifestyle) is only 40% - 68% successful (according to the research used). However, I have not read any such research (although this does not mean that none exists) that recommends a more sociological understanding of the model. I would argue that this 'lived experience' perspective of cardiac rehabilitation would have much to contribute to the substantial body of research knowledge in the field.

Another contribution that this study makes to existing knowledge regarding exercise adherence is in exploring the perspective on the non-complier. Most research tends to examine the reasons and explanations behind people's decisions to engage in exercise programmes – for example, to lose weight, gain muscle, improve health, meet people

– but there is very little information about why people fail to adhere to exercise programmes. I would argue that the perspective of the non-complier is equally as important as that of the complier. The things that make, or allow, people to drop out of an exercise programme need to be addressed if the public health investment is to achieve a successful return.

## 8.6 FURTHER RESEARCH

Qualitative research captures the essence of the lived experience of cardiac rehabilitation. If illness is something we do, rather than something we have (Turner 2001), cardiac rehabilitation is something that is 'lived'. It is not simply the case that a patient turns up for their exercise classes every week, then returns home and forgets about it, but more a matter of life choices such as observing dietary recommendations and ensuring that physical activity is not overdone. These things impinge on a person's daily life at many levels. Rich contextual information is required if an understanding of the complex behaviour patterns of the cardiac patient is to be reached. I have argued that the positivistic approaches to research are insufficiently sensitive to achieve this. In fact, this is one of my criticisms of the trend toward the quantitative accounts, such as the Health Belief Model, discussed previously. The ethnographic methodology that I used allowed me to develop a typology of self-presentation in exercise rehabilitation, which would not have been possible with any other methodology. Interviews alone would not have enabled me to observe the ways that some cardiac patients are keen to maintain role distance from exercise. Further, the symbolic interactionist framework that I used allowed me to understand the ways that cardiac patients were able to interpret and re-interpret the 'symbols' of their lives.

The finding that cardiac patients are able to use exercise participation as a resource – something to be engaged with during times of uncertainty - suggests that an interesting study would be to follow up all of these people to see what they are doing now. Many of them still attend Active Options sessions, but as mentioned, some of these were people who had previously dropped out, so it would be interesting to interview them again to see how their biographical work – their understandings of what exercise means to them – had been altered. Further, some of my respondents will attend for, say, three months or so at a time, then disappear for a while, then come back again. To place these cardiac patients into any one category of biographical work would be difficult – perhaps a third type exists, that of sporadic exerciser? However, the point that I am making is that people live reflexive lives and, as active and creative social agents, we are able to impose meanings to symbols according to their position in our biography *at that time.* A more longitudinal based study would provide further information on this interesting subject.

## 8.7 WHAT HAS BEEN LEARNT?

This study provides an example of an ethnographic approach to understanding why some cardiac patients adhere to exercise rehabilitation while others do not. This is not an approach that has been taken before and, because of this, it provides valuable information regarding the complex interplay between the individual and the influence of social structures. It shows that, in a culture that expounds the virtue of individual responsibility for health, cardiac patients are able to exercise their agency in creating an identity while adhering to, rather than acting against, the pervading social structure and culture. Further, in doing so they actually reinforce this existing arrangement because they use their agency in different ways to maintain or re-establish important degrees of continuity in their lives.

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Appendix 1

Dear Dr

**Research Study: Exercise participation in Cardiac Rehabilitation**

As the manager of the 'Active Options' Exercise on Prescription Scheme and as a part-time PhD student with Southampton University, I am undertaking a study into exercise participation in cardiac rehabilitation. My study aims to provide a better understanding of the factors that influence adherence and non-adherence to long-term exercise participation following MI/CABG, which will help to guide future interventions. My supervisors for this study are Dr Graham Crow, Reader in Sociology (gc@socsci.soton.ac.uk) and Dr Rose Wiles, Senior Research Fellow (raw@soton.ac.uk).

I am writing to request your permission to approach your patient (named below) to enquire whether he/she would be willing to participate in my study. The involvement of your patient involves an interview of around one hour's duration, which will be undertaken in a private office at the Leisure Centre. The interview will consist of questions related to the participant's experience of an exercise programme, and this has received clearance from the Southampton and South West Hants Joint Local Research Ethics Committee.

Name of patient: ______________________________________________

Address of patient: ____________________________________________

I would be grateful if you could complete the slip attached indicating whether or not I have your consent to approach your patient to participate in the study and return it to me in the stamped envelope provided. If you have any queries about the study, please contact me on 02380 720920 p.partington@southampton.gov.uk.

Thank you for your time.

Yours sincerely

Patrick Partington
Community Health and Fitness Co-ordinator
Southampton City Council

**Research Study: Exercise Participation in Cardiac Rehabilitation**

Patient’s Name: ______________________________________________

Patient's Address: ______________________________________________

______________________________________________

______________________________________________

*[ ] I **agree** to this patient participating in the above study.

*[ ] I **do not agree** to this patient participating in the above study.

**please tick as appropriate*

Doctor’s Signature: . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . .

Name: . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . (Block capitals)

Date: . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . .

**PLEASE RETURN IN THE ENCLOSED STAMPED ENVELOPE**

Appendix 2

## PATIENT INFORMATION SHEET

Patrick Partington direct line: 023 8072 0920

**Purpose of the study**

To gain an understanding of why some cardiac rehabilitation patients continue to exercise, while others choose not to.

**Background to the study**

The importance of participation in an exercise programme for the physical recovery and continued health and well-being of those who have experienced a heart attack is well acknowledged. Although exercise is thought to be beneficial, it is believed that around half of those who begin a programme will choose to drop out. In order to help patients to adhere to an exercise programme, and therefore gain the health benefits of exercise, it is important to understand the reasons given for exercise adherence, from the perspective of the patient. Equally important are the views of those who begin an exercise programme, but are unable to (or choose not to) maintain their participation.

