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THE PSYCHOLOGICAL EXPERIENCE OF WOMEN FOLLOWING HEART ATTACK

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Thesis submitted in fulfilment of the requirements for the award of the
qualification of Doctor of Philosophy in Psychology

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January 2002

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ACKNOWLEDGEMENTS

I should like to gratefully acknowledge the support and assistance that I have received from the following people over the last eight years.

My particular thanks to my supervisor, Charles Legg. He was always available to help, always sensitive to the barriers and pressures I faced, and never failed to provide me with wise judgement and guidance. Most importantly, through our stimulating discussions and the often difficult questions he asked of me, he ensured that I grew academically and produced a thesis that was in every sense my own work.

My thanks also to Pauline Jervis and Brian Feldman for all their assistance in analysing the transcripts.

Finally, I am grateful to my wife Sylvia for her encouragement, for sharing in my sacrifices over the years and particularly for tolerating my single-mindedness over the last two years. I am also grateful to other family and friends who have shown understanding at being neglected.

DECLARATION

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ABSTRACT

In the UK Coronary Heart Disease is the leading cause of death among women. It also causes an incalculable amount of morbidity and suffering. Despite these arresting facts, however, women have been comprehensively neglected by researchers and by the health care system. There is a vast database on Coronary Heart Disease in men which largely ignores the changes in disease prevalence that make it of equal importance to women.

Psychological adjustment to heart attack is of immense importance because of its impact on quality of life and because of its influence on bio-medical endpoints. Until recently, almost no research had been conducted on psychological adjustment in women, and much of the research that does exist is problematic. Most of it is predicated on androgenic assumptions, gender biased variable selection, adopts a cross sectional design and view heart attack as a discrete event. However, the data that do exist indicate that women's psychological adjustment to heart attack is less favourable than men's.

The study presented here adopts a qualitative process-based approach, seeking to describe and explain these apparent gender differences in psychological adjustment. Twenty women and ten men were interviewed at two time points following discharge from hospital, and the results were subjected to computer assisted content analysis. Many differences in participant's experiences were identified, and four superordinate themes emerged: perception, decision-making and action in relation to heart attack symptoms; the emotional aftermath of heart attack; making sense of what had happened; and issues surrounding subsequent health-related behaviour.

The problem encountered during analysis was that, although there appeared to be many differences between men and women, these differences were seldom exclusive or universal within either sex. By studying the exceptions to these sex differences, it was possible to conclude that much psychological adjustment

was a product of the social roles and norms rather than sex or any global notion of gender.

The thesis is divided into three parts. The first part includes four chapters providing background information including the literature, the research design and process. The second part comprises four results chapters. Finally, the third part consists of three chapters which draw conclusions from the research process and results, and consider their implications.

LIST OF ABBREVIATIONS

A&E	Accident And Emergency
AIDS	Acquired Immune Deficiency Syndrome
AMA	American Medical Association
APA	American Psychiatric Association
BACR	British Association For Cardiac Rehabilitation
BDI	Beck Depression Inventory
BHF	British Heart Foundation
BMJ	British Medical Journal
BPS	British Psychological Society
CABG	Coronary Artery Bypass Graft
CCU	Coronary Care Unit
CHD	Coronary Heart Disease
DoH	Department of Health
DSM	Diagnostic And Statistical Manual
ECG	Electrocardiogram
EMS	Emergency Medical Services
EWS	Early Warning Symptoms
GHS	General Household Survey
GISSI	Gruppo Italiano per lo Studio della Streptochinasi nell
GP	General (Medical) Practitioner
GTN	Glyceryl Trinitrate
HAD	Hospital Anxiety And Depression Questionnaire
HARP	Heart Attack Recovery Project
IPQ	Illness Perception Questionnaire
ITU	Intensive Care Unit
NDE	Near Death Experience
NHP	Nottingham Health Profile
NHS	National Health Service
NICE	National Institute For Clinical Excellence
NSF	National Service Framework
NUD.IST	Non-Numerical Data Indexing, Searching and Theorising

OPCS	Office of Population, Census & Surveys
PILP	Post-Infarction Late Potential Study
POMS	Profile Of Mood States
QLI	Quality Of Life Index
REC	Research Ethics Committee
sd	Standard Deviation
SIP	Sickness Impact Profile
SSM	Swedish Society Of Medicine
STAI	State Trait Anxiety Inventory
TABP	Type A Behaviour Pattern
USA	United States Of America
US	United States (Of America)
UK	United Kingdom

PART ONE

BACKGROUND AND PREPARATION

CHAPTER ONE

CORONARY HEART DISEASE AND WOMEN

1.1 Introduction

This thesis is about women and heart disease. More specifically, it focuses on the psychological experience of women who have suffered a heart attack. There is some basis for suspecting that women might experience heart attack and its aftermath differently to men: the purpose of the enterprise is to investigate that proposition and explain any such differences.

The thesis adopts the usual social science convention of using the term *sex* in relation to the biological difference between males and females, and the term *gender* in relation to the cultural definition and expression of biological sex (Siann, 1994:3). Thus, the terms *maleness* and *femaleness* refer to sex whereas *femininity* and *masculinity* refer to gender. However, both Siann and other authors (eg Golombok & Fivush, 1994:3) point out that these distinctions are not necessarily absolute and exclusive, which the writer accepts. Since the subject of this thesis is psychology the term *gender* will usually be the appropriate term to use, except where the issue clearly concerns biological sex.

The aim of this chapter is to provide a general backdrop to the rest of the thesis. Before discussing the detailed and specific cardiac literature on psychological adjustment in Chapter Two, it is first necessary to raise some general issues which will be taken up in subsequent chapters. These issues are presented in three major sections. The first section provides the reader with necessary information about coronary heart disease. The second section discusses women's general health and the third section discusses women's cardiac health.

1.2 Coronary Heart Disease

Importance

Coronary heart disease (CHD) has for some years been the major threat to public health in the UK. In human terms CHD was responsible for 137 153 deaths in 1998 (BHF, 2000a)¹, and for inestimable suffering and morbidity among survivors. Although there has been a steady decline in CHD mortality in the last two decades, the death rate remains stubbornly high and compares unfavourably with that of other developed countries (BHF, 2000a).

CHD is also of supreme economic importance in the UK, costing the nation more than any other health problem that has been the subject of economic analysis (BHF, 1998). In 1996 the costs to the National Health Service (NHS) amounted to £1 630 million, of which 99% was spent on treatment and 1% on prevention, but this figure is dwarfed by the cost of production losses which amounted to £8 500 million in 1996 (BHF, 2000b). Thus the total cost of CHD in 1996 was in the region of £10 000 million.

In view of the above, CHD has in recent years received recognition as the major public health problem in the UK and the government has published various White and Green Papers on the subject. In particular, the Health Of The Nation (DoH, 1992) is a strategy document for England which identifies CHD as one of five key areas for action. The subsequent 'Our Healthier Nation (DoH, 1999) sets targets for tackling CHD including a 40% reduction in cardiac mortality by the year 2010. Recent trends indicate that this target will probably be met, particularly since mortality was already in decline when the targets were set.

More recently, CHD was one of the first health problems identified by the government when it began publication of its National Service Frameworks (NSFs) (DoH, 2000). This is a large and detailed document that addresses issues in all areas including prevention and the major modes of treatment

¹ In this chapter government statistics referenced as BHF (2000a) apply to data for the year 1998.

including rehabilitation. It sets out national standards and interim goals over a ten year period.

Pathology

CHD is the result of atherosclerotic changes in the larger coronary arteries (Julian, 1995:4). These atherosclerotic changes result from the deposition of fatty streaks in the arterial wall, which are later compounded by the laying down of fibrous (scar) tissue, lipids (fats) and blood products (thrombosis). This has the effect of narrowing the lumen of the artery so that less blood is supplied to the myocardium (heart muscle). It also has the effect of creating rigidity so the artery is unable to dilate in response to increased myocardial oxygen demands, as in the case of exercise or psychological stress.

Post-mortem and other investigations have shown that atherosclerosis can pre-date the onset of cardiac symptoms by many years and at least one major coronary vessel is likely to suffer 70% occlusion before the disease becomes manifest (Scheidt, 1996).

Manifestations

There are two common manifestations of CHD that are of interest here: angina pectoris (angina) and myocardial infarction (heart attack).

Angina is precordial chest pain that occurs when myocardial oxygen demands are increased beyond the point at which the coronary blood supply can respond, ie during or after physical or emotional exertion. The deficit between demand and supply results in myocardial ischaemia, a transiently inadequate blood supply (Julian, 1995).

Depending on the detailed underlying pathology, some people live with angina for many years and are spared any real disease progression. Indeed, the development of collateral circulation in association with lifestyle modification might even lead to atheroma regression (Ornish *et al*, 1990) and an

improvement in symptoms (Julian *et al*, 1998). Other people experience unstable or escalating symptoms, perhaps necessitating surgery. Angina sufferers are at increased risk of heart attack, which is most commonly preceded by an exacerbation of their angina (Julian *et al*, 1998).

Heart attack is said to occur when there is a sudden and complete interruption of the supply of blood to an area of myocardium (Julian *et al*, 1998). This usually results from the rupture of an atheromatous plaque in one of the coronary blood vessels or its tributaries, thus leading to intra-coronary thrombosis (Julian *et al*, 1998). This results in the sudden cessation of blood flow to an area of myocardial tissue which quickly dies (infarction). This tissue death is permanent, though the infarcted area is surrounded by an area of myocardium that is threatened, ie it is highly ischaemic and dysfunctional but has the capacity to survive if the appropriate treatment is administered quickly.

Heart attack is a catastrophic event that leads to death within minutes in about 25% of cases (Julian *et al*, 1998). For those who survive the first few minutes, the natural (untreated) mortality rate is 15-30%. Mortality is higher among the elderly, higher among females and higher among those who have a previous history of heart attack (Julian *et al*, 1998). Appropriate treatment, however, can dramatically reduce this figure (see below). Subsequent fatal or non-fatal heart attacks may or may not occur in the future.

What is also increasingly recognised, however, but is less well understood, is that other underlying pathologies may lead to manifest CHD in the absence of atheromatous coronary arteries. Examples of such pathologies are microvascular ischaemia and functional (spasm) ischaemia. These non-standard forms of coronary pathology also lead to a mismatch between coronary supply and demand, and can also lead to all the signs and symptoms of CHD.

Symptomatology

Angina is a pain or feeling of discomfort that occurs most commonly in the middle to upper central chest, though it can radiate throughout the chest, neck

and arms (Julian *et al*, 1998). Patients frequently describe the feeling as tightness or constriction around the chest, or as a weight on the chest. Angina is usually provoked by physical exertion or emotional arousal although, particularly in the case of the latter, there may be a time lag of many hours between the stimulus and the response. The pain normally responds to rest and Glyceryl Trinitrate (GTN) tablets within a few minutes.

The classic presentation of heart attack comprises severe retro-sternal chest pain, which might radiate to both sides of the chest, neck, shoulders and arms (Julian *et al*, 1998). This may be accompanied by other symptoms such as breathlessness, sweating and nausea. The pain is typically described as piercing. It is not usually precipitated by exertion, is not relieved by rest or GTN tablets and is comparatively long lasting.

Diagnosis

Diagnosis is usually straightforward and depends on three assessments (Julian *et al*, 1998). The first assessment involves asking the patient about the nature of their pain and the circumstances in which it occurred along with physical examination. The second assessment is by means of an electrocardiogram (ECG), which is taken immediately on admission to hospital and then at regular intervals. The final means of assessment is by means of a blood test that measures cardiac enzyme levels, ie the biochemical consequences of infarction, and this is repeated daily. It can take two or three days before the blood tests show evidence of myocardial infarction. Thus problems in diagnosis can occur where the patient history, ECG changes or blood test results are equivocal.

Risk Factors

The cause of atherosclerosis is not yet fully established (Julian, 1995) but a number of risk factors have long been recognised by the medical profession. The standard or traditional risk factors, described by Julian *et al* (1998) as "the three best identified risk factors" are: cigarette smoking; high lipid levels (due to

dietary fat intake and/or genetic factors); and hypertension (high blood pressure).

Julian's classic and authoritative cardiology text almost ignores psycho-social factors as risks, mentioning "mental stress" in a very short paragraph and adding that there is no convincing evidence for this (Julian *et al*, 1998). This typifies the dismissive attitude of physicians towards the role of psycho-social risk factors, which is unfortunate in view of the fact that the traditional bio-medical risk factors account for less than half the variance of CHD (Jenkins, 1971).

Initial Treatment

Once a provisional diagnosis is made patients are admitted to a coronary care unit (CCU), which is a specialised intensive care unit. Initial treatment of heart attack is usually conservative and consists of two elements.

The first element involves monitoring the patient closely for about 24 hours in the CCU. There is a particular risk of heart rhythm disturbances during the immediate post-coronary period, and almost 50% of patients will develop clinically important arrhythmias during this time (Julian *et al*, 1998). Therefore cardiac monitoring, and where necessary intervention to correct cardiac rhythm disturbances, can save many lives.

The second element of treatment is the intravenous injection of thrombolytic medication, so-called 'clot-busters', which dissolve coronary thrombi and minimise myocardial damage. If thrombolytic medication is started within one hour of the onset of symptoms mortality is reduced by 50%, if given within three hours it is reduced by 23% (GISSI, 1986) and it must be given within four hours in order to be at all effective. The speed with which it is administered also has a direct impact on subsequent cardiac functioning (Simoons, *et al*, 1986). The risks involved in thrombolysis mean that most hospital protocols stipulate that this treatment may only be administered within the CCU.

Quite clearly, therefore, it is imperative that heart attack victims seek medical help as soon as they experience symptoms. It is estimated that 50% of deaths occur within an hour of the onset of symptoms, and yet all studies have shown that delay intervals are considerably longer than that. Delay intervals are composed of different phases and are variously categorised. For example, Ho (1991) proposes four terms to describe the different phases of delay.

Table 1.1 – Components Of Treatment Delay Interval

patient delay	onset of symptoms to point of contact with EMS
EMS delay	contact with EMS to arrival in hospital
hospital delay	arrival in hospital to start of treatment
total delay period	onset of symptoms to start of treatment

Recognition of the extra risks involved in delayed treatment has resulted in many policy initiatives leading to reductions in EMS (emergency medical services) and hospital delay intervals. However, by far the greater part of the total delay interval is patient delay (Ho, 1991), this remaining obstinately long.

As regards more invasive treatment, eligibility for this is normally assessed by coronary angiography. This is an intravascular examination of the coronary arteries which are accessed via a small incision in the groin or the arm. This is conducted where there is particular reason to be concerned about a person's likelihood of suffering a further heart attack or when functional limitations are extreme. The results of angiography might indicate the need for invasive treatment. The usual form of treatment is open heart surgery, ie a Coronary Artery Bypass Graft (CABG). The alternative is coronary revascularisation (angioplasty) which is achieved via an incision in the groin or the arm.

Rehabilitation

The National Institute For Clinical Excellence (NICE) recommends that, following initial treatment for a heart attack, patients should be offered access to a Rehabilitation Programme since this has a positive influence on survival (NICE, 2001).

Formerly, even within the writer's professional lifetime, heart attack was followed by weeks of bed rest in order to minimise demands on the injured myocardium. Bethel (1995) describes how this position has changed over the years. Despite medical resistance to change (eg Miller, 1976), this cautious approach began to erode in the early 1970s as studies started to show that early mobilisation was harmless and indeed reduced medical complications (eg Abraham *et al*, 1975). Since the 1970s there has been a gradual acceptance of the benefits of early mobilisation with decreasing periods of bed rest and the advent of formal in-patient exercise programmes. As hospitalisation periods decreased over the years, there was a slow growth in rehabilitation schemes.

Given this background, it is not surprising that many rehabilitation programmes are based on exercise. Physiologists understand the mechanisms by which exercise exerts its effects and longitudinal studies have demonstrated a wide range of benefits including reduced morbidity and mortality, as confirmed by two widely quoted meta-analyses (Oldridge *et al*, 1988; O'Connor *et al*, 1989) and by a recent Cochrane review (Jolliffe *et al*, 2001). Exercise also has important psychological effects in relation to anxiety, depression and self concept. Here the mechanisms of effect are less well understood and the research methodology less sound, but there is an impressive consistency of results (Shaw, 1996).

Some rehabilitation programmes are purely exercise based, others have exercise as the main intervention offered and yet others are truly multi-modal including education, stress management and counselling in addition to exercise (Thompson *et al*, 1997). According to the official British Association For Cardiac

Rehabilitaion (BACR) guidelines (Coates *et al*, 1995), cardiac rehabilitation is described as occurring in four phases:-

Table 1.2 Phases Of The Rehabilitation Process

phase	time span covered
phase 1	from hospital admission discharge
phase 2	from discharge up to four weeks
phase 3	from four weeks to 3-6 months
phase 4	from 3-6 months onwards

Cardiac rehabilitation programmes generally begin in Phase 2 and extend into either Phase 3 or Phase 4. Given the impact on survival, maximising attendance rates is an important issue for rehabilitation professionals.

1.3 Women’s General Health

Mortality And Morbidity In Women

The conventional wisdom is that ‘women get sick and men die’ and this is largely true. In the developed world males suffer from higher all-cause mortality rates than females. In the UK males born in the year 2000-01 can expect to live until the age of 75.8 compared with 80.6 for females (GAD, 2001)². Paradoxically, although females enjoy greater longevity, they suffer greater all-cause morbidity (Rodin & Ickovics, 1990) even when controlling for reproductive problems (Nathanson, 1975).

Thus women’s quality of life is significantly burdened by a variety of chronic health problems. These health problems include a wide range of non-fatal physical illnesses, both acute and chronic, involving most of the body systems (Verbrugge, 1985). This general pattern also applies to mental health problems.

² These figures are based on the period 1997-1999.

Males tend to have problems that are more dramatic and dangerous, often including violence of some sort or substance abuse, whereas females are much more likely to suffer from the more common neurotic and mood disorders (Gomez, 1991).

This sex difference in morbidity is evidenced by a higher General Medical Practitioner (GP) consultation rate, the amount of sick leave taken, the use of prescription and non-prescription medicines (Rodin & Ickovics, 1990; Verbrugge & Wingard, 1987) and restricted activities (Verbrugge, 1985). Females also have more surgery than males, report more symptoms and poorer subjective health status (Carroll & Niven, 1993:4).

There are a number of possible explanations for this sex difference in morbidity statistics. One explanation is that part or whole of the difference is an illusion. For instance, it might be that females simply report more illness than males.

Symptom Reporting By Women

Females might report more illness because they notice symptoms more readily and think about them differently. A number of authors suggest that females are more attuned and sensitive to bodily sensations, and more likely to interpret bodily discomforts as being symptoms of illness (eg Verbrugge, 1980). Carroll & Niven (1993:4) agree, arguing that it is "almost certain" that there are differences in how men and women attend to symptoms, in their mental representations of symptoms and that this must play a part in differential morbidity. These differing representations include a more diffuse and holistic view of illness than men in that they perceive their symptoms as being less specific to just one body system or organ, and the boundaries between mental and physical symptoms are less distinct (Verbrugge, 1980).

It might also be that females are more inclined than males to seek medical help when they experience symptoms (Verbrugge, 1980; Carroll & Niven, 1993:4), thus increasing the likelihood of early treatment. Men, on the other hand, are more likely to ignore symptoms, even of previously diagnosed illnesses, so by the time they do seek help they are likely to be quite ill (Verbrugge, 1980).

Referring to Last's (1963) iceberg analogy, Radley (1994:117) points out that, "Much illness never gets to the doctor...."

These ideas about symptom perception and reporting seem to enjoy agreement and support among authors but, as Verbrugge (1980) himself concedes, the evidence is weak. Another way that reporting bias might occur is through a greater cultural acceptability for women to express their symptoms, rather than be tough and tolerate discomfort as is expected of men (Nathanson, 1975). However, some studies have failed to confirm this (Kaplan *et al*, 1991).

Medical Perceptions

Given the arguments set out above it would seem plausible that females might behave differently to males during medical consultations. Women are also more knowledgeable than men about their bodies (Umberson, 1992), better informed about health matters, and Verbrugge (1980) reports that they ask more questions during consultations. He also suggests that women are more articulate than men, thus tending to give more elaborate explanations of their symptoms Verbrugge (1980). It seems reasonable to assume that all this might influence physician responses in some way.

Like other people, physicians have beliefs and expectations in respect of different groups of people including the two sexes. These beliefs and expectations might influence their perceptions and medical judgements. Several authors locate this in an historical context. For example Stanton (1995) explains how Victorian physicians viewed females as being naturally weak and sickly, and Radley (1994) cites studies that indicate this attitude still exists. It might be, therefore, that physicians are likely to perceive and diagnose women as being sick more readily than men with the same illness presentation. Systematic diagnostic bias is well documented in a wide range of areas of medicine and psychotherapy (eg Broverman *et al*, 1970; Franks & Clancy, 1993) including a tendency for physicians to attribute women's symptoms to a psychogenic cause (Bernstein & Kane, 1981).

However, deeming that the above explanations have some validity does not rule out the possibility that morbidity statistics also reflect some real differences in health and illness. If this is the case, either wholly or partly, then the controversial question arises as to how much these differences can be explained by reference to biological factors (sex differences) as opposed to socio-cultural and behavioural factors (gender differences).

Few would dispute that biological factors play a role in the distribution of morbidity. For example, Waldron (1983) gives a detailed review of how the mechanisms by which biological factors such as genetics, stress, hormone production and immune functioning are inter-linked and contribute to differential morbidity.

The Influence Of Gender

However, if biological factors were solely responsible for differences in morbidity, one would expect these differences to be universal within each sex. This is not the case, for there are also marked variations in morbidity within the sexes. For example, widowed and divorced men suffer higher levels of morbidity than married men (Umberson, 1992) and women who score high in androgyny and particularly masculinity have lower levels of morbidity than other women (Antill & Cunningham, 1979). So it would appear that the two sexes are not homogeneous groups in respect of morbidity and there are clearly sub-populations of women and of men which differ from the majority.

The argument is that these sub-populations of women and men differ as a function of the social construction of gender. It has long been recognised that women and men are often but not always exposed to different stressors, for example as a result of the social roles they occupy, and that those stressors can affect their health (Gove, 1972). Some females and males might be socialised to appraise stressors differently, adopt different coping strategies and even differ in their physiological reaction to stress. Most of these points emerge in later chapters.

In order to illustrate the point about social construction it is worth noting that known sex differences in physiological stress reactions (eg Polefrone & Manuck, 1987) are also influenced by socio-cultural factors. A number of laboratory and real life studies have shown that 'sex' differences in the stress reaction disappear at rest, and that they vary according to the gender-relevance of the situation (eg Frankenhaeuser, 1988; Rauste-von Wright *et al*, 1981). Thus, even apparently clear cut objective sex differences in physiological stress reactions are influenced by gender and, for that reason, vary not just between the sexes but within the sexes.

It is known that women generally engage in more positive health behaviours than men, eg getting sufficient sleep, eating breakfast (Nelson & McLemore, 1989), taking vitamin supplements (Moss *et al*, 1989) and tooth brushing (Vergrugge, 1982). It is also known that men generally engage in more negative health behaviours such as drinking alcohol (GHS, 1992). Rather than having their origins in sex exclusive genetic predispositions, Adesso *et al* (1994) argue that these differences in behaviour might derive from their socially prescribed gender appropriateness. They cite evidence for the example of smoking, which was considered "unacceptable for ladies" until relatively recently, and point out that the use of alcohol, drugs and frequent changes of sexual partners are still considered more reprehensible in females than in males. Equally, it is not considered masculine to be self nurturant and this discourages positive health behaviour in men (Adesso *et al*, 1994). According to this line of reasoning such socially constructed differences in health behaviour are liable to contribute to differential morbidity.

Research On Women's Health

A problem that comes through very strongly in the literature is that, while the higher mortality rate suffered by men has been much researched, relatively little research attention has been paid to higher morbidity among women (Haavio-Mannila, 1986; Nathanson, 1975). Females have been seriously under-represented in much health research. For example, they were excluded from the Western Electric study (Persky *et al*. 1987); the Western Collaborative

Group study (Rosenman *et al*, 1975); the Multiple Risk Factor Intervention study (Shekelle *et al*, 1985); and the great majority of AIDS (auto immune deficiency syndrome) research (Rodin & Ickovics, 1990). None of this can be justified by reference to disease prevalence or epidemiological trends.

A number of authors argue that this neglect by the research community is because males have generally been viewed as the standard for health, so that the healthy male is regarded as the healthy person (eg Adesso, *et al* 1994). Therefore findings derived from male samples can be applied to females. This attitude has been noted among clinicians (Broverman *et al*, 1970) and among researchers (Levy & Richey, 1988).

Various factors are purported to have acted as barriers to the inclusion of women in research samples, and these are enumerated in the literature (eg Carroll & Niven, 1993; Stanton, 1995). These barriers range from fears that women's hormonal fluctuations might contaminate the results; the need to protect women of childbearing age from toxic substances and hazardous procedures; and the fact that, in some cases, the distribution of illness would mean that females would be under-represented in samples. This last view seems particularly myopic since, where women constitute a minority within a disease category, including them in studies might be of benefit to both sexes if it revealed the factors that are according them their protective advantage.

Comment

In the last few years there has been an increase in research awareness and activity in respect of non-reproductive health problems of women, and evidence of this is detailed by Stanton (1995).

However, the longstanding androcentric approach to research means that the reasons for women's higher levels of morbidity are still poorly understood. Never-the-less, there seems little doubt that, although influenced by perceptual and behavioural factors, at least some of these health differences are real. In

most cases these real health differences are probably the result of interaction between biological and psycho-social factors.

1.4 Women's Cardiac Health

Cardiac Mortality And Morbidity

In Section 1.2 it was noted that CHD accounts for the majority of deaths in the UK. It also accounts for the majority of premature deaths, ie among people aged 75 and under (BHF, 2000a). These facts apply to both sexes, both when taken together and independently, though these figures vary according to the age group under consideration (BHF, 2000a).

In most age groups CHD mortality is higher among men than women, increasing markedly from middle age onwards. In women there is a steady increase with advancing age and then a very dramatic rise some time after the menopause with women's deaths exceeding men's in the over 75 age group. Even in the under 75 age groups, CHD is responsible for 26% of male deaths and 16% of female deaths (BHF, 2000a). Table 1.3 shows in numerical terms how women and men contribute to the total CHD mortality and demonstrates a difference of only ten points.

Table 1.3 – CHD Mortality By Sex (after BHF, 2000a)

	number of CHD deaths	proportion of total CHD deaths
females	62 611	46%
males	74 542	54%
total	137 153	100%

Even though women have much lower mortality rates than men in most age groups, these totals obscure the fact that CHD mortality is extremely high

among some groups of women, notably women of the manual classes (BHF, 2000a). Female manual workers suffer a CHD mortality rate twice as high as their non-manual counterparts. This socio-economic differential also applies to manual and non-manual male workers, but is nowhere near as great (BHF, 2000a).

In 1986 it was pointed out that the sex difference in CHD mortality was narrowing. Marmot & McDowell (1986) showed that the small decrease in CHD mortality that had occurred in the UK since 1978 had been more pronounced in men than in women, and indeed mortality had increased among working class women in this time. This trend continues today. The latest government figures show that the decline in CHD mortality has been greatest in the younger age groups: in men of 35-44 years the death rate has decreased by 44% between 1987 and 1997, whereas in women the comparable figure is 17% (BHF, 2000a). Thus the sex difference in overall CHD mortality is narrowing because of men's greater improvement relative to women.

CHD mortality is not the only statistic relevant to women. Differences in the natural history of the disease mean that non-fatal forms of CHD are more common among women so the actual prevalence is greater than the mortality rates suggest. For instance, analysis of data arising from a large prospective study in the USA, the Framingham Study, reported an equal incidence of angina in men and women (Haynes & Feinleib, 1980). Once again it is the case that 'women get sick and men die'.

CHD – Images And Perceptions

Despite the figures detailed above, the general image of CHD is that it is a disease of men. This image appears to be shared by the medical profession, by the research community and by the lay public.

Back in 1986 Bartley *et al* argued that women did not see themselves as being at risk of CHD, and since that time their argument has received the support of research findings. For example the National Council For Ageing (1997) in the

USA published survey results which showed that, whilst 60% of women feared breast cancer, only 9% feared having a heart attack. In the same year another USA study was published following telephone interviews with a stratified sample of 1002 women (Legato *et al*, 1997). Almost half the informants said they thought they were somewhat or very unlikely to have a heart attack at some point in their lives, and the majority saw breast cancer as the greater risk. This belief was reflected in women's health behaviour, for example neglecting to have their blood pressure and blood lipids checked as often as recommended.

Despite it's access to health statistics, the medical profession has also generally regarded CHD as a disease of men (Price, 1985). As long ago as 1768 William Heberden (cited in Higgins, 1990) wrote that heart related chest pain was far more common in men, and in the 200 odd years that have elapsed since this has become the accepted medical dogma (Higgins, 1990).

In an attempt to explain the masculine image of CHD, Price (1983) examines its metaphorical character. She rightly points out that writings on the subject are rich in the imagery of engineering, a good example of which was provided by William Osler in 1892 (cited in Feuerstein *et al*, 1986:319). Osler, a physician, described the person who is susceptible to CHD as

“.....not the delicate, neurotic person but the robust, the vigorous in mind and body, the keen and ambitious man, the indicator of whose engine is always at full speed ahead.”

Observations such as this were interpreted sixty years later as the Type A or Coronary Prone personality which Price argues is a metaphor for masculinity as defined by western society, ie aggressive, multiphasic and competitive. She argues that CHD emanates from man's instrumentalism that, as defined by Parsons (1951), exemplifies masculinity. The concept of Type A was conceived and developed from studies on men (eg Meininger, 1985) and the considerable overlap between the constructs of Type A and masculinity (Blascovich *et al*, 1981) may well have further cemented the perceived relationship between maleness and CHD.

McKinlay and colleagues argue that neither women, their families or the medical profession expect to see CHD among women and this leads to a mistaken perception of symptoms and signs of the disease by all concerned (McKinlay *et al*, 1993:1, cited by Shumaker & Smith, 1995:). They argue that official CHD statistics are based partly on reality and partly on the expectations of physicians and researchers, and refer to this as, "the social construction of disease prevalence." Thus, if official figures for CHD in women do not reflect the true prevalence, the submerged portion of Last's (1963) iceberg might contain many females with CHD (Verbrugge, 1985).

It seems odd that the medical profession, ancient and well educated as it is, should have such a distorted image of CHD. One source of medical education is textbooks, and a systematic study of these by Lawrence & Bendixen (1992) suggests that, although they have improved over the years, medical textbooks still contain a disproportionate usage of male-specific figures and descriptions. Another source of education is the research evidence on which physicians base their practice.

Research On Women And CHD

As early as 1985 White complained that women have been neglected by the research community in respect of CHD and in the intervening years numerous other authors have come to the same conclusion (eg Bartley *et al*, 1986; Eaker *et al*, 1988; BMJ, 1993; Weidner, 1994; Shumaker & Smith, 1995). It is now well documented that women have been neglected in almost all research including aetiological, epidemiological, natural history, diagnostic and therapeutic studies. The result is that relatively little is known about CHD in women.

The reasons for excluding women from study samples so consistently over the years are unclear. Only two studies have been found which offer an explanation. Bruhn *et al* (1971) excluded women from their sample of 56, "...because of the small number of cases", and Wynn (1967) excluded women from his sample of 400 because he thought that heart attack would cause

greater psychological disturbance in men in view of their role as "breadwinners and protectors of the family." (Wynn, 1967:847). The situation might be due to any of the factors discussed in Section 1.3. But some authors suspect that the real reason might be more to do with societal judgements about men's greater importance due to their economic contribution through the workforce (AMA, 1991; Stanton, 1995; Beery, 1995).

These explanations may or may not have been valid thirty years ago when relatively few women suffered from heart attacks and relatively few women went out to work, but do not explain or excuse the exclusion of women from studies in the years that have elapsed since that time. Furthermore, given the biological, psychological and social differences that exist between men and women, it is not logical to assume that data derived from male studies can be applied to women.

One effect of this has been a research focus on bio-medical rather than psycho-social risk factors. In her unpublished and unfinished thesis 'Cardiology and the Invisible Woman', Price (1985) was the first to argue that the gender bias in epidemiological and aetiological research was seriously distorting our understanding of the causes of CHD since it frequently led to the overlooking of clues. Large scale prospective studies such as Framingham (Hayes & Feinleib, 1980); Whitehall (Marmot *et al*, 1978); and the British Army (Lynch & Oelman, 1981) all indicate the importance of psycho-social factors. These studies showed that social, occupational and psychological factors might be at least as important in explaining the prevalence of CHD in both sexes than are conventional bio-medical risk factors, and yet research has been overwhelmingly biased towards the latter. As noted above, medical texts rarely make more than a brief and dismissive mention of psycho-social factors in CHD (eg Julian *et al*, 1998).

Clinical Management Of Women With CHD

More seriously still, this perception of CHD as a man's disease has influenced public health policy including the design of health education propaganda.

Research by Price (1985) showed that health education propaganda has generally ignored women except, for example, in exhorting them to buy healthy margarine for their partners and families: they are not portrayed as being at risk of CHD in their own right. These findings were replicated elsewhere (Karpf, 1988). This type of message does little to raise women's awareness of their vulnerability to CHD.

Even when a woman does present with cardiac symptoms there is evidence that she is unlikely to receive equal treatment compared with her male counterpart. It might be that, compared with men, physicians are reluctant to diagnose women as having a heart attack. McKinlay *et al* (1991, cited by Moser & Dracup, 1993) tested this by showing videotaped scenarios to physicians and asking them to make diagnoses. These scenarios consisted of a patient attending clinic for the first time with breathlessness and chest pain. The script used in the scenarios was identical, as were the blood test results, examination data and vital signs. The only difference was the sex of the patient, and physicians were consistently less likely to diagnose women's symptoms as cardiac compared with men's. They were also less likely to offer women appropriate treatment and advice (McKinlay *et al* 1991, cited by Moser & Dracup, 1993).

Evidence gathered over the last decade shows that there are consistent sex differences in the way people are investigated and treated by medical staff. This area of investigation began in the USA where several large studies identified very significant sex differences in referral for angiography, angioplasty and CABG (Tobin *et al*, 1987; Steingart *et al*, 1991; Ayanian *et al*, 1991). Women were significantly less likely to be referred for investigation and treatment, even when they demonstrated greater functional disability than men (Steingart *et al*, 1991).

Two UK studies have upheld these findings. Peticrew *et al* (1993) conducted a retrospective data analysis on all CHD patients admitted with heart attack in the then North West and South West Thames Health Regions during a one year period. The sample size was 23 807 of which 35.5% were female. After

controlling for age, co-morbidity and infarct severity, the results showed that women were less likely to undergo CABG or angioplasty. These findings are important because they are based on data collected in the UK and are therefore not subject to major bias by economic influence on health care accessibility.

In another UK study, Clarke *et al* (1994) report on the retrospective data analysis of 1 767 sequential heart attack admissions, 33% of whom were women, to a large Midlands hospital over one year. On experiencing symptoms women were more likely to contact their GP than an ambulance, thus increasing the patient delay interval. After controlling for age and infarct severity, men were 1.4 times more likely than women to be admitted to the CCU as opposed to a general ward. These two factors combined meant that women were less likely to receive thrombolytic therapy. Women were also less likely to be prescribed Aspirin or beta-blocker medication on discharge from hospital, both of which are known to reduce the risk of post-discharge recurrence and mortality (NICE, 2001).

The literature contains much debate about the possible explanations for these sex differences in clinical management, with physicians and surgeons offering justifications for their referral and intervention patterns. However, the data are clear that women receive less active investigation and treatment for their CHD than men and the only area for debate is why. The result of all this is that by the time women are referred for investigation and treatment, they are likely to be older and sicker than men (Khan *et al*, 1990).

Numerous studies have shown that, compared with men, women have a poor medical prognosis following heart attack including a higher mortality rate (eg Wilkinson *et al*, 1994). The reasons for this are open to debate, however, with some authors claiming the difference is due to late referral, greater age and more co-morbidities, while others claim to have controlled these variables.

Some Recent Signs Of Change

In 1991 the National Forum For Coronary Heart Disease Prevention hosted a closed symposium to investigate male-female differences (RCP, 1991) and this was later published as a book (Sharp, 1994). This was mirrored in a joint Swedish/US conference on women, stress and CHD (SSM, 1994) which was also published as a book (Ortho-Gomer *et al*, 1998). And in 1995 the British Association For Cardiac Rehabilitation adopted CHD and women as its annual conference theme (BACR, 1995). All this, along with a plethora of editorial type articles in health and medical journals, is a clear sign of increasing professional awareness.

In an attempt to increase women's awareness the British Heart Foundation published a pamphlet on women and CHD (BHF, 1998b) and a paperback book on heart health for women has also been published (Smart & Holdright, 1995). In 1995 a women's heart centre was established at the Glasgow Royal Infirmary with the object of developing a research base and increasing women's awareness of risk and a similar unit was opened last year at Guy's And St. Thomas's Hospital in London.

Comment

The evidence presented in this section indicates that, despite the importance of CHD as the leading cause of death among women, females have not been viewed by the medical profession or by health policy makers as an important group in respect of CHD prevention and treatment. Furthermore, women themselves seem unaware of their risks. All this seriously disadvantages women, who continue to suffer higher mortality rates than men.

Despite the encouraging signs listed above, however, and despite the fact that a number of studies are now underway in an effort to redress the imbalance, the available data still fails to constitute an adequate knowledge base for practice (Shumaker & Smith, 1995).

1.5 Conclusion

This chapter has provided a broad *context* within which the *focus* of the thesis can be located.

The *context* of the thesis is that of women's unequal plight in relation to maintaining and restoring health, and heart health in particular. There is a lack of awareness of women's CHD risks among both the medical profession and women themselves, and this is reflected in both illness behaviour and treatment.

The *focus* of this thesis is psychological adjustment to heart attack. Psychological issues that have been raised in this chapter, and which will be developed elsewhere, relate to women's health behaviour, symptom perception and illness behaviour. It has already been noted that these are related to bio-medical outcomes, but the thesis will aim to establish whether these factors are also related to psychological outcomes. And if so, whether these outcomes are related directly to biological sex or some socially constructed gender variable.

CHAPTER TWO

THE CARDIAC LITERATURE: ILLNESS AS AN EVENT

2.1 Introduction

This chapter will show that there is a large body of research literature describing men's experience of suffering a heart attack, the extent to which they are able to adapt to their changed circumstances and re-establish their psychological and social equilibrium. It will show that a wealth of data testifies to our understanding of men's psycho-social needs and that intervention studies have shown that much psychosocial morbidity can be avoided.

However, as might be expected following the comments in Chapter One, it will also show that only a small minority of these studies included women in their samples, and an even smaller number are comparative or women only studies. The result of this is that very little is known about the psychosocial experience of women following heart attack, so rehabilitation staff are poorly placed to anticipate and meet their needs. From what is known, however, there does seem to be a differential in post-coronary psychological morbidity in favour of men. Since so little is understood about women's psychological adjustment, it will be useful to include a discussion of what is known about men.

Studies on men have tended to view heart attack as an event and to focus on particular issues or endpoints that are traditionally seen as markers of psychological adjustment and which can be used to gauge recovery and the impact of interventions. The chapter is divided into sections accordingly. These sections are: disturbances in affect; return to work; resumption of sexual activity; compliance with health related advice; and global quality of life. Additionally, a section is included on family and domestic issues which, while not in itself a standard marker of adjustment or a focus of prior research, pulls together strands from other areas of study and provides a backdrop for following chapters. This area might be of particular relevance to women. Each

section begins with a brief summary of the research conducted on men and then gives a more detailed account of studies that have included women.

2.2 The Effects Of Heart Attack On Affect

Psychological distress is common following heart attack, both in the immediate aftermath and, for some people, in the following months and years. This includes anxiety and depression which, although generally regarded as two separate states, in some cases with different underlying biochemical concomitants, they frequently co-exist following heart attack (Stern *et al*, 1977; Frasure-Smith, 1999).

Anxiety

Anxiety is undoubtedly the predominant emotional response in the acute phase (Byrne, 1987) and it has been extensively studied in men. The very earliest studies showed that initial anxiety was associated with the technological environment of the critical care unit, but during the 1970s this perception changed and patients began to perceive the critical care environment as a source of comfort, reassurance and safety (Lewin, 1995).

The bulk of the literature originates in the 1970s and is overwhelmingly biased towards male samples. Most studies showed that anxiety tends to peak on admission to the Coronary Care Unit, then on transfer from the CCU to the ward, and then around the time of discharge from hospital (Dellipiani *et al*, 1976), though there are also indications of another peak at six weeks (Thompson *et al*, 1987). Studies have identified that, at least for men, initial anxiety is caused by fear of sudden death and fear of recurring chest pain (Baxter, 1975). Studies on men have also identified some of the coping mechanisms employed in this situation, eg inappropriate sexual behaviour and denial. Several studies have shown that denial is effective in reducing men's anxiety but negatively associated with their compliance behaviour (eg Levine *et al*, 1987).

A series of studies by an Edinburgh-based research group contributed much to our knowledge during the 1970s. In one study they recruited 203 consecutive middle aged male heart attack admissions and conducted structured psychiatric interviews "at intervals" while they were still in hospital (in the 1970s hospital stay would have been about three weeks). They found that 65% of the sample were "emotionally upset" in some way. Anxiety was common, occurring in 55% of first heart attack victims and 42% of those who had a previous history of heart attack. Subsequent studies by the Edinburgh group made use of standard psychometric instruments to measure anxiety and sometimes used a longitudinal design over several months (eg Dellipiani *et al*, 1976).

Quite apart from humane considerations, the importance of post-coronary anxiety is twofold. Firstly, high anxiety levels in ITU have been linked with increased mortality during the period of hospitalisation (eg Vetter *et al*, 1977). Secondly, although in most cases anxiety will subside over the months following heart attack (eg Cay *et al*, 1972), in some cases it might lead to chronic psychological distress. Cay *et al* (1976) argue that protracted anxiety can lead to depression (cited in Byrne, 1987), and evidence for this assertion is considered in the next passage. Other authors have shown that the occurrence of heart attack can in some instances be of such significance as to be traumatogenic, ie leading to post-traumatic stress disorder (Kutz *et al*, 1988; Doerfler *et al*, 1994).

Finally, anxiety is of clinical importance because studies on men have shown that it can be avoided or reduced. For example, patient education has been shown to reduce peri-transfer anxiety as reflected in physiological measures (eg Toth, 1980) and family support has been shown to reduce both Spielberger STAI (State-Trait Anxiety Inventory) anxiety, and to reduce the likelihood of cardio-vascular complications (Schwartz & Brenner, 1979).

In view of the clinical value of the knowledge base on post-coronary anxiety in men, therefore, it is unfortunate that so little is known about anxiety in women. The studies that have included women in their samples, however, indicate that they may be more anxious than men.

There are indications that women experience more anxiety than men in the early post-coronary period. In a UK study of 338 patients (m254:f84) admitted to CCU with presumptive heart attacks, Vetter *et al* (1977) showed that women reported higher anxiety levels than men when a subscale of Cattell's Neuroticism Scale Questionnaire was administered. Importantly, high anxiety levels were linked with fatal cardiac arrests in both sexes in the period leading up to discharge. An Australian study of 120 CCU patients (m93:f27) conducted by Byrne & Whyte (1983) found that female heart attack victims reported higher levels of state anxiety than males at the point of transfer from CCU. In this case a visual analogue scale was used.

A small UK study compared men and women (m22:f19) between the ages of 41 and 74 some months after their heart attack and found that women reported significantly more anxiety as measured by the STAI (Shaw, 1994). An Indian study conducted by Kumar *et al* (1987) found that female heart attack victims expressed higher levels of death anxiety than did males and higher levels than other patient groups, though details of measurement are unknown.

Stern *et al* (1977) studied a US sample of 68 (m55:f13) middle class sequential heart attack admissions under the age of 70. Subjects were interviewed in the CCU and again at various intervals up to one year. Using the Taylor Manifest Anxiety Scale, women reported and more anxiety while in hospital and at 12 month follow-up. Finally, an Irish study by Guiry *et al* (1987), using a "psychological interview" with a cohort of 264 (m208 f56) aged under 60 with presumptive heart attack showed higher levels of symptoms and "more overt" anxiety from CCU right up to one year follow-up. Both of these studies showed depression was also more common among women.

Depression

Depression was also the subject of much research attention in the 1970s, though many of the early studies, almost of which excluded women, attempted to measure imprecise constructs such as "emotional distress" (Wynn, 1967) and

“psychiatric morbidity” (Lloyd & Cawley, 1978). Following this spate of research interest there was a gap of perhaps 20 years with few published studies, though there has since been a resurgence of interest in the 1990s.

It is estimated that 15% of heart attack patients meet American Psychiatric Association (APA) criteria for major depression and a further 20% have minor depression (Frasure-Smith, 1999). In some people depressive symptoms appear straight after the heart attack, but in most cases they appear after a period of several days (Fielding, 1991). It has already been noted that anxiety and depression often co-exist. It is also the case that a greater incidence of depression occurs in second and subsequent heart attacks compared to first heart attack. One explanation for this is that, where anxiety is high and protracted at first heart attack, it can subsequently transform into depression (Cay *et al* 1976).

The Post-Infarction Late Potential Study (PILP) in Germany involved following 560 male heart attack victims aged 65 and under, over a six month period. There were several important findings published in a series of papers (Ladwig *et al*, 1991, 1992, 1994). The incidence of major depression in this cohort was 14.5%, though the reports state only that “standard instruments” were used to measure this.

Another focus of research has been Montreal where Frasure-Smith and Lesperance have conducted a series of studies. In one study they measured depression in a mixed sex sample of 222 post-coronary patients using the Beck Depression Inventory (BDI) and DSM-based structured interviews at two points in the fortnight following admission. They found that women were more likely to be depressed than men (Frasure-Smith *et al*, 1995), a finding that is supported by several studies. Stern *et al* (1977) used the Zung Self Rating Scale in his mixed sex sample of 68 confirmed heart attack patients and found that women were more depressed while in hospital and at 12 month follow-up. Guiry *et al* (1987) reported the same findings having applied their psychological interview to 264 presumptive heart attack patients and followed them up at 12 months.

However, researchers are unclear why that should be (Frasure-Smith *et al*, 1995).

The clinical importance of post-coronary depression is also well documented. Depression is strongly predictive of physical morbidity, readmission, re-infarction and cardiac mortality (Stern *et al* 1977, Ladwig *et al* 1991, Frasure-Smith *et al* 1995) In the Frasure-Smith study in-hospital depression was significantly associated with 18 month survival. The Ladwig study showed that the power of depression to predict fatal events remained after the control of known predictors and that illness severity made no contribution to mortality. This last point is supported by other findings including the mixed sex study by Stern *et al* (1977).

In addition to these physical outcomes, post-coronary depression has been linked with failure to resume social and occupational activity (Schleifer *et al*, 1989). Several studies have associated depression with low compliance (eg Ladwig *et al*, 1994) and a rehabilitation study of 101 men revealed smaller gains in aerobic power despite an equal intensity of exercise training (Kavanagh & Shepherd, 1975).

An interesting finding reported by Frasure-Smith *et al* (1995) was a relationship between living alone and depression. This is consistent with the more general literature which links singleness with ill-health, and with recent interpretations of the coronary prone personality in which depression and social isolation are said to have a synergistic effect (Dennolet *et al* (1996). Other post-coronary studies have also linked single status and social isolation with depression and poor outcome (eg Case *et al*, 1992; Frasure-Smith, 1999).

Comment

One question to ask of these findings about negative affect is whether it might pre-date heart attack. Indeed, both neuroticism and depression have been identified as CHD risk factors (Shekelle & Ostfeld, 1965; Shekelle *et al*, 1991; Barefoot & Schroll, 1996). And it is known that women in general score higher

on trait anxiety and depression than men, so this might account for some of the gender difference observed following heart attack. Many possible reasons for these gender differences in the normal population are debated in the clinical literature including the possibility that, as suggested in Section 1.3, women are simply socialised into being more forthcoming in reporting such emotions. However, based upon retrospective diagnosis and the chronological development of depressive symptoms following heart attack, the literature generally concludes that some patients are likely to have been depressed prior to heart attack whilst others develop depression as a reaction to heart attack (eg Fielding, 1991). As regards anxiety, the literature indicates that those people with high trait anxiety are more likely to exhibit high state anxiety following heart attack (Cay *et al*, 1976; Byrne, 1979).

Studies that have included women in their samples consistently indicate that females report more anxiety and depression than males for up to a year following heart attack, and some studies have linked these emotions with clinical outcomes. Thus, women might fare less well than men in emotional adjustment, and have poorer physical outcomes as a consequence, yet there is a much smaller knowledge base to guide practice.

For example, studies have shown the vital importance of assessing and influencing men's psychological state very early in their hospital experience in order to have a positive influence on long term adjustment (Naismith *et al*, 1979), but it is not known whether these male derived assessments and interventions are appropriate to women.

Studies of emotional adjustment have concentrated on using structured measures of anxiety and depression. These are the constructs that have been sought and these are the constructs that have been found. In women we know little about the underlying basis of anxiety or depression since the studies conducted provide too little detail to be of real clinical value. Indeed, the assumption that anxiety and depression are the appropriate emotions to focus on might itself be mistaken. Women and men may experience other disturbing

emotions following heart attack which have not been identified by the research instruments used so far.

2.3 The Resumption of Work

Another measure of poor psychosocial adjustment is the failure of heart attack victims to return to work where this cannot be justified medically. On average people resume work 60-70 days after discharge from hospital (Vuopla, 1986). This is very much a standard measure of adjustment in men because of its association with emotional adjustment (Maeland & Havik, 1986) and because of its historic economic importance.

In men work disability rates have been variously estimated at 10-50%, but such figures are almost certainly underestimates because of the tendency for some people to return to work, only to become unemployed subsequently. For example, a study by Mayou *et al* (1978a) showed that, although 60% of the male sample resumed work initially, only 52% were still working a year later. Another limitation of the figures offered is that they represent only a crude differentiation between those who return to work and those who do not. Even amongst those who do return to work, there is evidence of reduced satisfaction and performance (Cay *et al*, 1973). So perhaps the broader concept of 'work disability' is more useful. In either event, unfavourable psychological and socio-economic consequences are liable to occur in the long term (Wishnie *et al*, 1971).

In men we know a good deal about the causes of work disability, which can be minimised by early intervention. A classic study by Wynn (1967) followed 400 men for two years after their heart attacks. There was a widespread belief among subjects that the stressful nature of their jobs, either physical or emotional, was the cause of their heart attack in the first place. This belief was considered by the researchers to be false in most cases, but it never-the-less resulted in unnecessarily prolonged unemployment and inactivity associated with increased anxiety, decreased security and decreased self esteem. A similar though smaller study showed that, of the total number of subjects who

were advised to resume employment, 46% had failed to do so at six months (Wishnie *et al*, 1971). Furthermore, even those who did return to work showed considerable reluctance and anxiety about doing so. A study by Mayou *et al* (1978a) showed a delayed return to work at six months in 60% of those previously employed, though 92% had resumed by one year (N=100).

Thus, although the percentage of men eventually returning to work has increased over time, unnecessarily long delays accompanied by anxiety still occur and are to be considered harmful. All three of the above studies, along with numerous others, confirm that the predictive value of medical factors such as severity of the attack and the presence of symptoms is, at best, about equal to psycho-social factors in determining the likelihood of return to work. These psycho-social factors relate mainly to negative attitudes and expectations which develop during the first hours and days following heart attack, and which are amenable to influence by professional staff and relatives. For example, a study by Naismith *et al* (1979) showed that counselling and health education applied to a sample of 143 men resulted in a significantly earlier return to work.

Data on women are particularly scarce in this area since females tend to develop heart disease about ten years later in life than men, with a sharp increase after the menopause (Wenger, 1985). With retirement at 60 in women, therefore, only a minority is still working outside the home when they have their first heart attack. What data there are, however, seem to indicate that women are more likely than men to suffer work disability.

In the previously cited longitudinal study by Stern *et al* (1977), women who had previously been in paid employment prior to their heart attack delayed returning to work for an average of 13.5 weeks compared with men's 7.9 weeks. These results are supported by those of Boogaard (1984) who found that at 6 months 90% of men had returned to work compared to 33% of women.

The only sizeable study to examine work disability among female heart attack patients is that of Chirikos & Nickel (1984). In this study a sample of 474 patients (m387 f87), all of whom had been in paid employment prior to their

presumptive heart attack, were interviewed in hospital and then over the telephone at various points in time for two years. The overall response rate was 91%. A much larger proportion of women failed to return to work compared with men: 53% versus 32%. Although medical factors, functional limitations and age were influential, they explained only part of the variance.