**Your part in the study**

As someone who has experienced a heart attack, and participated in a subsequent exercise rehabilitation programme, your views on the subject are extremely important. Your part in the project will involve undertaking an interview that will last up to one hour and this will take place in the Active Options office at The Quays or Bitterne Leisure Centre. With your permission, I would like to tape record your interview so that it can be analysed at a later date. All information collected will be confidential and will not be discussed with anyone.

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I have read the above information about the study of exercise in cardiac rehabilitation.

I am*/I am not* willing to take part in the study.

**please delete as applicable*

Name ..................................................

Address ...........................................................

...........................................................

**Telephone ...................... Date .....................**

Appendix 3

Patrick Partington direct line: 023 8072 0920

Dear

As the manager of the 'Active Options' Exercise on Prescription Scheme and also a Research Degree student with Southampton University, I am undertaking a study into exercise participation among people who have experienced a heart attack. I am writing to ask if you would be willing to take part in this study, which will involve me talking with you about your experience of the exercise programme. This can be arranged for a time that best suits you and can take place either at the Leisure Centre.

I am particularly interested in finding out about the factors that encourage and discourage people from attending an exercise programme, so I would be interested in talking to people who have <u>not</u> continued with exercise as well as those who have.

I would be very grateful if you could read the information sheet attached, then complete the slip at the bottom of the page and return it to me in the stamped envelope provided. You are assured that whether you choose to participate in this study or not, your participation in your exercise programme at the Leisure Centre will not be affected. Similarly, if you have not been exercising recently, you are welcome to recommence your exercise programme, whether or not you agree to participate in this study.

If you would like to contact me to discuss things further, do not hesitate to call me on 02380 720920. Thank you for taking the time to read this letter and I look forward to hearing from you.

Yours sincerely

Patrick Partington
Community Health and Fitness Co-ordinator

Appendix 4

## INTERVIEW SCHEDULE

### Causes of good/bad health

Can you try to define good health? (absence of disease, fitness, ability ...)

Try to think of someone you know who is healthy. What makes you call him/her healthy?

On the whole, compared to that person how do you view yourself?

As far as you are aware, what are the causes of heart disease?

What do you think was the cause of your own heart disease?

### Healthism

How important do you think exercise is in cardiac rehabilitation?

How important to general good health?

How important has exercise been to you? (have you always exercised?)

How do you feel about people who don't look after their health?

How do you feel about the media representation of heart disease?

Try to gain a response to the TV advert on heart disease

Do you feel that the medical profession should be responsible for your health, or should you be responsible for your own?

### Identity

Do you feel that your MI/CABG has changed your identity in any way? (how you feel about yourself, how others might view you?)

Do you feel that exercise has helped you to regain an identity?

Do you view yourself differently?

Do you think that people have a different view of you now that you exercise?

Do you yourself have a different view of yourself now that you exercise?

### Body

Do you feel that your body has let you down in any way?

Are you more aware of your body since your heart attack?

Have you noticed any changes to your body since you started exercising?

### Other

What factors do you think are important in your rehabilitation from heart attack?

Have you made any changes to your life?

Do you think that these have been, or will be, beneficial?

Appendix 5

## INTERVIEW SCHEDULE

### Perceived severity

Begin with background

What do you think was the main cause of your heart disease?

(Try to find out if perception of heart disease was life threatening, etc).

### Protective value of exercise

How important do you think exercise is to general good health?

How important do you think exercise is in recovery from heart disease?

How important do you think exercise is in preventing further heart disease?

Elicit information related to the 'why', i.e. why do you think that is so, do you have any experience of this, etc.

### Physical activity

Would you say that you were a physically active person?

Do you feel that the type of physical activity that you take is as beneficial as structured exercise?

Do you feel that your level of physical activity is beneficial to your health/ in preventing another heart attack?

### Exercise history

Tell me a little bit about your exercise history. (Why have you not exercised?)

How important has exercise been to you? (Have you always exercised?)

Are/were your friends and relatives exercisers? Did you find it useful to have these people to talk to about exercise?

(Try to find out what has been happening in participant's life when they were exercising and if they knew other exercisers - <u>how attitude changed</u>).

Why do you think your activity levels dropped off?

<u>If a non-exerciser</u>: how do you think exercise might have helped you (health, quality of life, etc).

<u>Life stages</u>

Teenage years

20's

30's

40's

50's

60's

70's

80's

90's

### Present exercise

Discuss exercise routine - frequency, time, etc. (How do you fit it in?)

What do you feel is the main benefit of exercise (what is the stated aim)?

Do you find it useful to exercise in a group? Why, what are the benefits?

Do you also exercise alone (e.g. walking)?

Do you talk to anyone about exercise? What is their response? Is this helpful/supportive?

What do you like about coming to the leisure centre (friendly environment, professional support, social aspect)?

Do you feel that it is important to have an instructor about?

What does (or would) motivate you to exercise?

Do you have any idea about why some people exercise and others don't?

### Risk

Do you feel at risk from another heart attack?

Do you think that your lifestyle changes have/will reduce that risk?

### Lifestyle

What lifestyle changes have you made since your heart disease?

What do you think are the main benefits of this change? Has it been easy?

Have you had any support from friends/family for these changes?

### Identity

Do you feel that people see you differently since your heart disease? (do they help you more, have less contact with you, etc)?

Do you think that being an exerciser can help to change this? (are you pleased with peoples view of you as an exerciser?)

Do you have a different view of yourself now that you exercise?