The important contribution of this study is that it demonstrated that men and women may suffer work disability for different reasons. Among the men, the researchers found that those on higher incomes were more likely to return to work, and that those who were married were slightly more likely to return. However, among the women there was no such relationship with income and women were more likely to return to work if unmarried. The authors concluded that the main determinants of work disability among females were the way they responded to their disease and economic necessity. They further suggest that health professionals may have encouraged work disability among women by failing to give them the same encouragement to return to work as they gave men.

Another study that may further contribute to our understanding of this is a large US postal survey of CABG surgical patients by Zyzanski *et al* (1982). The results showed that men were more likely to return to work than women and that excessive delays in returning to work were less common among men. In support of the Chirikos & Nickel findings, this study found that men were more likely to return to work if they had high incomes and professional jobs requiring little physical exertion and having autonomy and flexibility in respect of their work, but this was not so for women. Those women who did not return to work tended to score high on Type A and showed the worst emotional adjustment. Again, the researchers suggested that women had been least adequately prepared for work by their physicians. It should be noted that this study focused on CABG rather than heart attack patients so subjects were less likely to have been in work prior to the cardiac event.

Although numerous studies have demonstrated associations between anxiety and depression and return to work (eg Maeland & Havik, 1986), the nature of

the relationship has yet to be established. Among the possibilities are that dysphoria leads to work disability, that dysphoria results from work disability or, more likely, that causality is bi-directional.

Comment

In conclusion, the meagre evidence we have suggests that those women who go out to work are less likely to return to paid employment following heart attack than their male counterparts, and those who do return are more likely to delay longer. It also suggests that different factors might apply in predicting return to work among men and women and that one such factor might be the attitudes of staff. However, work disability may not be a valid marker of psychological adjustment for large numbers of women such as the elderly and those for whom workplace is home.

2.4 Resumption Of Sexual Activity

Sexual functioning is another outcome that is frequently used as a measure of psychological adjustment following a health crisis including heart attack. Although notoriously difficult to measure for a variety of reasons, and although sometimes confounded by the effects of medication, ageing and penile atherosclerosis, the research evidence derived from men indicates very clearly that sexual activity frequently undergoes a decline following heart attack, and that this decline is usually unconnected with biomedical factors.

In the Mayou *et al* (1978b) study, for example, twelve months after heart attack 25% of men reported reduced frequency of sexual intercourse, 20% reported less satisfaction and around 50% reported no change (N=82). In the Skelton and Dominian (1973) study, of those men who were sexually active prior to their heart attack (N=38): 28% reported reduced frequency; 8% cessation; 50% no change; and 8% increased frequency attributed to the man's increased libido. A comparative study by Hellerstein and Friedman (1970) confirms the above with 58% of subjects reporting a reduction in frequency or complete cessation of sexual activity six months after the attack (N=48) and, as regards quality

(N=44), 52% reported no change, 25% a deterioration and 23% an improvement.

Quite predictably, one of the earliest studies of cardiac sexuality to involve women adopted the perspective of women as wives rather than victims of heart attacks. It is possible to conclude that women were considered important only in so far as they related to men's sexual adjustment.

In this study Papadopoulos *et al*, (1980) studied 100 wives of heart attack patients, all of whom were sexually active prior to the heart attack. The study showed that while their husbands were still in hospital, 20% of the wives wondered whether sexual intercourse would be too strenuous for their husbands in the future, and a further 20% worried that it may not be safe. Following discharge from hospital, however, 100% of wives developed concerns about sexual activity. The outcome was that 76% of couples finally resumed sexual activity within three years: 49% with reduced frequency; 46% to pre-morbid levels; and 5% with increased frequency due to emotionally closer relationships. Of those couples with reduced frequency, the reason given was fear of another attack or death (ie fear on the part of either partner) in 44% of cases, and a lack of desire in 38%. Of those who did resume sex 45% changed their technique or positions, presumably to reduce the energy demands upon the male, though this is probably neither necessary nor helpful (Nemec & Mansfield, 1974). Of the 24% who failed to resume sexual activity, some couples said they did not attempt sex, and others said they had discontinued due to male impotence. Interestingly, there was no significant relationship between high anxiety levels and failure to resume sexual activity.

Although the great bulk of the literature in this area focuses on men, several small studies have included women in their samples. Boogaard (1984) found that all her subjects (N=20) had resumed sex within three months but, within this, women had delayed resumption for longer than men. Shaw (1994) found that women were less likely to resume sex than men, and their mean delay was 7.3 weeks, compared with 5.7 weeks for men (N=40). Additionally, 44% of

women reported reduced frequency and/or enjoyment compared with 38% of men.

Larger studies have produced similar results. Hamilton & Seidman (1993) found that, within their sample of 62 (m42:f20) women reported a less satisfactory sexual relationships with a greater decrease in frequency than men. The Stern *et al* (1977) study referred to above found that women were less likely than men to ultimately resume sexual activity (40% did versus 93% of men), and tended to delay sex for longer than men (mean 11.5 weeks versus 6.1). Reduced frequency and quality of sex was reported by 20% of the sample, the majority of whom were anxious or depressed.

Two much larger comparative studies have been reported. The first is a US study by Papadopoulos (1978). He studied 135 (m118:f17) patients aged 37-80 years who had a history of heart attack in the previous six months. Patients were interviewed by their own physicians, but of the 80 physicians asked to participate only 11 agreed and carried out interview effectively. Papadoloulos inferred that this was a clear indication of discomfort with the subject on the part of physicians. No gender differences were reported, though the results did add to the knowledge base generally by identifying those factors that were barriers to resuming sex. On average, resumption of sex occurred at 10.7 weeks, only 25% of those patients who were previously sexually active maintained former levels of activity and 21% did not resume sex at all. Reasons given for non-resumption included fear on the part of the patient or spouse; impotence, usually believed to be psychogenic; and cardiac symptoms.

In a UK uncontrolled intervention study, Mann *et al* (1981) implemented a rehabilitation scheme in which advice on sexual behaviour was included and then assessed its impact at 12 months. The 88 subjects included 50 patients who were previously sexually active, of whom nine were female. The mean time of resumption was nine weeks with some patients resuming prior to advice and others not resuming at all in the first year. In addition to non-resumption, reduced frequency was reported by a majority of patients and the reasons given were: lack of desire; impotence: symptoms; and anxiety. Anxiety levels were

low compared with other studies, perhaps because of the counselling offered and sexual problems correlated with neurotic symptomatology. No gender differences were reported which may have been due to the small proportion of females.

Finally, Papadopoulos *et al* (1983) conducted a study on an exclusively female post-coronary sample. A total of 165 women were approached but 35 refused to participate due to personal or family objections to the topic, leaving a final sample of 130. All women were under 65 years of age and had suffered a heart attack between 4 and 51 months previously. The women were interviewed at home using self developed structured questionnaire. Of the 65% of women who were sexually active prior to their heart attack, 30% developed sexual concerns while in hospital. These were mainly about safety, about whether sex would be of the same quality as before, and about whether they would still be attractive to their husbands. Women were uncertain how long they should leave it before resuming sex. The mean time of resumption was 10.8 weeks with 72.6% of women ultimately resuming sex. Those who did not resume at all said that the reason was either loss of libido, fear of consequences or their partner's fear. A further 44% of women reported a decline in frequency. Of those who did not resume sex, half the couples reported a decline in their emotional relationship, but the direction of causality is not known. As in other studies of men and women, the absence of adequate advice emerged as a feature.

In conclusion, there is little reliable evidence, but from what we know it would seem that women appear to suffer the same or possibly greater sexual morbidity compared with men. Those studies which do indicate greater sexual disruptability in female heart patients contradict common assumptions about the fragility of male sexuality (eg Hailey & Hardin, 1988). However, this may not be a reasonable comparison for the following reasons. Firstly, women generally are believed to retain their libido for longer than men as they age (Hite, 1987). Secondly, women in high risk age groups are less likely to have a sexual partner than men of a similar age due to women's greater longevity and because women tend to enter the high risk age group about ten years later than men (Stern *et al*, 1977). And thirdly, a study of 100 female heart attack victims

compared with 100 controls indicates the possibility of a different sexual profile in women with heart attacks. In a retrospective data analysis Abramov (1976) studied the sexual histories of his subjects and found significant differences between the two groups including a high incidence of pre-morbid frigidity in the heart attack patients (65%) compared with the controls (24%). This frigidity was usually longstanding and was in most cases attributed to their husband's impotence or ill-health.

Hailey and Hardin (1988) report that 155 college students who were given patient descriptions generally expressed an expectation that male patients suffering such illnesses as heart attack would be more likely to experience sexual difficulties compared with female patients. The authors conclude that (US) society perceives male sexuality as being more fragile and disruptable, perhaps because men are seen as the initiators and simply do not initiate when they are ill. This perception of the masculine role in sexuality would explain the fact that, except for some of the Papadopoulos studies cited above, all the research literature seems to concentrate on sexuality as a male issue (eg Jones Watts, 1976; Thompson, 1980; Cooper, 1986).

Comment

A trend that the writer has identified in the literature indicates that excessive delays in the resumption of sex have declined over the years with early studies showing greater mean delays than more recent ones. For example, in 1964 Tuttle reported 14 weeks; in 1970 Hellerstein & Friedman reported 13.7 weeks; in 1978 Papadopoulos reported 10.7 weeks; and in 1981 Mann *et al* reported 9 weeks.

Although studies are few, there is some evidence of sexual difficulties among angina sufferers. For example, a sample of 30 men and five women reported the widespread experience of cardiac symptoms during sexual intercourse, these including breathlessness, angina and palpitations (Jackson, 1981). It seems plausible that concern and worry about nature of these symptoms might contribute to the decline in sexual activity among angina sufferers, some of

whom will go on to suffer a heart attack. Thus, in some CHD patients sexual decline might begin prior to heart attack.

2.5 Compliance With Health-Related Advice

The term compliance is very controversial, carrying as it does connotations of paternalism and authoritarianism. Indeed some health professionals distance themselves from such connotations by using terms such as adherence and concordance. Notwithstanding these reservations, the notion of compliance is widely used as a marker of 'good' or 'bad' adjustment to a variety of health crises including heart attack. Here the concern is with health related advice which health professionals believe will reduce the chances of complications or recurrence and, in some cases, improve the quality of life. Once again, the research literature is heavily biased in favour of males.

Rehabilitation Programme Attendance

The great majority of rehabilitation studies have been conducted on men. Indeed, cardiac rehabilitation programmes have been developed from knowledge generated from male research (Feigenbaum & Carter, 1987, cited in Schuster & Waldron (1991). This might reflect the more general androgenic bias discussed in Chapter One, ie assuming that women are the same as men or just ignoring them, or it might have been a utilitarian approach to getting men back to work.

Never-the-less, as noted in Section 1.2, there is good evidence that rehabilitation programme attendance has substantial physical and psychological health benefits for both men and women. The problem is that women are less likely than men to attend these programmes, and those women that do attend are more likely than men to drop out prematurely. This is despite the fact that several studies have shown that women obtain a training benefit that is equal to men's (Ades *et al*, 1992). Indeed, in view of their poorer psychological and physical condition, their potential for improvement might be greater.

As regards attendance Boogaard (1984) reported that 50% of the men (n=10) in her US sample enrolled on a rehabilitation programme compared with only 10% of women (n=10). McGee & Horgan (1992) analysed the attendance data of 583 men and women at an Irish cardiac rehabilitation centre and found that 49% of men attended compared with 34% of women. Other studies have reported the same results even when women and men were shown to have similar clinical profiles (eg Ades *et al*, 1992).

As regards dropout, women appear to fare worse on this measure too, as the next two studies demonstrate. In the US Oldridge *et al* (1980) conducted a study of 28 women who were undergoing a post-coronary exercise programme. Although the dropout rate was higher for women than for men, those women who continued to attend showed the same benefits as men along a range of physiological measures. They also had greater confidence in their coping with the activities of daily living and had fewer overall problems.

An Irish study by O'Callaghan *et al* (1984) involved a mixed group of 264 (m227:f37) heart attack and CABG patients who were attending an eight week programme thrice weekly. Although the initial enrolment rate was similar, the dropout rate for males was 7.8% and for females 18.9%. Again, the benefits of exercise were found to apply equally for both sexes along a range of physiological measures.

As regards the reasons for non-attendance and dropout, the most common reason given by women in the O'Callaghan study was domestic commitments. Furthermore, despite advice to the contrary, the women believed that they exercised enough at home and that it would have been "selfish" to have put their own health before their domestic responsibilities. Another finding was that women were less likely to be accompanied by their partner when attending the classes, and it is known from research on men that accompaniment is important in maintaining compliance (O'Callaghan *et al*, 1984). A study by Sharpe *et al* (1991) revealed that women's reasons for non attendance were often transport difficulties and family concerns, whereas men refused because of time constraints.

Older people are another group that is at risk of non-attendance and dropout. Several studies have identified that greater age is a significant and independent barrier to attendance. However, although women are likely to be older than men when they have a heart attack, studies show that age does not fully explain women's poor representation at rehabilitation programmes. For example, McGee & Horgan (1992) found that age and sex were independently predictive of poor programme participation. In their retrospective analysis (cited above) they report that men in their seventies were more than twice as likely to attend than women in their seventies.

Another possible reason for non-attendance may be connected with the quality of communication and the level of encouragement by hospital staff. Winefield & Katsikitis (1987) studied a mixed sex sample of 109 heart attack victims over the age of 75 and followed them up for three months following discharge. Women did not particularly value professional help and attributed their heart attack to bad luck. The authors suggest that the sex of the physician may be a factor, and that women may be less responsive to the usual rehabilitation advice that is offered. Other studies have produced similar results (eg Halm *et al*, 1999). Ades *et al* (1992) studied a sample of 226 consecutive heart attack admissions, 43% of whom were women, with a maximum age of 62. The most important factor influencing attendance was the strength of the physician's recommendation, and the recommendations were stronger for men than for women. It remains to be demonstrated whether physicians are biased in their referral behaviour, perhaps ignorant of women's capacity to benefit, or whether women are less inclined to attend, which would be consistent with their lack of exercise relative to men throughout the lifespan (OPCS, 1989).

Risk Factor Modification

In Section 1.2 it was argued that planned graduated exercise has physiological and psychological benefits post-heart attack, and has the added benefit of modifying other risk factors such as obesity and hypertension. However, it should also be noted that premature or inappropriate exercise can be dangerous (Littman, 1993). As stated in the previous passage, women are

generally less motivated than men to engage in exercise in all age groups throughout their lives. This also seems to apply to prescribed exercise following heart attack, whether at home (Sharpe *et al*, 1991; McGee & Horgan, 1992) or within the context of a rehabilitation programme.

Two studies have shown that men are more likely than women to engage in recommended aerobic exercise such as walking, thus promoting cardiovascular endurance (Hamilton, 1990; Boogaard, 1984). Women, on the other hand, are more likely than men to engage in household tasks which involve a combination of dynamic and isometric activities such as housework (*ibid*).

Having survived a heart attack, the one single action that an individual can take in order to improve their chances of avoiding recurrence and death is to stop smoking. In a study of middle aged men Rosenberg *et al* (1985) found that those patients who stopped smoking after their heart attack were 50% more likely to avoid recurrence and death than those who continued. Additionally, continued smoking is associated with silent (asymptomatic) ischaemia (Barry *et al*, 1989). This is important because of the value of pain as a warning. It also decreases the effectiveness of standard post-coronary medication including beta-adrenoceptor blockers and calcium antagonists (Deanfield *et al*, 1984). There is therefore a powerful case for recommending smoking cessation. Robinson *et al* (1988) examined the records of 980 (m643;f337) heart attack patients and found that women smokers were less likely than men to have given up following their heart attack (Robinson *et al*, 1988).

Comment

In conclusion, there seems to be evidence that women are less compliant than men, particularly in respect of smoking, exercise programmes and attendance of rehabilitation classes. Despite having an equal potential to benefit and despite believing in the benefits, women's behaviour may be subject to different motives and pressures. There are hints in the literature about barriers to attendance such as "family concerns" and "domestic commitments" but reports give no details about exactly what these terms mean. There are also questions

about women's beliefs, information needs and response to professional consultation, and the extent to which standard cardiac rehabilitation programmes, which have been developed and evaluated in relation to men, meet their needs.

2.6 Global Quality Of Life

Rather than the traditional reductionist approach whereby individual constructs are identified and measured, the relatively recent development of health related quality of life assessment instruments has enabled researchers to assess adjustment to heart attack in a more global way. Of course the majority of studies have used all male samples, but some studies have drawn comparisons between men and women.

The earliest such study found is that of Foley *et al* (1983) in which the Sickness Impact Profile (SIP) was administered to a sample of 218 (m218:f39) US heart attack survivors. It was administered in hospital, and then again at three months and at six months. Although the study revealed no gender differences in SIP scores, it did show a significant difference in the Activity Questionnaire, which was also administered, this showing that women returned to driving less frequently than men. This has been published only in abstract form so further details are unavailable.

Another study used the SIP and other questionnaires for a telephone survey (Sharpe *et al*, 1991). This was administered to a US sample of 364 (m52%f48%) elderly patients with documented heart disease. The response rate was only 45%. Men were more likely to be educated, married and employed whereas women were more likely to be widowed.

In this study women had higher total SIP scores than men, and scored higher on the physical dimension (body care and movement, mobility and ambulation) and on home management. They rated their health as being poorer than men did, had more symptoms and more functional limitations. Women also reported higher levels of stress in relation to household responsibilities. The authors

conclude that women's greater difficulty in daily activities was due to the fact that home-based female roles continue after retirement, no matter how old a woman is, whereas men retire completely from outside work. While men might increase their contribution to household chores upon retirement, women remain primarily responsible for most chores, and trying to maintain this responsibility in the face of illness causes stress.

A team of researchers at University Of Goteborg has provided an important focus for quality of life research. Two CHD studies have included women in their samples. In both cases they used the Swedish version of the Nottingham Health Profile (NHP), which is the British version of the SIP, along with other measures.

Wiklund *et al* (1989) conducted a postal survey of five year heart attack survivors from three Swedish hospitals. The NHP and other questionnaires were returned by 444 men and women, which amounted to an 82% response rate. In Part I, which includes emotional and subjective well-being, all patients showed greater dysfunction than normals, but this was more marked in females. In particular, women scored higher on the Sleep Dysfunction scale, though this was also true of women in a normal population used for comparison. Women also scored higher than men in Part II of the NHP which deals with health related problems in relation to occupation, the ability to perform tasks around the home, personal relationships, sex life, social life, hobbies and holidays. These results show that poor health had a greater impact on women's global quality of life than men's.

In a later study Wiklund *et al* (1993) collected data on consecutive heart attack admissions to a Swedish Hospital. The purpose of the study was to compare the quality of life between men and women twelve months after heart attack. A postal survey resulted in 660 subjects (m421:f174) which reflected a 90% response rate. The postal survey included the NHP, the Sleep Dysfunction Scale and some self-developed instruments.

At one year women complained of more cardiac symptoms such as breathlessness on exertion, tiredness, palpitations and chest pain than men. They also complained of more pronounced psychosomatic symptoms, anxiety and sleep disturbances. NHP scores showed that women had more health-related problems than men in the domains of housework and social life. Home and family activities tended to take priority with the women, and Wiklund speculates that this may be the reason for women's under-utilisation of rehabilitation facilities. She further speculates that the greater incidence of psychological and psycho-somatic problems in women might influence the way in which they are treated in the acute phase and later. Importantly, the major findings stood firm after controlling for age and co-morbidities.

Conn *et al* (1991) studied 197 (m117:f80) heart attack victims 1-2 years after the event. They were all over 40 years of age. A battery of psychometric questionnaires including the Perceived Quality Of Life Scale were administered by interview. Compared with men, women generally and older women in particular had poorer health as measured by reduced activity days, chronic co-morbidities and subjective health appraisal. Older women were also less likely to participate in therapeutic exercise. There were no gender differences in the overall quality of life or in psychological symptomatology, perhaps because of the lack of sensitivity of global quality of life measures.

Schron *et al* (1991) studied a US sample of 1498 (f264 m1234) heart attack patients. The Health Quality of Life Questionnaire was used and overall results were worse for females after adjustment for age and co-morbidity. Areas in which females were worse off were: health expectations; social support; social integration; life events; cardio-vascular symptoms; and emotional symptoms.

A recent UK cross sectional study involved the application of a structured interview to 60 women and 60 men about six months after their heart attack (Radley *et al*, 1998). The interviews included several questionnaires that together tapped into a broad range of domains. An important part of the study, and one that represents a novel approach to studying cardiac patients, was the analysis of problems. Problems were participant-defined and related to

experiences recalled from their time in hospital or the period that had elapsed since. The problems were classified and gender differences emerged as follows. Although there was no difference in the total number of problems reported by men and women, men were much more likely than women to claim that they were problem-free. If true, then the remaining men presumably had a very high concentration of problems. More problems were reported by people in low socio-economic groups and, worryingly, those who did not attend a rehabilitation programme. In both sexes problems were associated with poor health and the presence of symptoms, and in women problems were also associated with younger age and restricted social outlets. The researchers concluded that the greater concentration of problems among younger women was due to the combined effects of their responsibilities and their emotional reaction to heart attack. For men an important problem category was work and finance, whereas women were over-represented in the category appertaining to lifestyle change that included housework, leisure and recreation. In younger women problems arose from demands made upon them, whereas in older women the problems were more about coping with co-morbidities. Once again, the results point at an outward looking life for men which is centred on the provider role, and an inward looking life for many women which is centred on nurturing.

Comment

Although the results reported in the above studies vary in detail, ie from dimension to dimension, they do consistently show that women seem to experience a lower global quality of life than men following heart attack. There is much debate currently about the sensitivity and appropriateness of global quality of life measures following heart attack, but the results reported here are consistent with those yielded by more specific uni-dimensional instruments. Again there are hints that there may be qualitative gender differences in relation to family roles and relationships, though these are not properly revealed by the instruments used.

Whereas traditional uni-dimensional instruments are very narrowly focussed, global quality of life instruments sacrifice sensitivity in the interests of breadth. Studies are currently underway at several centres to develop and test cardio-specific measures such as the Quality Of Life Index (QLI) questionnaire. One such study using the QLI has already focussed on 96 post-coronary women and, although the response rate was only 26% the study confirmed the importance of return to work and social support in determining quality of life and self esteem (Wingate, 1995). It will be of great interest to see whether future comparative studies using cardio-specific instruments reveal gender differences.

2.7 Family And Domestic Issues

Previous sections have focussed on established markers of psychosocial adjustment that have been the focus for countless investigations on men. This section combines several thin and disparate strands of data around family functioning which have appeared in the results of some studies but rarely been the focus of research in its own right.

The Impact Of Heart Attack On Spouses

One area in which women have received abundant research attention is in their role as spouses of male heart attack victims. Only one or two studies have included male spouses in their samples and these have not discussed the possibility of sex differences in their results (eg Stern & Pascale, 1979). This may be partly accounted for by the fact that female heart attack victims are more likely to be older and therefore widowed (eg Stern *et al*, 1977; Case *et al*, 1992).

As regards what is known from the male literature, it appears that wives suffer as much emotional distress as their husbands, and that heart attack affects the functioning of the whole family.

Skelton and Dominion (1973) studied 65 wives and described their initial response as a grief reaction characterised by: numbness, panic, insomnia, anorexia, anxiety and depression. They suffered feelings of guilt and self blame in relation to the attack and developed various psychosomatic symptoms. The findings of Mayou *et al* (1978b) were very similar, with 38% of wives suffering moderate or severe distress while their husbands were in hospital (N=82).

The evidence is that wives continue to suffer distress after their husband's discharge from hospital and, according to Mayou *et al* (1978b), this lasts for at least a year. Wives find the period following their husband's discharge to be stressful, and they complain of anxiety, depression, tension and insomnia. Eight weeks after discharge, Hentinen (1983) found that 83% of wives complained of insomnia, 69% complained of fatigue, and there were widespread complaints of depression and anorexia. At two months Mayou *et al* (1978b) found that wives complained of fewer symptoms than before, though there was still considerable anxiety, depression, fatigue, insomnia and poor concentration. At one year Skelton and Dominion (1973) found that 25% of wives still had severe emotional disturbance, and that 40% fell ill during this time with 17% visiting their physicians more often than before. According to Hentinen (1983), the usual reasons for these increased consultations were anxiety, depression, chest pain and urinary tract infection.

Much more recently O'Farrell *et al* (2000) reported on a study of 213 self selected female spouses whose husbands were undergoing Phase 2 rehabilitation. The results support those of studies reported above, with many wives, particularly younger ones, experiencing emotional distress.

Impact Of Heart Attack On Relationships

Both the Mayou *et al* (1978b) and Skelton & Dominion (1973) studies capture the interpersonal tension that so often occurs as husbands become increasingly dependent and irritable. They often feel resentful, frustrated and humiliated at their changed role within the family and at watching their wives do "men's jobs", often not to their own standards. Meanwhile, wives become overprotective and

fearful of upsetting their husbands. Studies report feelings of guilt, as though wives regard themselves as being in some way to blame for their husband's heart attack. They try hard to suppress any feelings of grievance or hostility for fear of upsetting their husband and precipitating another attack, and this inevitably leads to resentment and tension. (Mayou *et al*, 1978b; Skelton & Dominion, 1973).

Studies vary in the amount of marital disharmony reported. For example, Wishnie *et al* (1971) reports that all 18 couples studied showed a steady and eroding conflict, largely stemming from confused and discrepant understandings of one another's roles in the rehabilitation process. However, Mayou *et al* (1978b) found that only 20% of marital relationships worsened and, in 18% of cases, general family relationships suffered. Furthermore, 25% of couples and 16% of families reported improved relationships due to a lasting re-evaluation, a cessation of taken-for-grantedness and a consequent increase in tolerance and consideration.

It would seem that a wide range of variables could explain these discrepant results. However, most studies conclude that the extra strain of heart attack leads to deterioration in a large number of marriages, and that a smaller but nonetheless significant number of relationships are characterised by increased closeness and commitment (eg Shaw, 1994). Studies also agree that the marital outlook is better if the relationship was sound in the first place, and if the wife maintains her outside work and leisure commitments (Mayou *et al*, 1978b). Although nothing can be done to influence the former, there is clearly tremendous scope for counselling by occupational health, hospital and community nursing staff in relation to encouraging an open relationship with an outward-looking lifestyle for both partners.

Impact Of Relationships On Adjustment To Heart Attack

Studies on men have consistently shown the importance of a supportive and optimistic wife for psycho-social adjustment. In particular, her importance has been shown in the role of helping him develop positive attitudes in the early

days after heart attack (Mayou *et al*, 1978b; Skelton & Dominion, 1973). More recent work by Waltz & Badura (1988) has highlighted the long term value of high intimacy marriages in men recovering from heart attack (Waltz & Badura, 1988). Following their longitudinal study of 400 men and their spouses over five years following heart attack, they found that high intimacy marriages resulted in the maintenance of self esteem and the lifting of depressed mood. In another men only study, Figueiras & Weinman (1998) reported on importance of wives's mental representations in influencing men's dietary changes, their emotional well-being and their sex lives. There are still no data on male spouses.

Little is known about the role of husbands in helping women adjust to their heart attacks. Two studies have shown that husbands are reportedly more likely than wives to be regarded as over-protective in the post-coronary period (Stern *et al*, 1977; Shaw, 1994), something which is thought to be unhelpful where men are concerned since it encourages unnecessary invalidism. There have also been suggestions that husbands may inappropriately withhold sex (Papadopoulos, 1978) and are less likely to accompany their wives to rehabilitation classes (O'Callaghan *et al*, 1984).

Following discharge from hospital, women have reported feeling more isolated, apathetic and in need of companionship compared with men, and had more marital and social difficulties at six months but not at one year post-heart attack (Stern *et al*, 1977). It is known from the general social psychology literature that women are likely to be more sensitive to marital disharmony than men (Bolger *et al*, 1989; Barnett, 1996 cited in Thomas, 1997).

Household Roles

As regards the resumption of household roles following heart attack, a handful of studies have examined this and indicated that there may be gender differences.

Mayou *et al* (1978b) found that, following their heart attack, 67% of husbands decreased their leisure activities and 65% undertook fewer household chores

such as gardening and decorating. This obviously had implications for wives who tended to take over heavy chores around the house, and decreased both work and leisure activities outside the home.

Boogaard (1984) conducted one-off qualitative interviews with her sample of 20 (m10:f10) between three and six months after heart attack. One week after discharge from hospital both men and women reported resting and relaxing within house, but women also engaged in light household work. During this early rehabilitation period all patients said their families regarded them as being ill and did not expect a resumption of normal household roles, but while men were waited on during this period women resisted such help. Half the females (n=10), even those with supportive families, said they felt guilty because they were unable to perform their usual chores around the house. No such sentiment was expressed by men. Boogaard suggests that women may not understand the high energy requirements of some household tasks and may not view them as work.

Also using a qualitative approach, Johnson & Morse (1990) studied 14 (m7:f7) heart attack patients. They found that many women attempted to protect their maternal roles, were uncomfortable accepting comfort from their children, downplayed symptoms and discouraged visitors. Many women found it very difficult to return home without resuming their work role, engaging in excessive physical activity against advice, regarding this as better than feeling dependent, and rationalising it by saying that housework is not real work. Even those women with outside jobs felt the necessity to resume housework long before their return to work. The authors suggest that it is culturally unacceptable for mothers to rest when there is work to be done.

In contrast to this, they found that men encouraged and enjoyed the attention of their family members, which was seen as a sign of love and concern. They were mainly worried by the threat to their bread-winning role, often had work brought into hospital to them, but generally rested while at home and offered minimal assistance with the housework, ie the tasks which they did undertake were less vigorous than those undertaken by the females. Men feared others would see

them as physically weak, incapable and impotent, and therefore demonstrated their ability by (eg) lifting heavy objects and doing other heavy tasks unwisely (Johnson & Morse, 1990).

Hamilton & Seidman (1993) conducted a survey of 62 (m42:f20) heart attack patients at an unspecified point following hospital discharge. They found that women reported having more responsibility for household chores within four weeks of heart attack, specifically cooking, washing up, bed making, laundry, dusting and sweeping. Women received less "counselling" than men. The findings of this study should be seen in the light of a 37% response rate.

An Irish study involving a mixed sample of 264 (m227:f37) heart attack and heart bypass surgery patients was published by O'Callaghan *et al* (1984). This showed that women received less family support following illness, with their husbands and family taking over household chores in the immediate post discharge period but maintaining this support for only a short time. In contrast to this, men remained 'ill' longer and received greater family care and support.

Comment

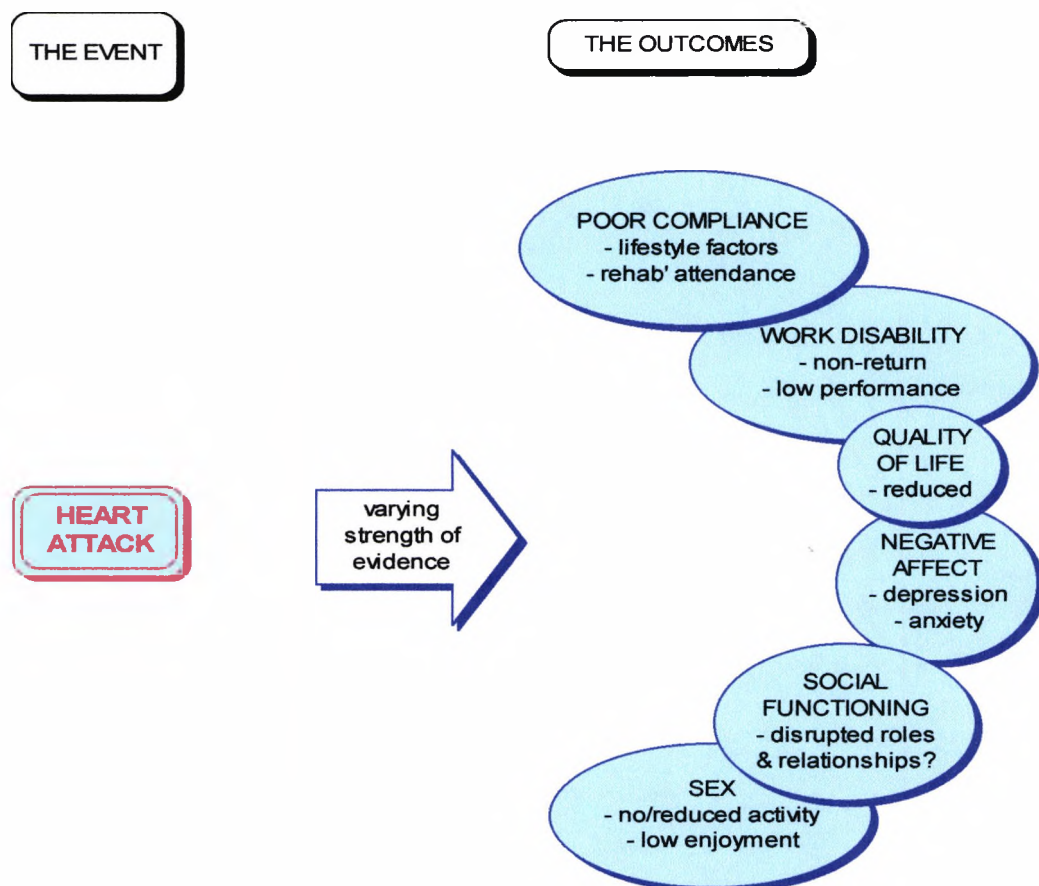
The whole area of family roles and relationships, including sick role occupancy and the salience of the home as workplace, has been little researched to date. However, there are indications that major qualitative differences may exist in the experiences and needs of women and men following heart attack.

2.8 Concluding Comments On The Cardiac Literature

In the last few years there has been some recognition of the need to develop a knowledge base on the experiences, needs and problems of women who suffer heart attacks. However, compared with the vast literature on men, it remains the case that there is a paucity of data derived from women.

Those studies that have included women in their samples and analysis consistently indicate that women are worse off than men on a number of key psycho-social dimensions following heart attack. Many of the studies cited above have used matched comparison groups and many of them made statistical adjustments to account for the effects of age and co-morbidity, both of which are particularly salient to women. Furthermore, the achievement of statistical significance is all the more impressive in view of the small proportion of women in many of the samples. Figure 2.0 depicts the state of the research to date that has examined the psycho-social impact of heart attack.

Figure 2.1 The Cardiac Literature



Despite the consistency of published results, however, the author regards this small but growing body of literature as being problematic in the following respects:-

- Considering the small number of studies that included women in their samples, there has been a remarkable variation in the measurement instruments used. For example, no less than six different instruments have been used to measure anxiety in the seven studies discussed, so like is not necessarily being compared with like.
- Sample composition has varied considerably, for example some but not all of the studies involved informants who had been subjected to interventions such as rehabilitation or counselling.
- There is considerable variation in time frame used, ie measurement points following heart attack vary between studies and often within studies.
- It is open to question whether women's apparent greater morbidity is real or simply a reporting bias, for example men may be less likely to admit to anxiety or reduced libido.
- It remains to be demonstrated how much of the distress and dysfunction that women report are the result of their heart attack and how much of it pre-dates the heart attack. For example, most studies indicate more sexual morbidity among women than men following heart attack, yet the Abramov (1976) study cited above suggests that in some cases this may pre-date heart attack.
- Prior studies have measured variation in constructs such as anxiety and usually demonstrated small correlations in respect of sex, eg women are more anxious than men. This kind of information does not provide the level of detail or explanation needed if prescriptions for practice are to follow. Health professionals need a clear picture of women's psycho-social experience so they can begin to base their clinical practice on sound evidence.

- Previous studies have been flawed by gender bias in variable selection, that is to say, they have tended to focus on the parameters and endpoints that were derived from male research. This approach runs the risk of perpetuating rather than diminishing the existing bias. The few qualitative studies that have been conducted provide hints that there may be issues and problems of concern to women, that have not been exposed by quantitative studies focused on male-derived constructs. Men and women might differ qualitatively whereas studies have searched for quantitative differences.
- The literature assumes that women constitute a single homogenous group. It may well be that the real issues lie within sub-groups within the female population that may have very different needs and problems. Examples of these might be Asian women, elderly women, disabled women, working women, housewives, and so on. And the same might apply to men.
- Finally, most previous studies have been cross sectional in design and have viewed heart attack as a discrete event that results in measurable outcomes. This type of research has provided little understanding of the subjective experience of undergoing heart attack, the context in which it occurs or psycho-social adjustment over time.

Thus, while the literature portrays women as being worse off than men in their psychological adjustment to heart attack, prior cardiac studies should be regarded as problematic. The next chapter will consider some of the research from other fields of health psychology that has focussed on processes and context rather than just outcomes.

CHAPTER THREE

THE GENERAL LITERATURE: ILLNESS AS A PROCESS

3.1 Introduction

Thus the cardiac literature is voluminous but is limited in a number of ways. It is comprised almost entirely of cross sectional studies that focus on outcome measures following heart attack in men: heart attack is typically viewed as a discrete context free event. In this chapter the wider health psychology literature will be drawn upon in an attempt to portray heart attack as part of a broader process.

It is clear from the information given in the passages on manifestations and symptomatology (Section 1.2) that the impact of heart attack is such that can be regarded as an acute illness episode to be survived. However, in another sense, it can be regarded as a chronic disease since there is no cure for CHD. Survivors therefore have to face a life crisis and must then find a way of adjusting to and coping with their new situation in the long term.

This chapter will consider studies and models from other areas of health psychology in order to re-cast heart attack as part of a health-illness process. This process begins with the experience of symptoms, proceeds to illness behaviour, facing the crisis and then coping with chronic illness.

3.2 Symptom Perception

Clearly the first part of the process of developing a health problem is the awareness of physical symptoms. Symptom perception is far more than the awareness of information that has been transmitted via neurones to the sensory cortex as a reaction to some kind of noxious stimulus. Psychologists have advanced several theories to explain the complexities of symptom perception. For example, Mechanic (1978) offers a behavioural or motivational explanation

in which the experience of symptoms is seen as being a function of secondary gains. Other authors stress the powerful socio-cultural forces that influence how symptoms are perceived, and still others emphasise the importance of mood. All of these approaches offer useful perspectives, but the approach that is considered most appropriate for the present purpose is the cognitive approach.

The cognitive approach to understanding physical symptoms was first advanced in the 1970s (Pennebaker, 1982). This argues that the perception of symptoms involves the same psychological processes that apply to the perception of external events, ie it is not where the information comes from (outside or inside) that is important in perception, it is what the individual does with it (Skelton & Pennebaker, 1982). It is therefore possible to draw on the wealth of evidence accumulated over decades by cognitive psychologists who have studied the perception of external phenomena. According to Skelton and Pennebaker (*Ibid.*) the cognitive processes involved in perception include:

- characteristics of the stimulus including salience, figure and ground effect, competing internal and external stimuli, and so on
- active hypothesis adoption about the meaning of the stimuli might be based upon prior 'knowledge', experience and expectations as well as logical deduction
- the selective search for information that will verify the hypothesis at the expense of disconfirming information

Many somatic sensations are vague and ambiguous, thus allowing the generation of several plausible but competing diagnostic hypotheses. However, once a hypothesis has been adopted there is a strong tendency to ignore or rationalise disconfirming information and adhere to the original hypothesis, often with very unfortunate consequences. Perceptual biases and errors of this type are not surprising since they are consistent with the findings of studies on the processing of external information.

Skelton and Pennebaker (*Ibid.*) recognise the influence of other factors on cognition including individual differences and gender. As regards gender, they argue that women's greater contact with the medical profession and purchase of over-the-counter medications etc (see Section 1.3) is the result of their greater attentiveness to bodily symptoms.

The cognitive theory of symptom perception explains why individuals perceive sensations and events differently: ie because they are appraised differently. As indicated above, cognitive appraisal is influenced by a number of factors. One important factor is the beliefs that an individual holds in relation to the presentation of a particular illness. Such personal lay beliefs or schema are referred to as illness representations and form an important part of the Self Regulatory Model (Leventhal *et al*, 1980) which is discussed below in Section 3.6. All illness representations comprise a number of elements including beliefs about the identity of the disease in question. Disease identity includes the meaning of the disease label and ideas about the signs and symptoms that accompany it. It therefore has great potential to influence the interpretation of symptoms and selection of diagnostic hypothesis.

Quite clearly, the way in which symptoms are perceived is important because of the potential to influence illness behaviour. Some individuals will ignore their symptoms, others will attempt self treatment whilst others will seek medical assistance. Each of these courses of action might or might not be considered appropriate or sensible in the circumstances. However, for one reason or another the majority of symptoms experienced by people do not result in help-seeking behaviour, or they result in excessive delays. Thus, like the 'illness iceberg' mentioned in Section 1.3 (Last, 1963) we can also conceive of a 'symptom iceberg' (Hannay, 1989).

Those symptomatic individuals who do seek medical assistance are likely to be diagnosed and assigned a particular illness label. The psychological impact of this process will vary according to the circumstances, the symptoms experienced and the illness representations held by an individual. In many cases, however, the experience of developing what is perceived to be a serious

and/or life threatening illness, particularly when it presents acutely, can be considered a life crisis.

3.3 Illness As A Life Crisis

The notion of life crises or transitions was originally developed by Erikson (1963). According to Erikson's developmental theory, crises or transitions are regarded as periods of difficulty and stress, turning points, dilemmas that must be resolved. The successful resolution of such a crisis involves adaptation, for example in terms of social roles and self concept, and this is necessary for continued growth and development.

Crises that are faced by most people during their lives and are termed normative crises. Normative crises are expectable and are consistent with social norms (Kimmel, 1980), eg house moving or retirement. Other crises are not expectable, at least not in their manner or timing, and do not happen to most people. These crises are more stressful and are termed idiosyncratic crises, examples of which are complicated bereavements and the experience of acute illness episodes such as heart attack.

Moos and Schaefer (1984) argue that serious illness is either so novel to the individual, or of such magnitude, that it can be regarded as an idiosyncratic life crisis. The individual experiences serious turbulence, dysphoria and their normal responses prove inadequate. They explain that crisis theory is based upon the notion of disrupted psychological homeostasis, following which individuals are motivated to return to the 'steady state' (Moos & Schaefer, *ibid*). Thus, people are naturally inclined to be self-regulating, a proposition that will be explored in Section 3.5. In order to cope with an acute crisis and return to the steady state, individuals have to adapt to their new circumstances and to utilise coping strategies.

3.4 Adjustment To The Crisis Of Illness

Moos & Schaefer (1984) propose a process model that comprises the stages of cognitive appraisal, adaptive tasks and coping. Although crises are usually thought of as beginning acutely, the model clearly acknowledges the ongoing aftermath of such events.

Cognitive Appraisal

This begins with the onset of symptoms as discussed in Section 3.2 but reappraisal is an ongoing process.

Adaptive Tasks

Moos & Schaefer identify two sets of adaptive tasks that need to be accomplished in order that the crisis of illness can be surmounted. The first set comprises four generic tasks that apply to all types of crisis and the second set comprises three specific tasks that relate to the crisis of illness.

Table 3.1 Major Sets Of Adaptive Tasks (after Moos & Schaefer, 1984:10)

GENERAL TASKS
preserving a reasonable emotional balance
preserving a satisfactory self image, and a sense of competence
sustaining relationships with family and friends
preparing for an uncertain future
ILLNESS-RELATED TASKS
dealing with pain, incapacitation, and other symptoms
dealing with the hospital environment and treatment
developing and maintaining relationships with health care staff

Some but not all of the general tasks are emphasised in the cardio-specific literature in Chapter Two, as in the case of mood disturbance following heart attack. Other general tasks are alluded to but not squarely addressed, as in the

case of sustaining social relationships and preserving a sense of competence. This also applies to the illness-related tasks with response to symptoms appearing quite clearly in the literature but the importance of relationships with health care staff is barely mentioned.

Coping

In order to accomplish these adaptive tasks, individuals must bring to bear coping abilities. Moos and Schaefer (*ibid*) use the term 'coping skills' to depict positive responses that are learned, flexible and situation-specific. This implies that coping is skilled only if it leads to a positive outcome. It also argues that coping responses are not fixed personality traits but vary according to the demands of the prevailing circumstances.

Stone *et al* (1988) state that coping is usually conceptualised as those actions or thoughts that make it possible for individuals to manage stressful situations. This also implies a positive outcome, a position with which Stone *et al* (*ibid*) rightly take issue. However, it does draw attention to the fact that coping has both cognitive and behavioural elements. Factor analysis has revealed a wide range of coping responses ranging from problem-solving to distraction and religiosity. These responses have been variously classified according to identified dimensions.

One such dimension is 'focus', and this was the basis of an early but very influential classification by Lazarus and Folkman (1984). Problem-focussed coping involves responses that are directed at the problem itself or its tangible consequences. It is essentially an instrumental approach whereby the individual seeks to take action in order to improve their circumstances. This group includes responses such as information seeking, problem-solving and confronting. If successful, these responses might be expected to lead to an increased sense of mastery or competence. There is no evidence of these responses in the cardiac literature. Emotion-focussed coping involves the use of responses to manage or regulate the emotional consequences of the crisis.

They include talking, the venting of negative feelings, resignation, self consolation, acting out behaviour, and so on.

The Lazarus and Folkman classification includes both cognitive and behavioural responses but other leading researchers have chosen to identify cognitive appraisal as a separate focus. Moos and Billings (1992) identify appraisal-focussed coping which involves attempts to understand and find meaning in ones situation. Responses used within this group include a number of cognitive techniques including anticipatory rehearsal, cognitive redefinition and comparison of self with others who are less fortunate. The search for meaning can involve making sense of events possibly amounting to reconstruction or 'normalisation' as it has been called (Cowie, 1976) so that the heart attack becomes intelligible with the benefit of hindsight and possibly the individual feels less out of control. Another appraisal-focussed response is denial, which appears in varying degrees of subtlety and can apply to the reality of the event, the significance, consequences, and so on. This is discussed in relation to heart attack in Section 2.2.

Another popular classification of coping responses is based upon the 'approach-avoidance' dimension (Roth & Cohen, 1986). An example of this dimension is provided by the clinical work of Miller (1980) in which surgical patients were found to be either blunters or monitors. Approach coping would also include many problem-focussed responses and avoidance coping would include many emotion-focussed and some appraisal-focussed responses.

The question of which coping responses are more or less effective remains quite controversial, not least because of conceptual and methodological issues. However, contemporary opinion has moved away from the idea of adaptive coping (usually approach or problem-focussed) and maladaptive coping (avoidance or emotion-focussed) in favour of judging skills according to their appropriateness in a given situation (eg Roth & Cohen, 1986). However, chronic reliance on particular responses irrespective of the stressor seem to result in poor adjustment (Stroebe, 2000).

3.5 The Self Regulatory Model

The Self Regulatory model was first formulated by Leventhal and colleagues in the 1970s, but attracted much interest and research attention among health psychologists in the 1990s. This is another homeostatic model in which the individual attempts always to regulate the self around the steady state. With the appearance of a symptom or threat, the diagnosis of illness or any other change in the *status quo*, the individual will take appropriate action to try and return to normality. Thus people are seen as active participants rather than passive responders.

Figure 3.1 outlines the Self Regulatory model. The process begins when the individual is stimulated by, for example, the experience of a symptom or the receipt of a health-related message from another person. Following this two parallel systems come into operation, cognitive and affective, in an attempt to regulate the self. Each of these two systems comprise three stages:-

1. The cognitive system begins with the stage of *appraisal* of the threat. The way in which this stimulus is appraised will depend to a large extent on its mental representation, an implicit cognitive model, that is held for that particular illness or symptom. The content of illness representations are illness-specific but their structure, which has five elements, remains constant across illnesses:

- disease identity including diagnostic label and symptoms
- time line, ie the chronological natural history of the disease
- consequences, ie the possible effects of the illness on their life
- causes
- controllability, ie whether the disease can be cured or otherwise treated

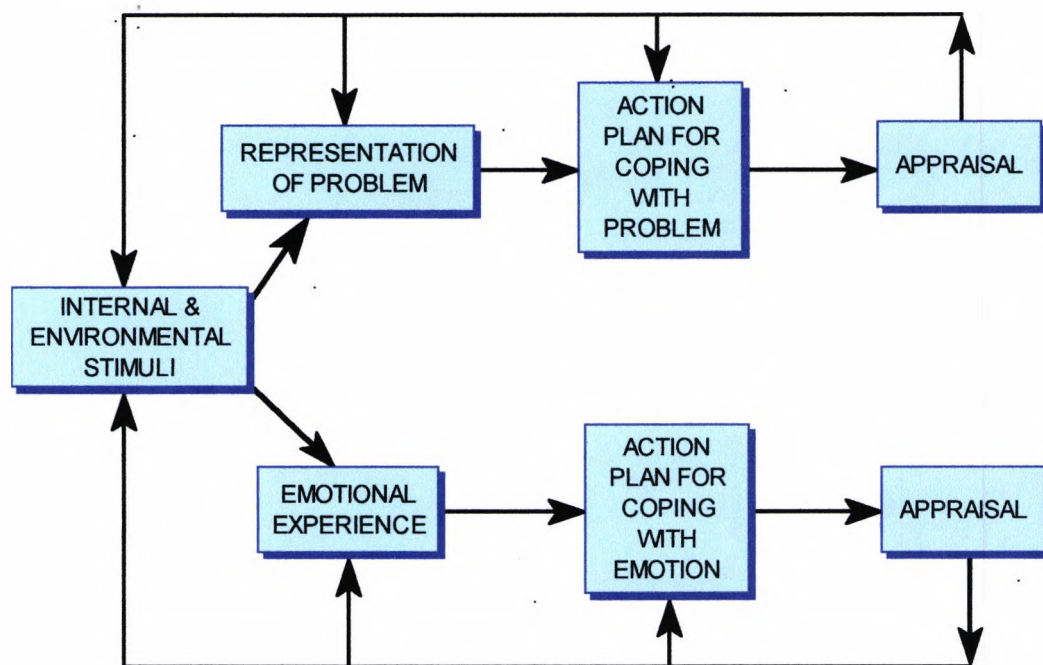
Having made sense of the information in the light of their mental representations, the individual then enters the action or *coping* stage. This

involves the possible adoption of problem-focussed coping responses, eg help seeking or self-treatment. The effectiveness of these is then assessed in the final stage of (re)appraisal.

2. In parallel with this the emotional system begins with the emotional experience accompanying symptom discovery or diagnosis, for example anxiety. The action or *coping* stage involves the possible adoption of emotion-focussed coping responses such as avoidance. The effectiveness of these is then assessed in the final stage of (re)appraisal.

The two parallel systems are partly independent but do also interact. For instance, for one individual fear arousal might be so great upon the appearance of a dramatic symptom (such as coughing up blood) that denial might predominate and so prevent help seeking behaviour. Another individual in the same situation might manage their fear by talking to their partner in parallel with the approach coping strategy of seeking professional help.

Figure 3.1 The Self Regulatory Model Of Illness Behaviour



(Leventhal & Cameron, 1987)

In the last few years the Self Regulatory Model has led to much research on a variety of different care groups and issues (see Petrie & Weinman, 1997a). These studies include the Heart Attack Recovery Project (HARP) in which 143 post-coronary patients and their spouses were examined at four time points in the 12 months following their first heart attack (Petrie & Weinman, 1997b). The assessment measure used was an instrument developed by Weinman *et al* (1996) called the Illness Perception Questionnaire (IPQ). The study was confined to patients aged 65 and under and was conducted in New Zealand.

In addition to individual experience and social messages from friends and family etc., the construction of illness representations is also influenced by illness prototypes. These are culturally shared general beliefs and understandings about particular illnesses. Therefore one needs to be wary of illness representation data acquired from other cultures or sub-cultures since they might be influenced by different illness prototypes. However, the Petrie & Weinman (*ibid*) study does have the important advantage of a longitudinal design. The researchers were able to track illness perceptions from just after the heart attack to 12 month follow-up. This identified that certain dimensions were stable across time (identity and consequences) whereas others (time line and control) changed over time. Detailed reference to the findings of this study will be made in Section 11.2.

3.6 Coping With Chronic Illness

Chronic illness is essentially long lasting in nature rather than temporary and is resistant to medical treatment. The symptoms of chronic illness might or might not always be present but, as Radley (1994) points out, individuals must live with the knowledge of an underlying disease process and the possibility of returning symptoms and complications: they have to live with uncertainty. He describes chronic illness as being "woven into people's biography" and reasons that its meaning centres on how it might affect the rest of the person's life.

One of the earliest chronic illnesses to receive process-based research attention was that of breast cancer. Breast cancer can be regarded as a chronic

illness in that treatment is often prolonged, the individual must cope with residual symptoms and the knowledge that the illness might recur at any time in the future. Some of the studies on breast cancer have focussed on the process from investigation, through diagnosis and on, in some cases, through to death. Greer and colleagues in London carried out a series of such studies during the 1970s including a prospective study of 69 women under 70 years of age undergoing surgery for breast cancer (Greer *et al*, 1979). Women were psychologically and medically assessed prior to surgery and then at intervals for a total of five years. A pilot study showed that there were four major styles of coping following diagnosis, and in the main study womens' statements during pre-operative assessment were independently assigned to one of these four style categories:-

1. Fighting spirit: characterised by an optimistic outlook, approach coping, and the absence of emotional distress.
2. Denial: ie of the existance or seriousness of the disease, characterised by the absence of emotional distress.
3. Hopelessness: these women felt helpless, engulfed, preoccupied with the disease and their lives were disrupted. They experienced emotional distress throughout.
4. Stoic acceptance: no active coping strategies were employed, people just tried to get on with their lives. They experienced emotional distress initially but it declined over time.

The Greer *et al* study was important because it linked coping styles with bio-medical outcomes. Five year recurrence-free survival was significantly more common among those women who had been classified in the denial or fighting spirit categories at three months. The authors argue that these coping styles were probably mediated through unidentified neuro-endocrine or immune pathways and led to the longer survival. However, they acknowledge that coping styles might be a response to the disease process, perhaps an occult disease process that was not identified during medical assessment. It is possible that the maladaptive coping styles were a response to premonitory symptoms or subliminal sensations that the other patients did not experience.

More recent studies by Taylor in the USA have also focussed on coping among women who have had to face life threatening events such as cancer and rape, which potentially have chronic consequences and therefore require long term adjustment. Rather than categorising women's' coping styles, however, Taylor constructed a Theory of Cognitive Adaptation that identifies three "themes" that form the focus for cognitive adjustment in most women (Taylor, 1983).

1. A search for meaning: consistent with the work on attribution theory, Taylor has found that most women try to formulate causal attributions and to understand the implications for their future. This might involve life reappraisal leading to the development of a new attitude to life, greater self knowledge or the reordering of priorities. She concludes that particular causal attributions are probably not important in predicting psychological adjustment but holding such an attribution is important. And when positive meaning is construed from such an experience it is likely to lead to positive psychological outcomes.
2. Attempts to gain mastery or control: events such as the diagnosis of cancer tend to undermine ones sense of control. Re-establishing a sense of control over ones circumstances can be achieved via cognitive reappraisal such as achieving a sense of discontinuity between pre and post-event circumstances, eg believing that the cause of the cancer is no longer present so the disease will not recur. A sense of control can also be achieved through direct behavioural methods such as the adoption of a special anti-cancer diet, the use of imagery, involvement in treatment decisions etc. Another way in which a sense of control can be achieved is through acquiring information, ie informational control, in relation to ones circumstances. Taylor's results indicate that the (now) large volume of health psychology literature on the importance of personal control might also apply to coping with chronic conditions such as cancer.
3. Attempts to gain self-enhancement: again, there is a tendency for self-esteem to fall following stressful life events and people often make

cognitive efforts to rebuild this. For example, some people manage to construe personal benefit from negative events, eg 'it has brought us closer together'. Others operate downward social comparison, eg 'I am not as badly off as him'. These strategies that Taylor has observed in breast cancer patients and other women are consistent with a more general body of literature which attests to the tendency to use self enhancement strategies when under threat.

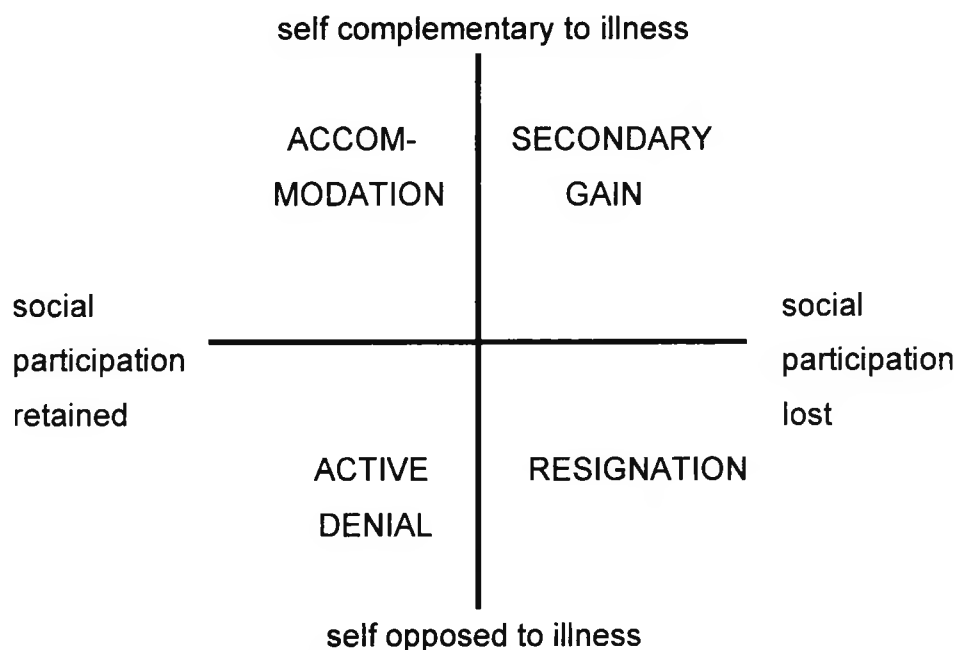
Taylor argues that the cognitions by which meaning, mastery and self enhancement are achieved are largely based on "illusions." For instance, someone might hold a causal attribution for which there is no evidence, or they might compare themselves with a hypothetical person who is less well off than themselves. So illusions do not necessarily contradict reality but are likely to be self enhancing positive interpretations of reality. Taylor points out that, in contrast to prior psychological opinion, defences like illusions and denial are increasingly seen as being functional she considers them to be necessary for cognitive adaptation and good mental health. Taylor's position is supported by research on the importance of depressive cognitions (Beck *et al*, 1979) and the value of denial (Levine *et al*, 1987). Like the Self Regulatory and the Moos & Shaefer (1984) models described above, the Theory of Cognitive Adaptation views people as active self-regulators. And one study by Taylor focussed on a group of mixed cardiac patients (N=60 m46:f14), some of whom had a history of heart attack, and found that downward comparison was associated with better psychological adjustment (Helgeson & Taylor, 1993). This cross sectional study involved patient interviews at variable time points during the 18 months following their cardiac event.

Support for Taylor's 'search for meaning' cognitions comes from as far back as 1946 (Frankl, 1987). More recently, in 1984 Williams (cited by Radley, 1994) described the process of 'narrative reconstruction' whereby people tend to link surrounding events up and reinterpret them in such a way as to make sense of their chronic illness. This presumably makes their situation feel more understandable, stable and predictable.

Another focus of research into coping with chronic illness was developed simultaneously in the UK. Radley conducted a study in which he attempted to gain an understanding of people’s experience of living with CHD. He did this by interviewing one group of patients (n=40) just before CABG and another group (n=40) about a year post-operatively (Radley & Green, 1985). The study was a deductive one based upon Radley’s model of styles of adjustment to chronic illness (developed from earlier work by Herzlich, 1973), which states that there are two dimensions to adjustment:

- 1. The relationship between the individual and society. In chronic illness a tension exists between the need for individuals to, on the one hand, meet their duties and role commitments (social participation) and, on the other hand, the need to pay attention to and/or contain their symptoms (loss of social participation).
- 2. The relationship between the individual and the disease. At one extreme the individual is able to fit the illness into the self (successful adjustment), and at the other self is fitted into the illness (maladjustment).

Figure 3.2 Modes Of Adjustment To Chronic Illness



(Radley & Green, 1985)

Figure 3.1 depicts these two dimensions, which result in four quadrants representing distinct styles of adjustment. In the upper quadrants the individual is not overcome by the illness but is in some way able to incorporate it within the self. The individual might be able to *accommodate* the illness by finding ways around any limitations in such a way as to retain social participation. Alternatively, illness might represent a *secondary gain* whereby the individual ceases trying to maintain social participation and is thereby freed of social burdens and responsibilities.

In the lower quadrants the individual is less successful in developing a satisfactory relationship with their illness. Some individuals are characterised by *resignation*, whereby the illness has permeated much of their lives and resulted in the loss of social participation. They are “vanquished.” The alternative style is *active-denial*, whereby the individual attempts to fight the illness by maximal social participation and minimal attention to the illness in terms of symptom control, compliance and so on.

These data were collected using a tailor-made interview schedule that included five questions directed at each of the four adjustment styles, ie the study was predicated on an existing theory. The participants were mainly male, with only eight women in the sample, and all were 65 years of age or under (mean 53.5). Furthermore, it was a quasi-longitudinal study in that it was based on separate groups at different time points in their illness trajectory. However, the findings are consistent with those of other studies involving a variety of different patient populations.

It can be seen that there is some correspondence with the coping styles identified by Greer. Self might be seen as complementary to illness in fighting spirit but perhaps not in the other styles. The dimension of social participation is retained in fighting spirit and denial (associated with survival), perhaps attempted in stoic acceptance but lost in hopelessness.

3.7 The Sick Role

The notion of 'sick role' was originally formulated by the functionalist sociologist, Talcott Parsons and is best understood in relation to his well known definition of health:

“....the state of optimum capacity of an individual for the effective performance of the roles and tasks for which (s)he has been socialised.” (Parsons, 1972:117)

Thus, if health is the ability to perform ones roles, then it follows that sickness must be some sort of disturbance in role performance. In 1951 Parsons examined the relationship between the sick person and others in this light. The resultant notion of sick role represents an analysis of the patient-doctor relationship and of family dynamics. When illness strikes the individual is no longer able to fully discharge all their role obligations and is instead permitted to enter the sick role. The power to grant this permission resides with medical practitioners, so one must seek medical help in order to enter the sick role.

Individuals who are medically labelled as being sick are accorded two rights as follows:-

- exemption of other social roles and responsibilities, eg work
- exemption from responsibility for the illness itself, ie whatever might have led to the illness it is accepted that the patient does not have the resources to make him/herself better

In return for these rights, sick role occupancy is conditional on the following:-

- seeking technically competent help
- wanting to recover: by entering the patient role the individual is obliged to co-operate with medical staff, eg by complying with advice

It is evident that sick role entry transfers responsibility and control to the medical staff and requires passivity and obedience on the part of the patient, who should minimise their needs and potential criticisms. Parsons and Fox (1952) describe this as relinquishing independence and reverting to a child like status. Another implication is that some patients might be labelled as good or bad according to how closely they adhere to the sick role, for example asking too many questions or continuing to smoke against advice. And finally this functionalist conception of health and sickness would exclude individuals who are able to fulfil their social roles but experience subjective illness such as pain or depression.

The Sick Role And Acute Illness

Entry to the sick role is a possible consequence of experiencing symptoms, though this is not necessarily the case. It is possible to imagine a variety of reasons that some individuals will resist taking their symptoms to a doctor. These might include a failure to appreciate the importance of the symptoms, fear of consequences, a belief that self treatment will suffice and the existence of more immediate concerns that demand the individual remains in role. Alternatively, an individual might take his symptoms to a doctor but be denied entry to the sick role due to (say) the absence of physical signs, the suspicion of malingering or medical error.

Once labelled as sick and admitted to the sick role the individual might be hospitalised or, for example, sent home with medications and advised to rest. Sick role occupancy is legitimised by a 'sick note' and the prescription of treatment. Provided the patient complies with any such treatment or advice, they will be entitled to relinquish their other roles. Thus, the person will not need to go to work and might be excused their normal household duties.

The Sick Role And Chronic Illness

Radley (1994) argues that the sick role is less applicable in chronic illness. This is partly because, except in the most severe disability, individuals must surely resume at least some of their social roles in the medium to long term.

Furthermore, in chronic illness the role of the medical practitioner is minimised since there is no prospect, by definition, of the condition being cured. Individuals with chronic health problems are likely to engage in self management and, in the absence of a medical solution, perhaps turn to alternative medicine or lay sources of help. Radley (*Ibid.*) suggests that chronically ill individuals must attempt to normalise their lives but retain access to the sick role during exacerbations of their illness.

The sick role corresponds with the 'loss of social participation' dimension in Radley's model of coping styles. It is clear from the model that some chronically ill people are able to adjust, adapt and come to some sort of compromise with their illness so that social participation is maintained, at least in part, or at least from time to time.

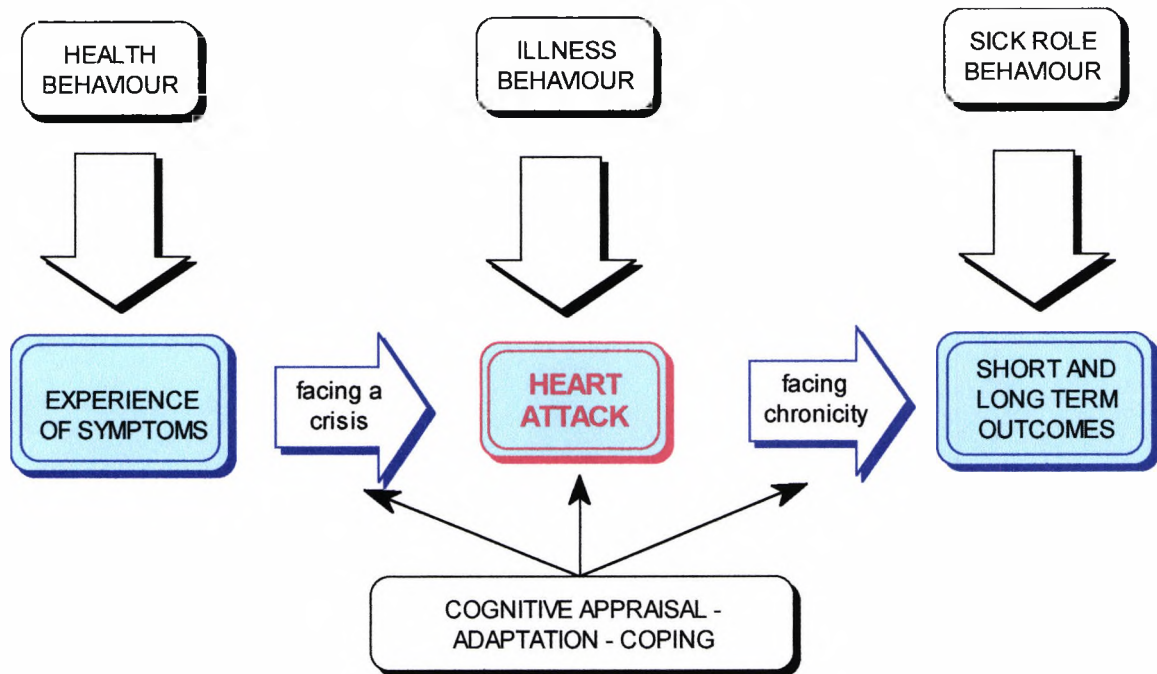
3.8 Conclusion

This chapter has shown that process-based longitudinal research has led to useful insights in other fields of health psychology. It has shown that the crisis of illness occurs as part of a process with psycho-social antecedents as well as psycho-social consequences. It also occurs within a context. This research approach has been particularly illuminating in chronic illness where various psycho-social and biological factors can be seen to interact and change over time. Researchers in quite different clinical fields have reached similar conclusions. These include the importance of cognitions including a search for meaning and a human propensity for self-regulation by a process of adaptation and coping. In view of the advances made in these other areas of health psychology, it seems reasonable to suppose that this research approach might offer new ways of examining the cardiac problem.

Viewed in this way, CHD can be seen as a context-based process that begins prior to heart attack and persists into chronicity. Figure 3.2 shows that such a view of CHD incorporates but is not limited to psycho-social outcomes. However, this model is developed from piecemeal evidence derived from different studies, using different samples and different methods. Therefore it

represents but a tentative step towards developing a more comprehensive model of psycho-social aspects of the heart disease process and it's usefulness remains to be demonstrated.

Figure 3.3 CHD As A Process



The next chapter will show how this perspective has influenced research design, and subsequent results chapters will consider whether the models arising from this research provide a useful way of understanding the data.

CHAPTER FOUR

DESIGN, METHODS AND PROCESS

4.1 Introduction

In Chapter Two it was argued that, as regards research into psychological adjustment following heart attack, women remain a neglected group. Although a number of studies have tried to fill this knowledge gap over the last few years, and have provided consistent indications that women may have special needs and problems, the data gained so far are piecemeal, tentative, lacking in detail and explanatory power. This paucity of research provides clinicians with a very limited knowledge base for practice. Furthermore, the cardiac literature that does exist is almost all biased by the masculine assumptions and preconceptions that inform it.

The writer therefore set out to study women's perceptions of their needs and problems in the period following heart attack. It was hoped that the resultant data would make a much needed contribution to the knowledge base with the ultimate aim of providing guidance for practice. This chapter is divided into sections setting out the way in which the study was conceived, planned and conducted, explaining how the data were analysed and the characteristics of the sample studied.

4.2 Research Design

Background

The state of the literature meant that a hypothesis driven quantitative study would not have been justified. Instead, the research would begin with a qualitative exploratory study. It was originally intended that this qualitative study would be limited in scope and would simply identify issues to be investigated further by means of a quantitative study such as a survey. The qualitative study was to have been Phase One and the survey Phase Two. However, as data collection and analysis progressed, it became clear that the depth and richness

of emergent data warranted its pursuit as a qualitative study in its own right, and it was decided that Phase One should be expanded to become the study itself.

Further justification for a purely qualitative approach was provided by a growing commitment to the idea that heart attack should be viewed as part of a process rather than a discrete event. This is supported by Miles and Huberman (1994) who make the case that qualitative research is appropriate for studying processes. It is also supported by Radley (1999) who argues that illness experiences differ qualitatively so they need to be studied, described and understood qualitatively. The advantages of viewing heart attack as a process are illustrated by research in other areas of health psychology, as set out in Chapter 3. Finally, the need to understand background and contextual factors also argued for a qualitative approach.

Approaches To Qualitative Research

Qualitative research is generally based upon text of some kind rather than numbers (eg Lyons, 2000) though it might be more accurate to think in terms of whether the data, of whatever type, are subjected to quantitative or qualitative analysis (Breakwell & Rose, 2000). In addition to this focus on language rather than numbers, Miles & Huberman (1994) add that qualitative research is essentially naturalistic and they proceed to list several key features that characterise most qualitative research:-

- intense and/or prolonged contact with the situation or people concerned
- holistic and contextualised view of the phenomenon under scrutiny
- aims to capture the perceptions of the informants
- faithful representation of informants' views as originally represented
- explication of how individuals come to understand, account for and take action in given situations
- acknowledgement that more than one interpretation of the data is possible
- relative lack of standardised instrumentation, instead relying on the researcher as the main "measurement device"
- most of the analysis involves words

Despite these commonalities, the literature identifies several differing qualitative research strategies including: case study; ethnography; phenomenology; grounded theory; biographical; historical; and action research (eg Denzin & Lincoln, 2000). Each of these main strategies may be interpreted and enacted in different ways so there are, for example, different types of phenomenology and of ethnography. Other authors prefer a pragmatic and eclectic approach to qualitative enquiry rather than aligning themselves to a particular methodological and philosophical tradition (eg Dey, 1993).

However, whatever approach is adopted, qualitative research strategies vary along several dimensions including:

- the aim: descriptive versus explanatory
- the ontology: realist versus relativist
- the epistemology: objectivist versus subjectivist
- theory: deductive versus inductive
- quality criteria: traditional rigor versus intuitive flexible

(eg Guba & Lincoln, 2000; Miles & Huberman, 1994)

Study Design

For the present study an inductive approach was adopted in order that women would have the opportunity to identify issues and problems of concern to them rather than to the researcher. This meant that explanations or theories would be grounded in the data rather than imposed by the researcher. Perhaps the best known inductive approach is Grounded Theory which was originally developed by Glaser and Strauss in 1967. However, since the present study had already been preceded by an extensive literature review, a grounded theory approach would not have been appropriate. Although there has been a softening of this stance with the various reiterations of grounded theory over the years, deep immersion in the literature is still considered by grounded theorists to carry the

danger of constraining or stifling creativity and is a threat to 'data emergence' (Strauss & Corbin, 1998).

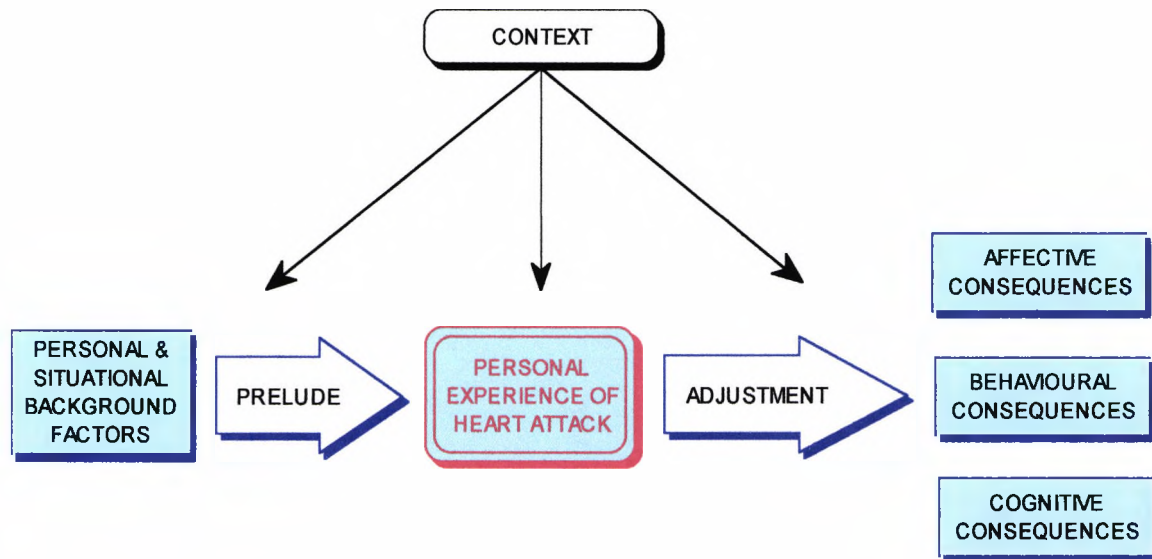
The strategy adopted was based upon the framework provided by Miles and Huberman (1994) which they describe as being in the vein of 'transcendental realism'. The approach acknowledges that there is an objective reality to be discovered in the social world, that is to say, some "...lawful and reasonably stable relationships...." exist through which social and individual phenomena can be understood (Miles & Huberman, 1994:4). The approach acknowledges the importance of the subjective and the phenomenological, but seeks to transcend these by building and testing theories to account for real world phenomena. Thus, the Miles and Huberman approach is inductive and goes beyond description by attempting to explain events by building defensible theory from the data. As regards the present study, the aim was to describe the reported experience of heart attack victims and then develop an explanation for it.

Miles and Huberman propose a fairly orderly and formalised approach, though they encourage the reader to select only those elements of their sourcebook approach that seem useful to their particular study. They defend this formalised and explicit approach by arguing that qualitative researchers should be accountable for the rationality and trustworthiness of their methods. At the operational level, Miles and Huberman identify a sequence of steps to be taken. These begin with the building of a conceptual framework (Figure 4.1) since, they argue, even the most inductive of approaches comes laden with expectations. In this case there was a serious attempt to suspend or 'bracket' any such expectations and the conceptual framework was therefore very restricted in detail.

The first component of the conceptual framework refers to individual biographical factors such as prior experience and social circumstances. The prelude to heart attack might have involved warning signs or precipitating factors that precede the uniquely individual experience of heart attack. This is followed by adjustment which might include tasks to be accomplished and

coping strategies, all of which might have the potential to influence outcomes. Thus, the study was not to be restricted to measurable outcomes but would attempt to explore the whole process of having a heart attack.

Figure 4.1 Conceptual Framework



The next step advocated by Miles and Huberman is the formulation of a research question. The purpose of this study was to illuminate the psychological experience of women in their social context and provide a detailed description of the issues and problems of recovering from heart attack, as perceived by women. It was further intended that the data would provide explanations for any sex or gender differences that might emerge. The research question and subsidiary questions were as follows:

Table 4.1 – The Research Question

Are there special issues around being woman rather than a man in the psycho-social experience of having a heart attack?

(a) How do people identify that they are experiencing a heart attack and how do they behave?

(b) What factors influence how people adapt to the knowledge that they have had a heart attack?

(c) To what extent, and in what ways, does gender relate to the experience of having a heart attack and adapting to it?

In order to answer the research question it was decided that data would be generated through interviews. The interview is a commonly used and versatile form of qualitative data collection which, "...opens windows into the experiences of people..." (Rubin & Rubin, 1995:1). It was decided that this would be the best way to learn about the experiences of women who have had heart attacks, as stated in the research question. The researcher was interested to know what events had taken place in the period surrounding the heart attack, how these had impacted on women and what attempts had been made to adjust to the situation. Interviews like this, which are characterised by a relatively specific focus and defined boundary, are termed topical interviews.

Topical interviews were to be conducted at two pre-determined time intervals following their heart attack, thus avoiding the cross sectional approach which is a hallmark of most previous studies. The first interview was scheduled for three weeks after discharge from hospital (four weeks after the heart attack) in order that recent events would still be fresh in women's minds, and because memory is notoriously unreliable when people are asked to recall stressful events. In order to learn about women's experience subsequently, a second interview was conducted three months later (four months after the heart attack). It was believed that by that stage events should have unfolded in terms of returning to normalcy or otherwise.

4.3 Research Methods

Interview Structure

The uncertain state of the literature and the absence of an existing validated instrument meant that structured interviews would have been inappropriate. Heavy structuring may have also failed to address points of particular importance to participants that had not been included in the interview schedule, and would have been inconsistent with the commitment to an inductive approach whereby an openness to the unexpected must be maintained. On the other hand, the topical nature of the interview required some degree of focus in the interview schedule, as did the requirement to generate theory rather than simply portray the views of participants.

A semi structured approach was selected because it achieves a compromise between the advantages of comparability and generalisability of heavily structured approaches, and the internal validity and contextual understanding which are maximised in unstructured approaches (Miles & Huberman, 1994). This format addresses pre-determined themes while still leaving participants free to determine the content and describe experiences in their own way. This latter point is particularly important here because the pre-determined themes were derived largely from the male dominated literature and may therefore have failed to address points that are important to women.

The semi-structured approach also allows the researcher flexibility to respond to what emerges, eg probing, clarifying and pursuing clues with subsidiary questions. Questions can be framed differently according to the researcher's sense of the moment and using language considered appropriate for the individual participant. Wherever possible open questions were preferred, thus giving participants the opportunity to disclose their own perspectives in their own way, but sometimes closed questions were considered acceptable, for example in order to steer the participant back onto the subject.

The Interviewer

The importance of the research relationship in qualitative interviews has been emphasised by numerous authors (eg Lee, 1993). All aspects of the researcher as a person (eg general demeanour, style of interaction, accent, gender, perceived status) have the potential to interact with the subject matter and influence participant responses. Good & Watts (1989) argue that the researcher needs to be sufficiently knowledgeable about the culture under scrutiny so as not to miss the subtle nuances of psychological interactions but, balanced against this, one needs to be impartial and committed to a high level of scientific validity. In a very real sense, therefore, self can be regarded as the instrument of data collection (Rew *et al*, 1993). A short biography will provide evidence of the former and efforts to maintain methodological rigour will be discussed below.

The researcher is a white male and at the time of data collection was in his mid-forties. He had worked with cardiac patients throughout his career, initially as a cardiac technician, then as a cardiac nurse rising to Charge Nurse. For some years he has been employed as a lecturer in health psychology teaching a variety of health and welfare students. He spends one day per week teaching in clinical settings within the mental health unit of a local hospital. Additionally, he has undertaken various counselling training courses and currently provides cardiac counselling and bereavement counselling on a part time basis.

The researcher conducted all the interviews himself. He always wore a jacket and tie, never a suit, and introduced himself by his full name, ie both fore and surnames. Participants were always referred to by their surnames at the outset.

The researcher is a Registered Nurse, a member of the British Psychological Society and a member of the British Association For Cardiac Rehabilitation. He was therefore bound by professional codes of conduct that had to be considered alongside research imperatives.

Pilot Interviews

Piloting was conducted on a sample of five participants in order for the researcher to gain fluency and confidence in the interview technique and use of equipment. In the event, operating error resulted in the loss of a tape containing two pilot interviews, thus providing the researcher with a valuable lesson in the use of technology.

As a result of the pilot interviews, some adjustments were made to the interview questions and to the preliminary discussion. Questions seeking biographical information were excluded from the interview and were instead asked informally in the pre-interview discussion, thus providing an opportunity to develop a rapport with participants and saving transcription time. Because of these adjustments pilot data were not included in the analysis.

The questions in Tables 4.1 and 4.2 were identified in advance, and the researcher attempted to maintain some overall rhythm and coherence by a chronological ordering of questions around the main topics of interest. However, the precise wording and sequence of questions was not fixed, with the content, pace and formality of the interview being very much a response to the situation as perceived by the researcher. The advantages of spontaneity and professional intuition were not sacrificed in the interests of consistency. Participants often raised issues out of sequence and when this occurred the matter was either discussed at that point or deferred by agreement and returned to later in the interview.

The interview schedules were established as follows:-

Table 4.2 - Schedule For Interview One

Preliminaries:

- re-state purpose of study and sign consent form, remind about confidentiality
- outline of what I plan to cover in interview
- will ask a few broad questions in order to get you talking
- really interested in hearing about what you think is important
- any clinical queries arising during the interview can be discussed afterwards
- collect biographical information
- any questions or concerns before we start

I would like to begin by developing a picture of your life prior to the heart attack.

- make-up of household
- whether working outside the home (details, attitude)
- allocation of household chores (who did what, paid help?)
- whether a car driver, other ways of getting about
- whether sexually active
- details of any hobbies or social interests?
- role as regards wider family and friends/neighbours

Now I would like to move on to the heart attack itself:

- how and when it happened
- interpretation of symptoms
- actions taken and by whom
- whether surprised
- beliefs about causation
- what it was like in CCU/ITU (feelings & thoughts)
- what was it like on the ward? (feelings & thoughts)
- ways the hospital staff could have done more/better

Now some questions about life since you went home:

- how you got home
- activities on first day (detailed examples)
- activities on subsequent days (detailed examples)
- how partner has taken it
- any changes in their behaviour, who does what
- opinion of recovery so far
- present or expected difficulties
- understanding of what physical activity is advisable
- intentions regarding rehab' attendance
- outlook for the future?

- whether being a woman has made any difference

Is there anything else that I have not asked you about which would help me understand what it has been like for you?

Table 4.3 – Schedule For Interview Two

Preliminaries:

- remind first meeting three months ago
- check still happy to participate
- briefly recap my understanding of main points raised
- thought of anything after the first interview?
- interested in hearing about your life since that time
- few questions, just want to hear what you think is important

How have you been in the last three months?

- physical health, symptoms
- emotional state and partners
- any changes in life (eg job, home, chores, lifestyle factors)
- whether rehab' classes attended, and if not why not
- prompting as necessary in relation to issues raised in first interview

Is there anything else that I have not asked you that would help me understand what it has been like for you?

Further adjustments were made to the interview schedule once analysis began to identify themes that were worth pursuing. For example, a number of early interviews revealed home-based stress in relation to lay care-giving roles prior to the heart attack, so questions about this were incorporated in subsequent interviews when the issue it did not arise spontaneously.

4.4 The Research Process

Interviewing Conditions

Interviews were tape recorded in order to avoid the necessity for note taking and to allow the researcher to engage fully in the process. Audio-taping has the important advantage of reducing researcher bias in both the process and interpretation of data and, according to Breakwell (2000:249), there is no real evidence that it constrains participants. Never-the-less, an attempt was made to put participants at their ease prior to the interview by obtaining simple biographical information about them during the preliminaries before the tape recorder was switched on.

In almost all cases participants were interviewed in hospital premises, either in an outpatient consulting room or in the Quiet Room of the hospital library, this being a condition of access by one of the Research Ethics Committees (RECs). The average duration of each interview was half an hour.

The researcher often felt a sense of conflict between the research tradition of neutrality and non-contamination, and his duty of care as a health professional. In some situations he took measured decisions to violate research traditions by offering encouragement, reassurance or advice, though wherever possible this was done after the interview. Quite apart from ethical imperatives, he had to respond to participants in such a way as to ensure the maintenance of the relationship, otherwise there may have been no second interview.

Ethical Issues

Prior to piloting, permission to conduct the study was sought from two NHS Hospital Trust RECs. In both cases this involved written application and oral defence.

A major issue of discussion at the RECs was negotiation of access in respect of patients' rights to refuse to participate and their concern that this right should be

a genuine choice. By negotiation, it was agreed that the researcher would identify suitable patients shortly after admission and then ask a member of the hospital staff to approach these patients on his behalf. Patients would be told briefly about the research and permission sought for their phone number to be passed to the researcher. The researcher would then make telephone contact with patients and give full details of what participation would entail. They were given the opportunity to ask questions and a meeting arranged.

At the first interview participants were given a full and honest written account of the purpose of the research and asked to sign a consent form. They were also told that the interview would be tape recorded, and that all tapes, transcriptions and questionnaires will be identified only by code numbers. The relationship between personal details and code numbers was available only to the researcher and his supervisor. Participants were assured that any material presented to a wider audience would be anonymised in such a way as to make recognition very unlikely.

Given the length of time between the initial approach and completion of the second interview, and the potential for events to unfold during this period, the process model of consent was adopted. The process model was first applied to qualitative research by Munhall (1988, 1991) who saw it as a way of enhancing informed consent by keeping it in the present tense. In practice this meant reaffirming, at regular intervals (four occasions), that participants were willing to continue with the research and that they were happy with the way it was being conducted.

Despite the fact that no hospital patients were to be involved in the study, one of the Ethics Committees insisted upon the researcher seeking permission in principle from all relevant hospital consultants for their patients to be included in the study. This involved writing to all the consultants, quite often meeting with them individually and usually involved reminders via their secretaries. As and when individual participants were included in the study, a standard letter was sent to their GP informing them of the general outline of the study and their patient's involvement. This was considered a professional courtesy.

As a result of the sampling technique utilised it was necessary on two occasions to return to the Ethics Committees for permission to extend the research to other patient groups.

Inclusion Criteria

Inclusion criteria were based upon the age and sex required by the study, though the RECs also stipulated that no-one under the age of 18 should be recruited. Inclusion was also restricted to those who had no history of cardiac surgery including angioplasty, no history of heart attack and who could communicate adequately in spoken English.

Sampling Strategy

The method of selecting participants for inclusion in the study was by purposive sampling. This means that participants were selected for what information they could give in order to help answer the research question. It is an efficient sampling method whereby the research question can be answered by studying fewer participants than would be necessary with random sampling.

“....most information of greatest utility from the limited number of cases to be sampled...” Patten 1990:181.

The initial sample was of fifteen women. Miles and Huberman (1994) recommend that in areas of high complexity, fifteen ‘cases’ should be regarded as sufficient since the volume of data can become unwieldy after that. All women admitted to the Coronary Care Unit with a confirmed first heart attack were asked to participate, though an upper age limit of 65 was set in order to allow comparison with male studies, most of which have focussed on the middle aged. It was also believed that women in this age group would be more likely to occupy gendered roles than would older women.

In response to the emerging data five women aged 65-75 were added to the original sample of 15. On conclusion of the first twenty interviews it was decided that some male interviews would provide a useful comparison. Such comparison was not possible by reference to the literature because, although there were considerable data on men, few if any studies have adopted this research approach. The male sample included retired men under 75 and working men under 65 in equal proportions. Recruitment was terminated when saturation had been reached, that is to say, no new themes were emerging from interview data.

Access

Access was difficult because it relied very heavily on the goodwill and co-operation of busy hospital staff, and particularly a key staff member in each hospital, usually the cardiac rehabilitation nurse/co-ordinator. Full written details and visits to both hospitals to discuss the research with staff preceded the study. And in some cases access to women had to be negotiated through their husbands, who apparently saw themselves as having some sort of gate-keeping protective role (eg P5). This has also been noted by Brannen (1988) who often had to gain the permission of husbands and undergo "interrogation" before their wives could be approached for recruitment onto her study.

As expected, data collection proved to be very time consuming, mostly involving hospital visits to see only one participant at a time. Participants often had to cancel interviews when they were unwell or had transport difficulties. It was totally dependent on the availability of patients meeting the inclusion criteria and, despite a careful analysis of previous admission rates, the work of CCUs is notoriously tidal with quiet periods alternating with busy periods.

The Hospitals

Participants were recruited from two comparable District General Hospitals, both of average size and situated on the outskirts of London. Henceforth, they shall be referred to as Hospital A and Hospital B.

1. *Hospital A*

Hospital A is situated in new purpose-built accommodation and serves a population of 250 000 residents and light industrial workers who fall within its catchment area. Patients presenting to the Accident and Emergency (A&E) department with chest pain which might be of cardiac origin are admitted and then transferred to the Intensive Therapy Unit (ITU). This ITU is a general one in the sense that a variety of critically ill patients are admitted, eg those having undergone major surgery, following serious injuries and following heart attack. The unit is staffed by health professionals with post-basic education in the care of the critically ill, but who are not specialists in coronary care. It is a small unit with only five beds, and is usually full. Indeed, there is often pressure on beds so that admission and discharge decisions are often made on the basis of relative priority rather than individual need. The ITU policy states that patients should be admitted according to priority of need and does not state an age limit.

Patients arriving in A&E with a provisional diagnosis of myocardial infarction are admitted to the ITU immediately, subject to bed availability. However, for many patients this is not possible and they are admitted to a general medical ward. Once in ITU, patients are stabilised and monitored for an average of 24 hours before being transferred to a general medical ward where, provided their recovery is uneventful, patients remain for five or six days before being discharged home. The level of staff education and expertise on these general medical wards is just what the name suggests. Some patients are admitted under the treatment of the hospital Consultant Cardiologist, but many others are treated by general physicians or consultants with some other specialism.

The hospital employs a cardiac Clinical Nurse Specialist, whose job it is to provide specialist expertise and bridge the gaps between the various hospital departments and home. The system requires that she is informed of all patients admitted to the ITU or a general medical ward with a presumptive heart attack. She then makes contact with these patients before they go home in order to provide individual counselling, health teaching and invite them to attend the hospital cardiac rehabilitation programme.

This rehabilitation programme is run by the Clinical Nurse Specialist, who is supported by a specialist physiotherapist. The programme aims to provide ongoing support for heart attack and other cardiac patients and their families following discharge from hospital. There are no other exclusions. Contingent upon medical clearance, patients and their relatives are invited to attend sessions three weeks after discharge from hospital. Sessions are of 1.5 hours duration and comprise a mixture of activities including: cardiac health teaching (risk factors, medications etc); graduated physical exercise; relaxation; professional and peer support. Sessions are offered on two lunchtimes per week, and 15-20 patients attend at any given time. The duration of attendance is a very individual matter, varying according to severity of illness and pre-morbid fitness level etc. Many patients continue to attend for as long as 12 weeks before discharge from the scheme is agreed between staff and patient.

Hospital B

Hospital B is housed in 1960s built accommodation and serves a population of 250 000 comprising mainly middle class residential areas but also including some large occupational groups such as the nearby military bases, and an international airport. Patients presenting to the A&E Department with chest pain which might be of cardiac origin are admitted and then immediately transferred to the CCU. The CCU is staffed by health professionals with post-basic education in the care of coronary patients, but it is a small unit with only four beds. The CCU is often full, and there is often pressure on beds so that admission and discharge decisions are sometimes made on the basis of relative priority rather than individual need.

Transfer from A&E to the CCU is therefore subject to bed availability. Where this is not possible patients are transferred to a general medical ward instead. Once in CCU, patients are stabilised and monitored for an average of 24 hours before being transferred to a general medical ward where, provided their recovery is uneventful, patients remain for five or six days before being discharged home. The level of staff education and expertise on these general

medical wards is again very general. Some patients are admitted under the treatment of the hospital Consultant Cardiologist, but many others are treated by general physicians or consultants with some other specialism.

All heart attack patients admitted to the CCU receive health teaching during their stay in the unit, and are invited to attend the hospital cardiac rehabilitation scheme. The hospital does not employ a Clinical Nurse Specialist, but instead looks to the CCU staff to provide ongoing specialist support. The nurse responsible for managing the CCU also has a remit for organising the rehabilitation programme, which is run by nurses and physiotherapists on a 'time back in lieu' basis. This scheme, which is run as a series of weekly evening classes, is aimed at providing ongoing support, exclusively for heart attack patients and their families following discharge from hospital. There are no other exclusions.

Provided patients are medically cleared, they are invited to attend classes a week or so after discharge from hospital. Classes are of 1.5 hours duration and comprise a mixture of activities including: cardiac health teaching (risk factors, medications etc); graduated physical exercise; relaxation; professional and lay support. Classes are offered on one evening per week, and an average of ten patients attend at any given time. This programme is more structured than that of Hospital A and takes the form of a 'rolling' five week programme which patients can join at any point. Relatives are welcome to attend too.

4.5 Data Analysis

All interviews were tape recorded, and the audiotapes were subsequently transcribed fully in such a way as to include non-verbal utterances, emphasis and pauses etc. Standard conventions were used in writing up the interview transcripts which were then subjected to thematic content analysis. Analysis was carried out in batches of five, ie while subsequent interviews were still in progress.

Transcription

The following chapters contain many direct quotations by participants. Minor quotations of a few words are embedded in the text and enclosed by quotation marks. Quotations exceeding about six words are inset and single spaced but not enclosed within quotation marks.

The main focus of analysis was on content. However, in order that important meaning immanent in non speech sounds, non-verbal language or the actual use of speech should not be lost, the following discourse marking system was applied:-

- words written in *italics* indicate a stressing of the word
- words written in **bold** indicate an increase in volume
- words written in ***bold italics*** indicate an increase in stress and volume
- the symbol (?) indicates unintelligible sounds that could not be transcribed
- the symbol / indicates an interruption
- a series of dots at the beginning or end of a quote indicates that a portion of that conversational 'turn' was omitted
- a series of dots....elsewhere indicates a pause
- non-verbal behaviours are set in parentheses (eg laughter, crying, angry, embarrassed)

All names and other obvious identifying features that appear in this thesis are fictitious. Where it would have interrupted the flow of text explanatory comments are added in [square] brackets.

Because this is a qualitative study based on a small purposively selected sample, very limited use is made of statistics. Their use is restricted to a description of the sample and they are not applied to the results. Where descriptive statistics are used, however, figures have been taken to two decimal places and rounded to the nearest number.

Two sample transcripts are included in the Appendix.

Coding And Analysis

Coding was conducted broadly in line with the method recommended by Grounded Theorists such as Strauss & Corbin (1998). Thus it began with Open Coding, which is the process of identifying and studying major themes. It then proceeded to Axial Coding whereby the themes were reduced to fine detail with the identification of sub-themes and the relationships between them. And finally Selective Coding was conducted, whereby the material was integrated and ideas synthesised.

Coding and analysis were conducted using three different methods:

1. The Traditional Method

Transcripts were scrutinised and marked up by hand for 'themes' defined as major concepts or issues raised by the participants. This involved the use of different coloured emphasiser pens that were used to code themes, eg everything related to anxiety was coded in yellow.

In order to increase reliability and reduce the threat of idiosyncratic interpretation by the researcher, some of the literature recommends the utilisation of 'experts'. Sandelowski discusses five types of expertise: clinical; field; methodological; researcher; and personal (Sandelowski, 1998).

The expertise of two colleagues, both of whom were qualified up to master's degree level in their respective disciplines, was utilised at various stages during data collection and analysis. One colleague was a cardiac nurse specialist who, in view of her command of the field of knowledge and considerable understanding of the clinical issues involved, could be described as a 'field expert'. The other was a social work manager with an academic background in social sciences, who could be said to possess a measure of methodological expertise and who had the advantage of working outside the area under study.

The co-raters were briefed on the purpose of the research study and asked to analyse the transcripts for content. This analysis was conducted 'blind' so that the assistants were not influenced by the researchers perceptions or emerging conclusions. The research assistants contributed to descriptive and interpretative validity.

Formal university supervision also provided a source of methodological expertise and, through extended discussions, assisted in ensuring theoretical validity.

According to Sandelowski's typology, researcher expertise is concerned with a knowledge of people, events and data which can only result from engagement and deep immersion in the project. Finally, personal or member expertise resides in the participants. Member checking did take place in the second interviews by means of offering a synopsis of the researcher's understanding of the main points arising from the first interview.

In the event inter-rater reliability was high and there was full agreement on themes following several detailed discussions with the co-raters. In addition to supporting the researcher's perception of themes, the co-raters were asked to judge the effects of leading and closed questions, interpretation of ambiguous answers, the use of metaphors and so on. They were also asked to make comparisons between the different sub-groups of participants.

2. Computer Analysis With QSR NUD.IST, Version 4.0

As this process progressed, however, the sheer volume of transcript data became very difficult to manage and the researcher anticipated problems in writing it up. It was therefore decided to utilise a computer software programme that was designed to assist the management and testing of qualitative data. The programme NUD.IST (Non-Numerical Data Indexing, Searching and Theorising) was chosen because of its reputation and its availability.

The data were coded into categories denoting units of meaning, in NUD.IST these are called *nodes* and the relationships between categories are identified by *links*. Node organisation was mostly hierarchical like the branches of an inverted tree, and in NUD.IST this is referred to as an *index tree* (see Figure 4.2). In addition to serving as a powerful word processing tool, NUD.IST also has the capability to conduct searches of two main types. *String searches* identify all instances of a word or phrase in much the same way as a bibliographical search, ie one must enter different key words in order to retrieve all references to a given concept, eg anxiety/tension/pressure. *Index searches* are able to identify relationships between nodes, for example the overlap between the nodes of female and anxiety. This was useful for comparing female and male responses in order to highlight gender differences.

At the beginning of the computer analysis process, the researcher had a clear idea of some of the categories that would be relevant to his research question, so some nodes were determined in advance of coding. These categories were subsumed within the super-ordinate category of *Base Data* which subsumed second level categories for sex, age, interview (1 or 2) and hospital (A or B) etc.

Modern day software such as NUD.IST has now become accepted by many as a major tool for qualitative data analysis, not least because it enables the researcher to get 'close' to the data. Richards (1998) describes closeness as the acquisition of full and detailed knowledge of the data, along with the ability to move swiftly through text, taking extracts, jumping instantly to the source of extracts, and so on. However, Richards argues that qualitative research, "requires an in-out process" whereby researchers can zoom in to the fine detail and then escape the data to take a wide angle view of the larger picture. This would certainly seem relevant to inductive theory building research such as the present study, whereby the object is to synthesise understandings that the participants could not.

The very tools that have provided unprecedented closeness to data have now produced what Richards calls "the closeness cult" and made it more difficult to

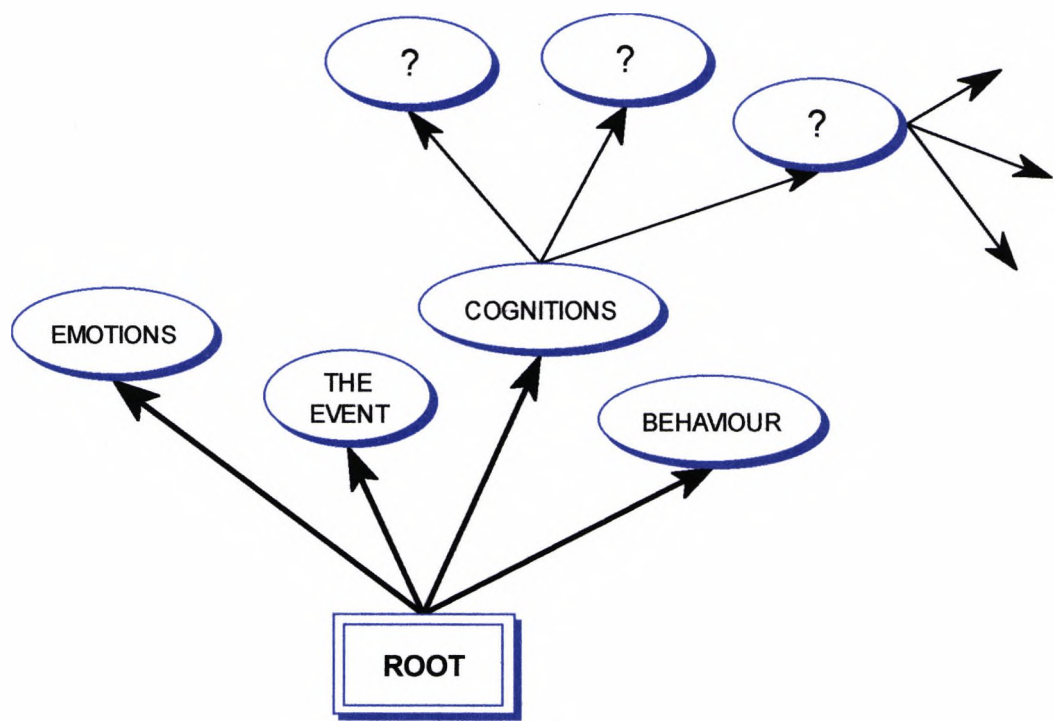
achieve distance. When Richards wrote this in 1998 she argued that the challenge of the next generation of qualitative software was to achieve distance.

3. *Computer Analysis With QSR NVivo, Version 1.1*

When a successor to NUD.IST was produced in 1999, therefore, it was decided that the data would be re-analysed. By this time the decision had been taken that the exploratory phase should be expanded to become the study itself, and it was considered important to use the best and most up-to-date software available.

NVivo claims many advantages over its predecessors in the domains of editing, coding and searching. It has a system for dealing with case data (attributes) outwith the node structure. This means that descriptive and categorical nodes can be dispensed with, leaving the researcher free to concentrate on conceptual nodes. It also has a modelling facility that encourages contemplation of the data from a distance, and this facility is extensively utilised as a means of producing models (figures) in the following results chapters.

Figure 4.2 – Tree Structure Showing Superordinate Themes



The superordinate themes were large categories that captured most of the data between them, though some 'free nodes' were also used where coding did not fit within the hierarchical index tree structure. Axial Coding resulted in the repeated breaking down of superordinate themes into much more conceptual sub-themes and sub-sub-themes etc (see Figure 4.2).

4.6 Sample Characteristics

This section provides a profile of the sample characteristics, and this is based upon relatively objective categorical data, which were treated as attributes during analysis. The importance of this section is to provide a basis for judging whether differences identified in the following chapters were a function of gender or some other factor such as biographical, medical or social factors.

Inclusion Criteria

All interviewees met the inclusion criteria, as set out in Section 4.4, with the exception of two women who were inadvertently recruited despite the fact that each of them failed to meet one of the inclusion criteria. This came to light during the interviews, which were carried through to completion anyway.

In one case it transpired that the woman had recently undergone coronary bypass surgery. In view of the different circumstances surrounding coronary bypass surgery, and the fact that the operation is treated differently from heart attacks by both clinicians and researchers, the data gained from the interview were discarded.

The second woman (P3) revealed that she had in fact suffered a heart attack some 33 years before. Since this very unusual event had occurred so long ago, it was thought unlikely the experience would have markedly influenced the participant's reaction to her current situation, and the data were included in the analysis.

Refusal And Attrition

Hospital staff reported that a number of patients declined to participate in the study because of general distress, transport difficulties or poor health. In other cases, staff took the initiative in excluding patients when it became clear that the demands of participating would be onerous because they were too unwell or too stressed. Further, given the different portals of entry to the hospitals, it is likely that other patients may have passed through the system without being identified at all. For example, in Section 1.4 it was shown that women are more likely than men to be admitted directly to a general medical ward rather than a CCU (Clarke *et al*, 1994). Attempts were made to keep track of such admissions through contact with medical wards and hospital information departments.

No one refused to participate once they had reached the point of discussing the matter with the researcher. Only one woman refused to undergo a second interview (P2). This woman had expressed much anger and distress during the first interview and, although initially agreeing to a second interview, made several excuses for postponement and then cancelled altogether. One man left home after the first interview, apparently having driven to the continent with his wife and caravan for a prolonged and indefinite period of time (P26). Finally, another man died of a heart attack before the second interview could take place (P27).

Sample Profile

A total of 30 people participated in the study: twenty women and ten men. Interviews took place between February 1996 and July 1997. All participants were interviewed about three weeks after discharge from hospital (mean = 3.83 weeks, sd = 7 days) and 27 of them were interviewed again about three months later (mean = 13.5 weeks, sd = 13 days). The sample had the following attributes.

1. Comparison Of Ages

The following table shows that female participants were older than males. The age difference reached statistical significance using the independent samples t test and a one-tailed prediction ($t=1.82$, $P=.04$).

Table 4.4 – Mean Age In Years Of Men And Women

	n	mean age	sd
women	20	61.85	6.68
men	10	55	10.9
sample	30	59.57	8.79

The mean age of participants was rather younger than that of the coronary population at large as a result of the upper age limit. This applied more to women than to men.

2. Comparison Of Hospitals

Of the 30 participants, 16 were recruited from Hospital A and 14 from hospital B. As Table 3.2 shows, there was no noticeable difference in the age or sex of participants recruited from the two hospitals.

Table 4.5 – Comparison Of Hospitals

	hospital A		hospital B	
	n	age	n	age
women	11	62.64	9	60.89
men	5	54	5	56
total	16	59.94	14	59.14

3. *Marital Status*

As shown in Table 3.2, all men were married or cohabiting at the time of their heart attack, whereas this applied to only 12 of the women, the remaining eight being widowed or divorced in equal numbers. As might be expected, widows were older than other women. Six of the single women lived with family members, and the remaining two lived alone.

Table 4.6 – Marital Status Of Participants

status	women	men	age
married	12	10	58.5
widowed	4	0	70.25
divorced	4	0	54.75
sample	20	10	59.57

4. *Occupational Work*

A total of 11 participants were in part time or full time employment and the remaining 19 had retired from work. There was no relationship between marital status and work. As one might expect, however, there was a negative relationship between advanced age and work. The average age for male workers was 48.5 years and for females 58.4 years, compared with sample means of 55 and 61.85 years respectively.

Table 4.7 – Employment Characteristics

	men	age	women	age	total
employed	6	48.5	5	58.4	53
retired	4	64.75	15	63	63.37
sample	10	55	20	61.85	59.57

5. Household Work

As regards the division of labour within the home, some participants reported traditional roles with the woman taking responsibility for cooking and cleaning, the man taking responsibility for repairs, and either or both taking responsibility for gardening. Others claimed to have a less traditional approach with sharing of labour across many household chores, and three participants lived alone. More male than female participants claimed to have a shared approach to household work.

Table 4.8 – Distribution of Household Labour With Mean Ages

	traditional		shared		n/a
	n	age	n	age	
men	3	49	6	59.17	0
women	15	60.27	3	69	3
total	18	58.38	9	62.44	3

Overall, those who reported a traditional approach to the division of household labour were younger than those who reported sharing, with a mean age of 58.38 years compared with 62.44.

6. Means Of Transport

The following table indicates the proportion of participants who had an independent means of transport compared with those who relied on someone else to drive them around and those who had no means of private transport at all. It can be seen that car ownership was much more common among male participants and among younger participants.

Table 4.9 - Means Of Transport

transport	women	men	total	age
independent	5	9	14	56.8
dependent	8	0	8	60.12
none	7	1	8	65.12
total	20	10	30	59.57

7. *Pre-Morbid Health Problems*

Table 4.10 shows that many participants had at least one health problem prior to their heart attack. The most common problems were cardio-vascular disorders, locomotor disorders such as arthritis and endocrine disorders, particularly diabetes.

Table 4.10 - Pre-Morbid Health Problems

condition	women	men	total
cardio-vascular			
• angina pectoris	3	2	5
• hypertension	1	3	4
• other	6	0	6
locomotor	5	1	6
endocrine	5	0	5
miscellaneous	4	2	6
Total	24	8	32

4.7 Conclusion

This chapter provides a description of the way in which the research design and planning developed, how it was conducted and how the data were analysed. The last section, which provides details of categorical sample information resulting from the assignment of attributes, will assist in assessing the meaning of the themes arising from conceptual analysis that are presented in Part Two.

These conceptual themes are arranged into super-ordinate categories which form the basis of the four results chapters that comprise Part Two.

PART TWO

THE RESULTS

PART THREE

DISCUSSION AND CONCLUSION

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CHAPTER NINE

DISCUSSION OF THE RESEARCH PROCESS

9.1 Introduction

This chapter considers the main issues associated with the way in which the study was conducted. In particular, the value of the longitudinal design is assessed. This approach was chosen in preference to the cross sectional approach adopted by most previous studies because it enabled the researcher to study processes that changed over time. Furthermore, as Oakley (1993) and Cunningham-Burley (1985) have argued, the interval between interviews provides an opportunity for development of the research relationship, reflection by both parties, and subsequent interviews are likely to yield a fuller, deeper and more complete account. These arguments were judged to be more convincing than those of Brannen (1988) who advocates the one-off interview because, she argues, the greater sense of anonymity encourages more self disclosure.

The transcripts provide much evidence that the second interview was indeed worthwhile, with a number of participants making disclosures that they had not been willing or able to make earlier and others recounting changes in their emotions, thoughts, behaviour or circumstances that had occurred over time. These issues are discussed in relation to the process literature that was presented in Chapter Three and are illustrated by the use of 'exemplar cases'. Additionally, in some cases it was evident that increased disclosure was the result of reflection and the development of the research relationship and this is discussed in the final section.

9.2 Changes In Emotionality Over Time

For some participants, changes in reported emotional status occurred with the passage of time, often strongly associated with their style of coping. This meant that interviewing over two time points provided a fuller picture of the

process of adjusting from health, through the acute crisis of heart attack and then into chronic illness.

Exemplar 1 - P1

P1 was a 56 year old woman who lived with her husband and dogs. Osteoarthritis forced her to give up work eight years prior to the heart attack. This represented a loss since she depended on work to provide her with a life outside the home and her family caring roles. Around this time her arthritis also forced her to stop driving, thus depriving her of an independent means of transport. She also developed non-insulin dependent diabetes. Prior to her decline in health, P1 would spend her leisure time fishing, gardening, horse riding and country walking. By the time she had her heart attack she had lost the ability to participate in all these activities except gardening and visiting her grandchildren. Although she appeared to have had an otherwise happy marriage, arthritis had led to a premature cessation of sexual activity. Thus, the run up to her heart attack was characterised by widespread losses.

Following her heart attack, this woman developed chronic heart failure causing continued breathlessness and angina. The medical outlook was bleak indeed. When asked at Interview One how she saw the future, she replied:

P1 I don't know, I don't know. I can't even think about it at the moment. All I know is I'm frightened.

R You're still frightened?

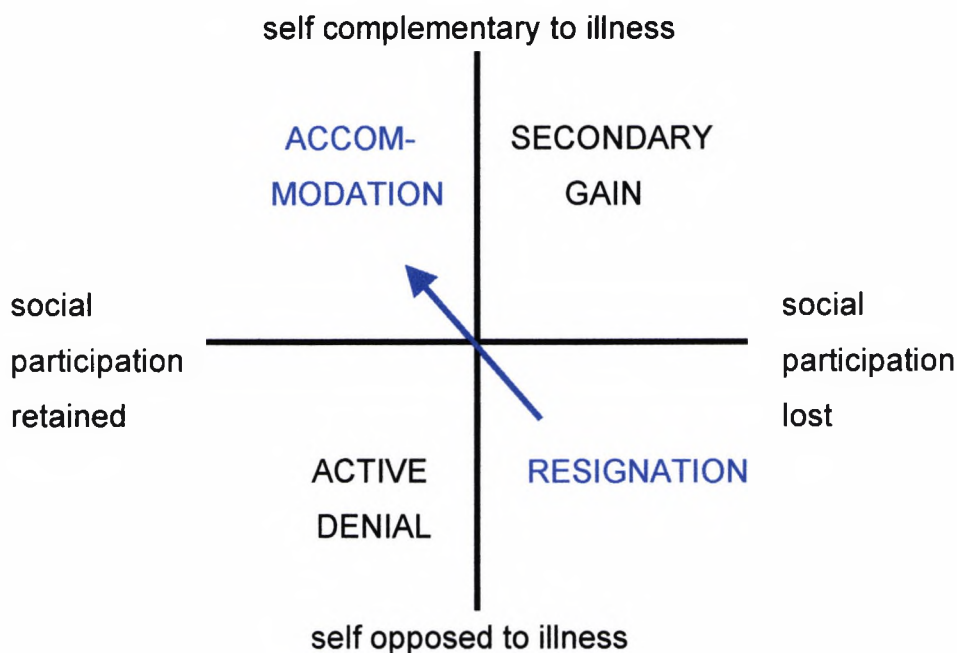
P1 I'm still frightened I'm going to have another heart attack. You know, I get that fear during the night and I, it wakes me up, that I, I am frightened of another heart attack, you know, and I'm frightened to push myself too much. Especially when the heart starts to beat a bit funny or feels a bit heavy or there's a pain, I get frightened again.

Clearly, P1's over-riding emotional problem was severe anxiety. In the early post-coronary period she was overwhelmed by her illness, this leading to constant feelings of fear and helplessness, with consequent withdrawal from such social and leisure pursuits as she had been able to enjoy prior to her

heart attack. Her adjustment style at Interview One could therefore be described as primarily that of 'resignation'.

By Interview Two P1 had been readmitted to hospital with severe symptoms on four occasions. Medical staff had told her that "half her heart was dead" and that there was no curative treatment they could offer. She was under no illusions and knew that she was likely to relapse or die at any time. Despite this knowledge, P1 had adopted a different attitude toward her illness by Interview Two and no longer experienced anxiety. As reported in Section 6.5, she attributed this change to a very significant 'dream' that she had on her second hospital readmission. Somehow she had learned to 'accommodate' her illness. She had accepted her situation, had modified her activities in such a way as to maintain social contact and was much less distressed.

Figure 9.1 Mode Of Adjustment: Exemplar 1



As regards maintaining social participation within her physical limits, P1 re-negotiated visiting arrangements with her grandchildren so that they started visiting her rather than she visiting them. She discovered that some garden centres make wheelchairs available to customers, so she and her husband

were able to resume these outings. They also re-arranged their garden so there were parts where she could sit on a stool and do light gardening.

P1 also adjusted to her illness by attempting to exert control in several ways. She developed an action plan for future relapses so her husband and her were able to act calmly and appropriately. She learned to manage her occasional feelings of anger by retreating to a hot bath and avoiding her husband. Finally, she stopped smoking and started paying attention to her diet. Personal control has long been recognised as an effective way of dealing with stress (Averill, 1973) and is one of the themes identified in Taylor's theory of cognitive adaptation (Taylor, 1983). P1 appeared to have reduced her anxiety levels by means of behavioural control, ie direct action on the environment. As the following passage shows she also increased cognitive control by seeking information about her condition.

At Interview One P1 made it clear that she had rejected health related advice during her initial hospitalisation because she "wouldn't accept it" and "wasn't ready to step back." However, by Interview Two she was taking a very active interest in health-related information. When asked what advice she would give to a woman who had just had a heart attack, she replied that:

P1 Well I'd say to her, give it time and try to....what I do is, now any heart programmes on the television, anything to do, I sit and I watch and I record, and I go back on. If you go back and you listen to other people, there are people in this world that are worse off than what you are, and if you learn to adjust your life to what you can't do, what you could do before, things will be a bit easier.

Additionally, this demonstrates a clear shift from avoidance to approach coping (Roth & Cohen, 1986), and provides an example of downward comparison as a means of self enhancement, another cognitive coping theme identified by Taylor (1983). This also raises the issue of 'readiness to learn', an issue that is taken up in Section 11.2.

Exemplar 2 – P18

P18 was a 64 year old woman who lived with her husband and had three grown up daughters. The background to her heart attack was difficult and was characterised by a series of losses over a period of six years. Her hard times began when her husband was made redundant and they were evicted from their tied council accommodation. They were therefore forced to move to a much smaller house in a council estate and they found it hard to get along with neighbouring teenage children. They were also hard up so her husband was forced to return to work. In order to help ends meet they took in a series of homeless and drug-abusing young people.

Apparently they had adjusted well to these losses. P18 and her husband took a great pride in their garden, grew orchids in the greenhouse and played an active role in the local Orchid Society. Formerly they had regularly entered competitions but the expense of heating the greenhouse became prohibitive so they satisfied themselves with growing plants for their own enjoyment. Other aspects of their social life also contracted over this period. Further, the presence of young people in their small house did have an impact on their relationship and there were signs that their sex life was faltering.

P18 Very stressful. It did create quite a few problems between myself and my husband too, so...

.....

R Okay. Can I ask you whether you had an active sex life prior to your heart attack?

P18 Reasonable, stopping for arguments sometimes. Em, (laughter) my hus, my husband thinks I, I'm old and, em, and I should, er, go in for, er, this hormone replacement treatment, and I resist to do it (laughter). I said it was his problem not mine.

Following the heart attack P18 immediately resumed her caring role by helping other patients in hospital before she should have been out of bed herself. At that time her concerns were directed at others and she was emotionally stable. However, her feelings changed with the passage of time.

R Okay. How did you feel at that time, emotionally?

P18 Not...all right really. Em, I don't think it's the actual fact that I'd had a, that I'd actually died for a few minutes, had actually hit me until I got home.

At Interview One P18 expressed some understandable sentiments about loss of confidence following her cardiac arrest but this appeared to be quite in proportion to her situation. She was also frustrated because breathlessness prevented her from doing what she wanted to do, namely gardening and some household tasks. However, she was coping quite well said she was optimistic about the future and expected to resume her previous lifestyle.

At Interview Two, however, she reported a very different story. In the absence of help from her husband she had stopped attending the rehabilitation scheme. She had finally given up trying to cope with heavy household chores and gardening. Her GP had prescribed medication for both breathlessness and sleeplessness. Quite apart from her physical limitations, P18 had simply lost her motivation to engage in pursuits that had formerly given her pleasure including gardening, knitting orchid jumpers and she had lost her sex drive. Watching the weeds grow and worrying about her marriage caused her some emotional distress.

P18 I don't garden at the moment and I don't do the greenhouse I'm afraid.

R You've let that go. Is that a disappointment to you?

P18 Yes it is. I just do, I just do not feel that I want to do it. I, I one, one thing I, I would like to mention is the fact that I, I used to always when I sat, do something and....

R The orchid jumpers?

P18 You know the orchid jumpers and things, and for ages and ages I could not rake up any enthusiasm for doing anything at all, nothing. I mean nothing would come into my head that I wanted to do, you know.

She then went on to talk about her "great disappointment" that she was not having a "proper relationship" with her husband due to her lack of libido. Although she denied being depressed, she clearly demonstrated a number of the hallmarks of depression, was quite sad and emotionally distressed. She said she had changed from her normal "bubbly" personality, spent too much

time thinking about herself and typically felt fed up by the end of the day. P18 spent time thinking about death and planned to write letters to her grandchildren,

“...so that they’ll have something of mine when I’m not here.”

In addition to these emotional changes, P18 also spent the period between Interview One and Interview Two searching for causal meaning. When asked at Interview One she immediately attributed her heart attack to smoking, though probing revealed that this was her GPs opinion and she was less sure. When the question was repeated at Interview Two, however, the immediate answer was the stress involved in her care-giving activities and, following a pause, she added, “...and probably smoking.” She had been thinking about it.

Figure 9.2 Mode Of Adjustment: Exemplar 2

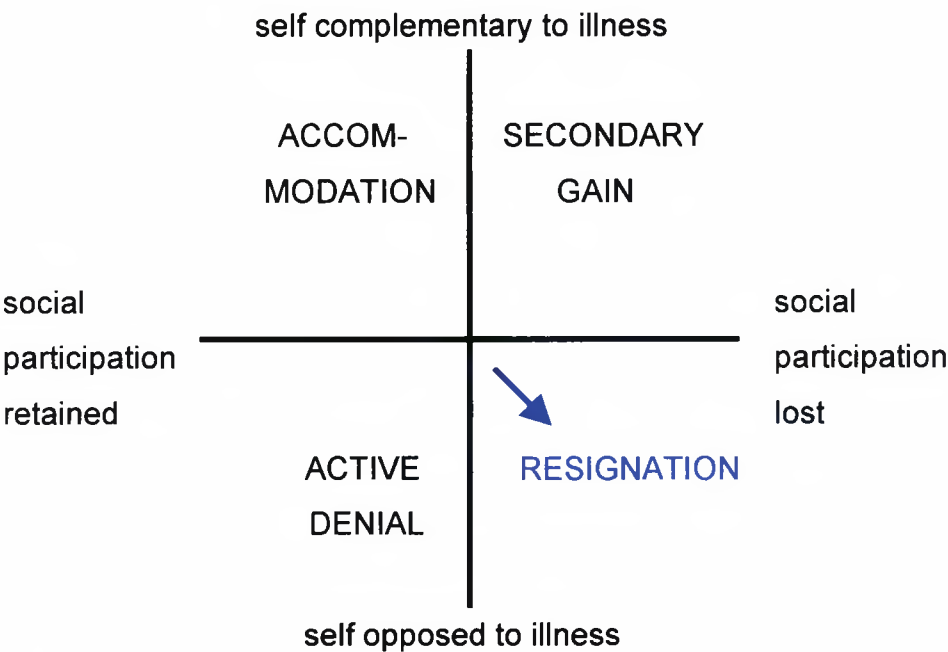


Figure 9.2 plots P18s coping trajectory. She began her recovery with an assumption that, once back in circulation, she would be able to resume her family and other roles. Frustration turned to depression as time passed and it became evident that her symptoms would not permit her to do the things that she wanted to do. She refused to accommodate her illness by taking regular exercise, attending rehabilitation classes and confronting her husband about

his lack of practical support. Instead she reduced social participation and the illness enveloped her causing increasing emotional distress. She appeared to be moving deeper into resignation as time passed.

Comment

Like P1 some participants fitted neatly into a particular paradigm within Radley's typology of adjustment styles, while others seemed to span more than one style or move from one to another. Radley argues that individuals have access to all four modalities as they adjust to their changing illness situation over time (Radley & Green, 1985). Rather than trying to locate a person within a particular quadrant, therefore, it is more helpful to think of balance, ie the extent to which an individual uses a particular modality at a given time, or moves from one to another over time. The modalities are not mutually exclusive, though an individual might show overt signs of only one or two modalities at a particular time (Radley & Green, *ibid*).

Another confounding factor is that, as reported in Section 6.4, is the number of participants who had already had to adjust to health and other problems prior to their heart attack. Thus there is no assurance that the coping behaviours identified were a direct result of the heart attack since they might have had their origins further back in the process of moving from health to illness. This applies to both the exemplar cases described above.

Another area in which emotions changed over time was the distress reported by some participants as a result of smoking cessation (see Section 6.4), which was sometimes not experienced immediately and was therefore not reported until Interview Two.

9.3 Changes In Circumstances Over Time

In Part Two much evidence was presented in respect of the factors that appeared to influence adjustment. These included emotional and practical support, family finances and role occupation. Some of these factors changed

between Interview One and Interview Two, and would therefore not have been fully evident in a cross sectional study.

Exemplar 3 – P21

This 62 year old working class man lived with his wife, his son having moved some distance away. Prior to the heart attack his main concern was to look after his 70-year-old wife. In the preceding year she had been hospitalised thrice for surgery which left her with distressing symptoms in-between operations. Her illness also meant that she was dependent on P21 for everything. This meant that, in addition to the physical demands of working shifts as a postman, he had to do all the household chores and look after his wife's activities of daily living. In practice this meant getting up at four o'clock in the morning in order to prepare breakfast for his wife before work, then coming home in-between rounds to check that she was alright, and finally retiring to bed at 22.30 hours.

Although he quite enjoyed his job, this P21 did experience conflict in respect of imposed changes in working practices, the union's response and his position in all this.

P21 You know we've had a few strikes and, er, I'm not in favour of them to be quite honest, but er, you have to go with the, you know, with the majority. (deep sigh)

Quite clearly going to work put P21 under considerable stress because of his domestic roles and his opposition to strike action. However, he was keen to work right up to retirement age because he needed the money.

By the time P21 had his heart attack, his wife was somewhat less dependent but was still elderly and frail. He worried little about his own welfare throughout his time in hospital but was desperately worried about his wife and about whether he would be allowed to return to work. However, his wife's niece stayed with her while he was in hospital and after his discharge continued to visit in order to help with heavy chores such as shopping, thus allowing him some respite. At Interview One he said he was quite happy in

himself, had already driven down to the West Country to visit his son and was optimistic about the future. He was planning to order winter seeds for his vegetable garden.

R How would you describe your emotional state now?

P21 Quite good actually. Actually I feel a bit of a fraud to be quite honest. I honestly do. But er, I do notice I get tired if I, if I try to step over the mark, I do notice it. But I feel quite happy actually.

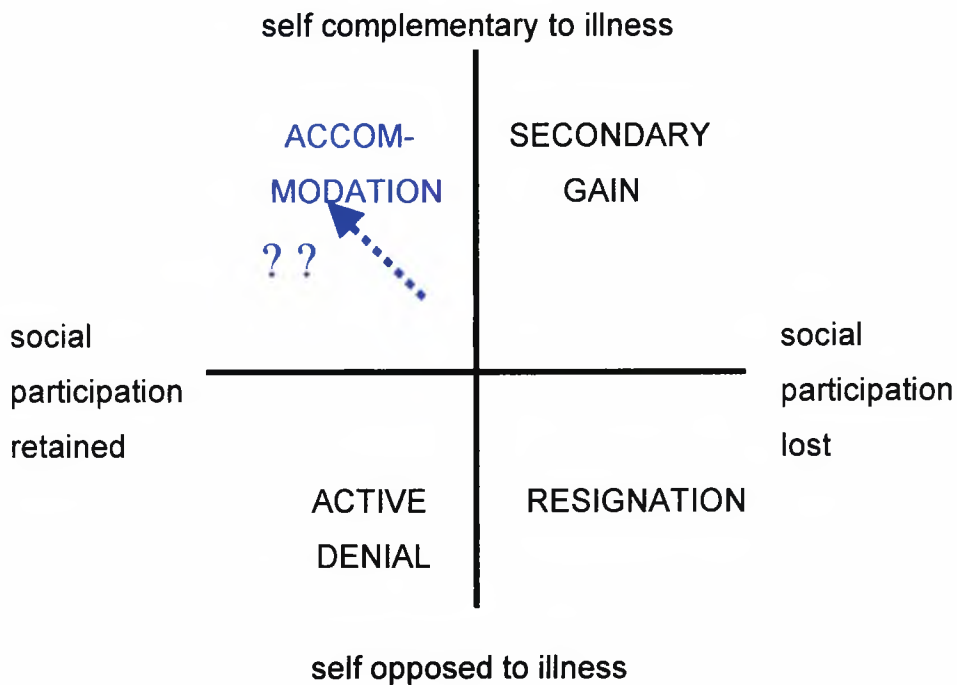
At Interview Two P21 had just returned to work. The arrangement was that he would work part time for a month, at which time the situation would be reviewed. He was on 'three months retention' which meant that medical reviews would subsequently take place on a three monthly basis until he reached retirement age. This was a matter of some concern since P21 needed to continue working.

Within three days of returning to work P21 encountered problems. Despite organising his day so that he could push a bicycle along which supported the weight of the post bag, he had found it hard work indeed.

P21 Yeah I just, bit apprehensive how I would cope. And I did find it a lot harder than I thought I would actually. I didn't, though I was doing the exercises and going for walks, different type of exercise when you start work and I found it quite hard.....Well actually last Wednesday I was talking about going down the doctors and see about going sick because it really got to me. That was the wind I think, going back against the wind. Although I got three speed on me bicycle, it was just too much.

The circumstances surrounding P21s rehabilitation changed markedly when he resumed his work role. Up to that point he had accommodated well to his illness. As his wife's niece withdrew support, he and his (recovering) wife organised the household so that they shared chores between them. They also invested in a washing machine. However, the difficulties in returning to work were only revealed at Interview Two. Thus P23 was making serious efforts to accommodate his illness but further interviews would have been necessary to establish how successful they were ultimately.

Figure 9.3 Mode Of Adjustment: Exemplar 3



Exemplar 4 – P11

P11 was a 75-year-old woman who, having been widowed eight years previously, lived with her daughter and son-in-law. Her other daughter lived across the road and she saw her grandchildren daily. P11s live-in son-in-law had for some time been out of work, so he undertook all the household chores, thus allowing both P11 and her daughter to go out to work.

This participant worked in a fish and chip shop for 27.5 hours per week. Although the work was demanding she enjoyed it since she liked, “meeting people and being out.” She was a remarkably energetic and sprightly woman who prided herself on her physical prowess. She enjoyed travelling everywhere by bus and took a great pride in her garden that extended to heavy digging.

It was interesting to note that P11 claimed to have no idea what had caused her heart attack.

R What do you think it was?

P11 I don't know, I honestly don't know what caused it. Whether it was because of the hours I was doing and the dashing around, 'cos I can't slow down, a little too active.

Furthermore, she claimed that hospital staff had given her no information about the cause of her problem and, despite a reminder by the researcher, the Clinical Nurse Specialist had still not invited her to the rehabilitation scheme by Interview Two. This left her in ignorance about her condition.

R Em, what did the hospital think caused it then, did you ask anybody?

P11 No, they never mentioned anything, what they think caused it.

.....

P11 No, she hasn't mentioned anything about it.

R Hasn't she. I think she talked to you on the phone though didn't she?

P11 Yes but she didn't mention anything about going to the classes.

When recounting her feelings in hospital, P11 said she was very surprised, shocked and dazed. She could hardly believe it had happened. However, this wore off after a few days and by Interview One she claimed to be absolutely fine.

R Um. How do you feel emotionally now?

P11 Well I'm alright, yes.

R You are not particularly worried or anything like that?

P11 No.

However, it was evident to the researcher and co-raters that P11 appeared to be stilted, overly optimistic and cheerful during this interview. She answered questions very quickly, her answers were frequently monosyllabic and the word count was low compared with other participants.

R Okay, em, how would you say you are recovering so far?

P11 I feel I'm coping pretty well.

R You're doing well considering your age.

P11 Yes, yes.

R What about the future, do you think the future looks good for you?

P11 I think so, yes.

R Anything you're concerned that you won't be able to do that you used to do before, like digging the garden or anything like that?

P11 No.

By Interview Two, however, both her feelings and her expression of them were very different.

R Okay. What's life been like for you in the last three months?

P11 Very traumatic really.

R Has it?

P11 Yes. I can't do the things now that I want to do. I've slowed up such an awful lot. I can't walk as quickly as I like to, and I'd like to do more than I'm doing.

.....

P11 Yes.....and if I go out I can't walk as fast as I'd like to.

This deterioration in her demeanour was strongly related to changes in circumstances related to the resumption of social roles. In particular, when returning to work after the recommended period, P11 was distressed to find that she could no longer cope and was forced to discontinue after a week.

This attempted resumption of her work role was accompanied by changed circumstances at home. In the period between Interview One and Interview Two, P11's son-in-law had become ill and was awaiting admission to hospital for surgery. This meant that he was unable to contribute much to household chores. Being fiercely house-proud, P11 felt compelled to step in and take responsibility for cleaning, cooking, gardening and even shopping for three, and this caused her problems.

P11 Yes, I can't now. Even the housework seems to take it out of me. I feel so exhausted after I've done any housework.

R What kind of jobs make you feel exhausted?

P11 Well, hoovering, dusting and polishing.

R And obviously digging the garden?

P11 Yes.

R What about lighter jobs like weeding or dusting, even dusting, light jobs like that?

P11 Yes that seems to exhaust me.

By Interview Two she had become very frustrated at her inability to resume her former roles, to lead an active life and "trot around" the way she used to.

This had emotional consequences and resulted in a less positive view of the future than she had previously expressed.

P11 Well I've been, I just don't know really.....I get very upset at things. If things don't go right I get very emotional.

R Do you?

P11 Yes.

R Um, what kind of things?

P11 Well if I can't do the things I want to do, that's the sort of thing I get really upset about and that's quite/

R Is that a sort of frustration?

P11 Yes.

R do you think you're going to get better and the future is good?

P11 Well I hope so.

R Or do you get quite glum when you think about the future?

P11 I do yes unfortunately. (laughter)

R How glum do you get?

P11 Very. (laughter)

It can be seen from the following quotation that the process of searching for causal meaning continued over time, and her inability to find an answer contributed to the distress.

P11 I still can't find out why.

R You've no idea whatsoever?

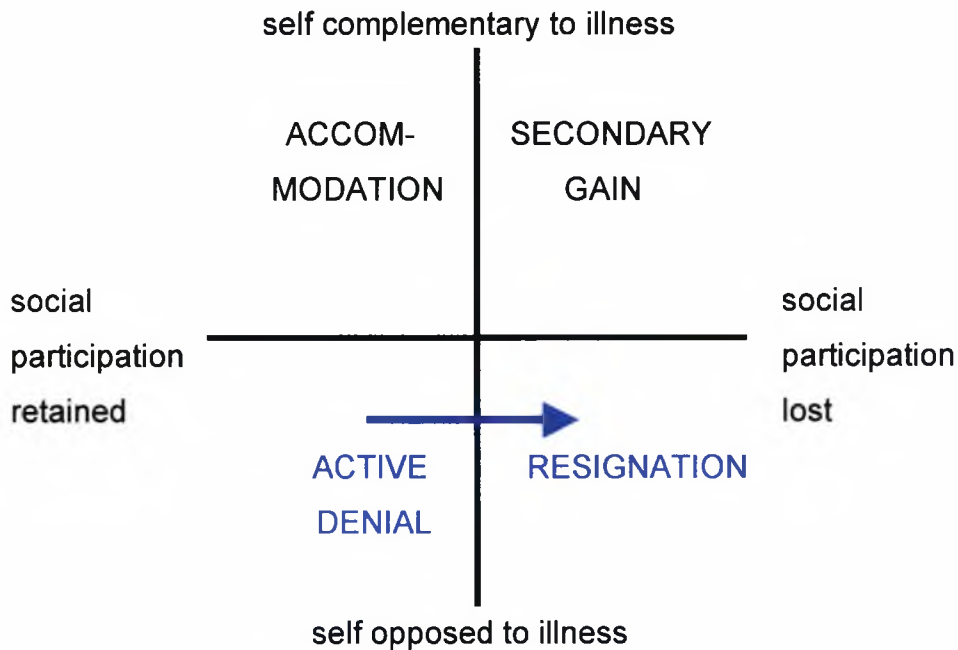
P11 No, no idea at all.

R Does that bother you, not knowing what?

P11 It does at times yes, wondering why it happened. What I'd, what I'd done wrong....that caused the heart attack.

This elderly lady was bright and cheerful at Interview One, behaving almost as if nothing had happened. Her undue cheerfulness and optimism represented a denial of the seriousness of her situation and enabled her to re-engage with her social roles. However, with the changes in her circumstances at home and with her return to work, she was forced to confront the reality of her limitations. This led initially to frustration and then to depression.

Figure 9.4 Mode Of Adjustment: Exemplar 4



Comment

These two exemplars show how changing circumstances and the type of social roles previously occupied can act as barriers to the resumption of full social participation. Other circumstantial factors that, for some participants, influenced progress over time were the impact of coronary angiography (Section 6.5) and the changing availability of practical support (Section 8.4).

9.4 Changes In Disclosure Over Time

Some participants had clearly spent time reflecting on matters discussed in Interview One and thinking about their situations. At Interview Two these people were more forthcoming in their personal disclosures, sometimes raising issues that had been avoided in Interview One.

Exemplar 5 - P10

P10 was a 52 year old woman who lived with her two sons, one 14 years of age and the other 22, and her two dogs. Her life before the heart attack was

characterised by serving the needs of others within the home. She willingly accepted responsibility for all household tasks and her sons contributed nothing. Additionally, she had a full time clerical job that was very demanding. P10 neglected herself in respect of diet, rest and relaxation and was a smoker. Over the years she had gradually discarded hobbies, most socialising and her sex life. Her whole life seemed to revolve around the roles of mother, housekeeper and provider. One can speculate whether this pattern of behaviour was connected to single parent status, but the following comment indicates that it might also have been learned:

P10 I did work a lot, you know, because I mean my mother was very active in work and I don't relax much and sometimes I never got home 'til seven o'clock at night. And still cooked the dinner, and still walked the dogs.

At Interview One P10 denied any feelings of anxiety but was distressed by the suffering of other patients. She clearly identified with the dying patient in the next bed who shared the same forename as herself. So P10 seemed to avoid personal anxiety by focussing on the suffering others. She also seemed to cope by asserting on several occasions that she was a very "independent person" and was "infallible".

By Interview Two, however, there was considerable 'leakage' of anxiety, which was still denied. P10 began talking in a way that was interpreted by the raters as dramatic evidence of implicit death anxiety. First, she talked about her own expectations of an early demise and the fact that she arranged her possessions accordingly.

P10 I've got this terrible feeling that I am going to die very young. I don't know what it is, I just cannot see me living to a great age.

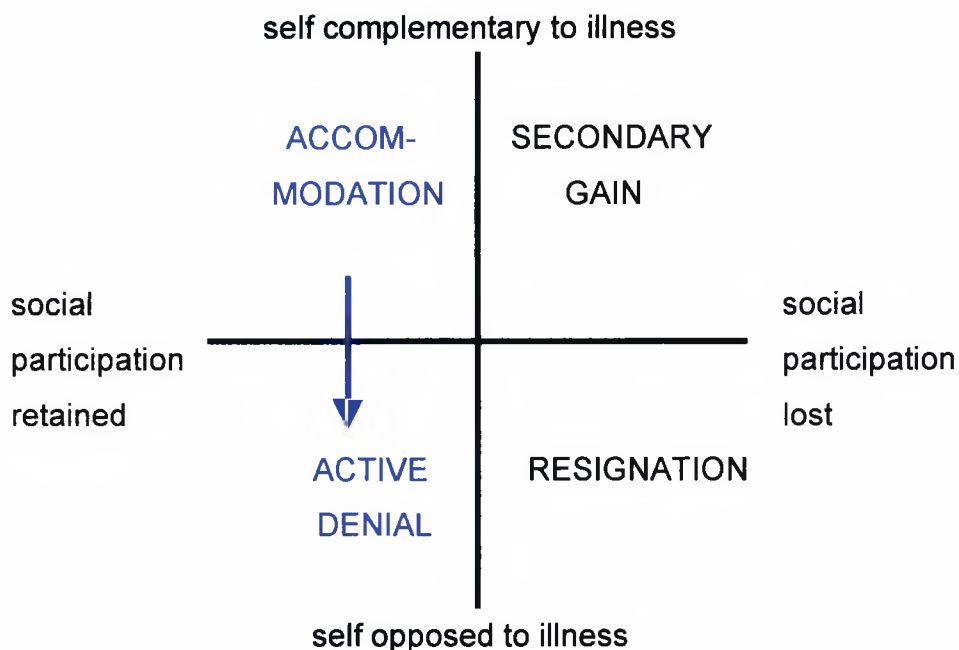
On probing, it transpired that this feeling of anticipated early death pre-dated the heart attack and appeared to follow the recent demise of her twin sister. She talked a good deal about her twin, who shared her habits of smoking and dietary self neglect. She also shared the diagnosis of CHD following her sisters death from a heart attack three years earlier. Furthermore, there were

also references to the death of her parents. P10 appeared calm and unemotional when discussing these things and repeatedly denied any fear of death.

In parallel with this gradual revelation of death anxiety, P10 modified some risky aspects of her lifestyle initially and then, after she had completed the rehabilitation programme, gradually resumed harmful elements of her pre-coronary lifestyle. She resumed driving prematurely, accepted promotion to a more pressurised job, continued to do everything for her two sons and resumed smoking. She also ignored chest pains. As her friends told her: "You've gone back onto exactly what you were before."

It would appear that, according to Radley's typology, P10 began to accommodate her illness in the early stages but, by Interview Two, had adopted the adjustment style of 'active denial'. This prevented her from being engulfed by her illness and permitted her to resume full social participation.

Figure 9.5 Mode Of Adjustment: Exemplar 5



These changes took place over time and would not have been revealed in a single interview. This also shows another benefit of a second interview. Whilst

studying the transcript of Interview One, the researcher noticed a passing reference to her sister's death. No apparent importance or significance was attached to this and it had gone unnoticed at the time. However, the researcher raised this at Interview Two and this is what led to the disclosures. Thus a second interview offers a second chance to follow up issues that, for one reason or another, were not explored in the first.

Exemplar 6 - P29

P29 was a man of 49 when he had his heart attack. He lived with his wife and daughter, though the daughter was away at university most of the time. It seemed that they were a very close family. His house was a large detached Victorian property extending over three floors and with a big garden. The garden contained out-houses which he used as workshops for his light engineering business.

At Interview One P29 presented as a 'happy-go-lucky' person. He worked hard but spent his money freely, enjoying an active social life and expensive foreign holidays. Although he expressed a very relaxed attitude to money, he did have a mortgage to consider alongside his daughter's university fees and living expenses.

The heart attack came as a big shock to P29 since, he reasoned, he had none of the classical risk factors. He reacted with strong denial, saying that ,

P29 Erm, it wasn't happening to me, it was like a dream. You know, I'm having a bad dream, I'll wake up in a minute.

His relative youth, the absence of risk factors and the fact that his initial ECG failed to reveal evidence of a heart attack, all contributed to the denial. He believed that his blood specimen, which did finally provide evidence of heart attack, could have been mixed up with someone else's. He was cheerful, 'chirpy' did not admit to the experience of anxiety. This was not a classic case of denial in the Freudian sense since P29 openly admitted that he was blocking it out and asked the researcher whether this was normal.

This denial is consistent with P29's behaviour throughout the process of becoming ill. When his chest pain began he delayed for some time and, when he finally called an ambulance, turned the paramedics away since his symptoms had abated somewhat. Following discharge he resumed work within 48 hours and engaged in premature physical activity such as laying a concrete path.

After Interview One was completed he mentioned that his basement had been flooded three times in the last year and that he had had business problems during the recession and was forced to shut down his factory and become a "one man band". Also his wife had undergone surgery recently resulting in a punctured bladder. She had to wait six months for further corrective surgery, during which time she had distressing problems of urinary incontinence. These problems were described in a very light-hearted and cheerful way.

At Interview Two, however, it was revealed that P29 had been thinking a good deal about his heart attack and his situation. In the absence of a medical explanation he had arrived at his own causal attribution:

R Okay, looking backwards again, what er, what do you reckon was the cause of your trouble?

P29 I don't know, it was stress or not I don't know.

R Stress from your wife's illness...?

P29 Well stress from work.

R Work?

P29 Well, you know, the actual build up of trying to complete everything on time and do everything and rushing around and not sitting back and, not taking life easy but taking it in your stride.

R I think last time you said that you thrived on that.

P29 I did, I do thrive on it now but is it good for you? This is what I'm thinking now. Is it, it that what caused it and it's 'cos they haven't really told me here what actually caused it. Because they, they don't know, Dr Wilkinson said, "We'll class you as an unlucky one."

The fact that he had searched for an explanation of cause was evidence that his denial had receded markedly since Interview One. Having decided that his heart attack might have been due to work stress, this set in train a change in the way he thought about his present and future life.

R I don't think you'd even reached that point last time.....you said that you didn't really believe that you'd had a heart attack.

P29 Nah, no I do now. I honestly do now. And er, life's sweet and work is not the only thing in life.

R What happened to sort of change things, is it just something that happened with time or...?

P29 I don't know. I suppose I see two, two big events happened. I was (?) me fiftieth birthday and our silver wedding anniversary. And when you actually get to 'em you think, "Well I want to see me sixtieth, I want to see me ruby wedding."

This is consistent with one of the themes identified in the Theory Of Cognitive Adaptation in which part of the 'search for meaning' can involve life reappraisal and re-prioritisation following a life crisis (Taylor, 1983).

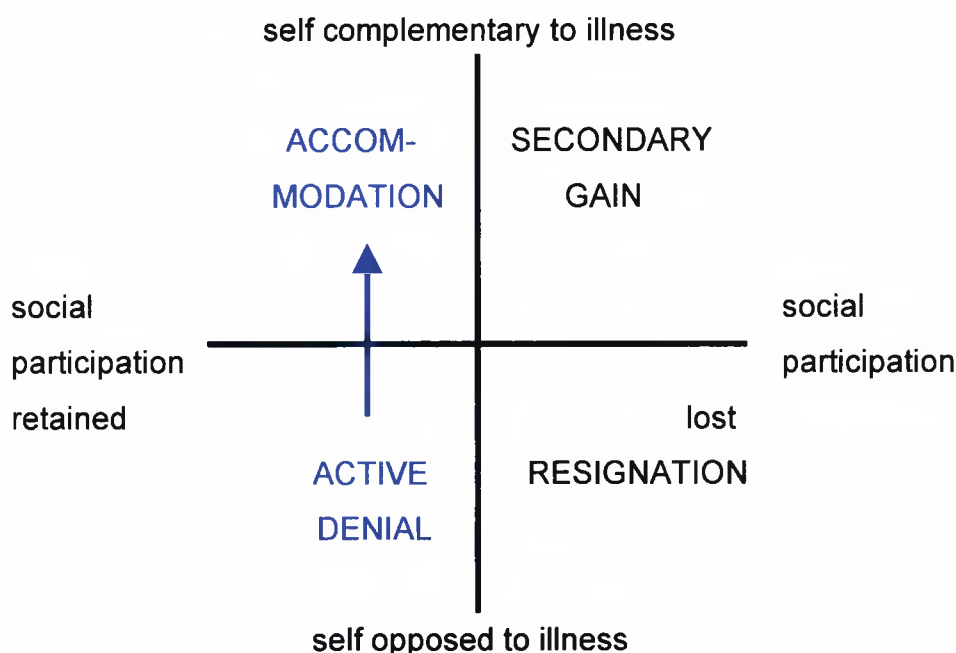
This change in the way P29 thought about his situation had resulted in a change in behaviour aimed at not provoking further cardiac problems. He described how he had developed the ability to stop when tired rather than pushing himself to finish a task. He had less of a sense of urgency and had developed a "Well things'll get there in the end" mentality. Examples of this include taking his time over chores like shopping and breaking away from his previously rigid work schedule.

P29 Yes. I will erm, I would, if I've had a hard morning I'll stop and have a cup of tea earlier. If I feel like I want a cup of tea then I'll stop and have a cup of tea then. Whereas before it was, "Oh, there's ten o'clock, stop and have a cup of tea." I would now, "Nah it's only half past nine, so what I'll have a cup of tea now."

By Interview Two P29 had also begun sub-contracting out work in order to limit his own workload.

Overall, this change in attitude had enabled P29 to develop a harmonious relationship with his illness: he had accommodated it within the self. He was still able to earn sufficient money to meet his commitments and continued to enjoy occupying social roles including dining with friends and having exotic holidays. In Radley's terms he appeared to have moved from Active Denial to Accommodation.

Figure 9.6 Mode Of Adjustment: Exemplar 6



Comment

Thus, in some cases information was disclosed only at Interview Two and there are at least three possible reasons for this:

1. For some participants the processing of information in-between over time might have led to insights.
2. It might have been the case that the development of the research relationship was such that, for some individuals, willingness to disclose information only occurred at the second interview.
3. At Interview One some participants were still in denial. They had not yet accepted their situations and were therefore not ready to disclose their feelings to another. An example of this is provided by P24 who explained that at Interview One he was still in "cloud cuckoo land."

9.5 Development Of The Research Relationship Over Time

This section considers the influence of the research relationship. It sets out the efforts made to develop this relationship and considers its influence on the

data yielded. The minimum amount of contact between researcher and participant was as follows:

1. Written information about study given to participant by hospital staff.
2. Upon participant's agreement, researcher telephones offering more details and seeking recruitment.
3. Interview One (preceded by informal discussion).
4. Letter from researcher thanking for participation and reminding of his wish to conduct a second interview.
5. Telephone call seeking to arrange Interview Two.
6. Interview Two (preceded by informal discussion).
7. Thank you letter.

In many cases several telephone conversations were necessary in order to arrange or rearrange interviews. And on some occasions the researcher happened to meet participants in-between interviews at the rehabilitation centre. On these occasions the opportunity was taken to develop the relationship by remembering participant's name and enquiring about the general health etc. However, like any other relationship the research relationship begins and develops in a physical setting of some kind. The importance of this setting is established in the voluminous literature on interpersonal relationships, and invariably occupies a position in communication models such as the Extended Model of Interpersonal Interaction (Hargie, 1997). Thus, considerable thought was given to where the interviews should be conducted.

The Interview Setting

The main choice of settings faced by the researcher was to interview participants in some kind of formal premises such as a hospital or health centre, or to interview them in their own home.

It was reasoned that hospital premises would have the advantage of providing the appearance of legitimacy and would offer very similar interview conditions

for all participants. Furthermore, a suitable environment would be virtually guaranteed as regards seating arrangements, appropriate siting of audio-recording equipment, privacy and the avoidance of interruptions. However, the venue clearly had the potential to lead participants into perceiving the researcher as being part of the health care system, and some may have been unwilling to speak frankly in these circumstances.

The alternative would have been to interview people in their own homes, with the potential advantages of a more relaxed atmosphere and the possibility of greater insights afforded by viewing the person in their natural environment. The disadvantage of widely varying test conditions was not considered crucial in this qualitative study. However, there did seem to be a threat of interruptions and, based upon his counselling experience, the researcher was wary of a perceived lack of privacy if family members should be present in another room, especially since some of the conversations were bound to enter sensitive areas of family life. Another reservation about home-based interviews was based on the researcher's vulnerability to false accusations or misinterpretation of behaviour. However, this was not seen as an insuperable problem, and is indeed part and parcel of professional life. Finally, one of the RECs (Hospital A) regarded home interviewing as intrusive and forbade it.

In the event, two participants insisted on conducting Interview Two in their homes and another in his office at work (Hospital B). These were all men. In two cases this was because it was because a home interview fitted in better with their work commitments (P22, P23) and in the other case it was because the man had transport problems and would not accept money for a taxi (P28). Whilst this was obviously much more convenient to the participants, it did alter the dynamics of the interactions. In one case, the senior military officer demonstrated his power and authority by sitting behind a very large desk, and the interview was twice interrupted by his subordinates (P22). As regards the two home-based interviews, other family members could be heard moving about the house during the discussions and, in one case, an interruption occurred (P23, P28).

Establishing The Relationship

'Breaking the ice' was seen as an essential part of establishing rapport, particularly in view of the sensitivity of the interviews. Interviews can be regarded as 'sensitive' if they pose a significant threat or risk to participants (Lee, 1993). Lee discusses a range of potential threats, but the interviews conducted in the present study certainly merit the term sensitive by virtue of their intrusion into personal matters and the discussion of emotionally charged issues such as sex and death. Additionally, neither interviewer nor interviewee could be sure what issues would arise in the course of these semi-structured interviews.

A number of writers emphasise the importance of approaching sensitive topics with care (eg Lee 1993, Brannen 1988). In an attempt to break the ice a brief overview of the topics of interest was included in the preliminaries preceding each interview was, though the researcher stressed that it was the participants concerns that were of primary interest.

"I shall begin by asking you about your life before the heart attack, your home life, work, hobbies, sex..... It's obviously up to you how much or how little you choose to say on any given topic. The questions are really just to get you talking. I really want to know about what *you* think is important in relation to your heart attack."

Writing from experience, Brannen (1988) counsels against this practice due to the danger of bounding the topic too tightly and thereby defeating the object of a loosely structured approach, instead advocating issues to be allowed to emerge gradually. However, this option was considered to be ethically dubious since it conflicts with the model of informed consent that was adopted. It was considered important that participants were reassured that they were in control and that this honest and open approach would be helpful in establishing rapport. By 'immunising' participants about some of the topics that would be raised, it was reasoned that they would be more inclined to answer fully and honestly or, alternatively, decline to answer without awkwardness.

There was seldom any sense that participants were in the least concerned about confidentiality or the presence of a tape recorder, although one or two rather anxious participants were nervous about the interview itself. In only one case did a participant seek assurance that the conversation would not be relayed to his wife or GP, this being because of his concern about the 'double life' he was leading (P28).

Effects Of Gender On the Research Relationship

Several writers have stated that perceived similarity leads to greater self disclosure (eg Breakwell & Rose, 2000:248) and, although no evidence is offered, this observation is consistent with the literature on psychotherapy and counselling (eg Luborsky *et al*, 1971). In this case, perhaps the most obvious area of dissimilarity with most participants was gender, ie that of a male researcher investigating the personal experiences of females.

Some feminist researchers take the view that female participants should be interviewed by female researchers because they are in a position to identify with one another as oppressed women and thus better able to form a rapport (eg Oakley 1993, Finch 1984). Presumably it follows that the lack of such identification would act as a barrier for men wishing to interview women. Other feminist writers, however, disagree, arguing that gender is less important in determining the success of an interview than the structural relations between the two parties, the skill and personal style of the interviewer (eg Brannen 1988, McKee & O'Brien 1983, Wise 1987). In any case, recruiting a female assistant would have been impractical, it would have detracted from the experience to be gained and would have prevented the researcher from being in intimate contact with all aspects of the study.

In the opinion of Brannen (1988) female participants are more co-operative than males since they are more practised at being respondents, more used to talking about themselves and more likely to use the interview for catharsis. In contrast, men are disinclined to reveal sensitive information about areas of

their lives such as marriage. This is supported by Kavanaugh (1997) who, in another study, found that men were reluctant to talk about emotive issues compared with women. Kavanaugh & Ayres (1998) examined a small sample and found that men participated in the study in order to help others whilst women were motivated to meet their own needs.

In Chapter Six it was noted that men talked more than women throughout the interviews despite there being slightly fewer conversational turns in the male interviews. This was marked in Interview One and marginal in Interview Two. The finding is highly counter-intuitive since all three raters had a strong impression of women talking more and more openly. It is also at odds with previous studies which have found that women interviewees have higher word counts than men (Lunn *et al*, 1998). Perhaps this perception was based on expectation.

Another explanation for this is that men felt more comfortable talking to another man and responded accordingly. Alternatively, women might have simply been more practised at reflection and more experienced at articulating their thoughts and feelings concisely.

A final possibility is that this was an artefact of the interview technique. As the researcher progressed from one interview to another, the word counts increased but the number of turns did not. This suggests that the researcher became more skilful in the use of questions and other prompts as he gained experience, and that his conversational turns elicited greater participant responses. It will be recalled that female participants were recruited and interviewed before males. This would explain why the gender differences in word counts apply to Interview One and not Interview Two, ie by the time second interviews were started the researcher already had much experience of conducting first interviews. Also consistent with this chronological trend is the fact that, following the first batch of five interviews, the schedule was deliberately altered in response to emerging findings and this might have resulted in more talking.

The Costs And Benefits Of Participation

Data collection was entirely dependent on the goodwill of participants, who almost always had to go out of their way to help, often making special trips to their local hospital for the interview with consequent costs in time and money. Transport was not always easy, especially for the first interview when all participants had to prevail upon friends or family to drive them in. As described above, the researcher tried hard to nurture this goodwill by maintaining contact after the first interview. Where it appeared that the participant might be short of money the researcher offered to pay their expenses, but this offer was always refused.

Some commentators such as Oakley (1993:235) argue that the way to intimate interactions is through reciprocity, ie the participant must also gain something from the encounter. Reporting on her study into the experience of motherhood, Oakley states that almost 75% of her sample reported that the interview had affected them, usually by means of promoting reflection on their experience more than they would otherwise have done. Other benefits were reduced anxiety and the provision of an outlet for negative feelings. There were many references to the therapeutic benefits of talking, and there were no reported negative effects. And Cunningham-Burley (1985) talks of participants vicarious enjoyment in fulfilling the researchers task.

In this study it is clear that the interview had a cathartic effect for some participants, as in the case of P2 who used the opportunity to give vent to much pent up hostility. For others it clearly resulted in the reprocessing old material, as in the case of P19, who talked of unpleasant childhood experiences and their relationship to the way she copes with stress as an adult. Other participants talked about recent traumas which were clearly still painful and sometimes resulted in tears, as in the case of P12 who was approaching the first anniversary of her daughters suicide, and this revelation resulted in the researcher referring her to a bereavement counsellor. Some participants actually stated that talking about their situations with a stranger was helpful (eg P5). Eight participants became tearful during the interviews

and, quite possibly, others might have experienced intense emotions too. Studies support the commonly held belief that the expression of emotions through tears is helpful (eg Carmichael, 1991) and it is possible that the processing of traumatic memories might be of value to participant's health (Pennebaker, 1990).

The experience of Kavanaugh & Ayres (1998), in which participants were asked about the effects of participating in a study on peri-natal loss, bears out much of these alleged benefits with most parents saying the interview was helpful or at least innocuous. Another study examined bereaved organ donor relatives and found that, with only one exception, participants had found the interview experience helpful, albeit distressing (Sque & Payne, 1996). Few had had a previous opportunity to discuss their bereavement.

This raises the issue of managing any distress that might become apparent as a result of discussing sensitive issues. Coyle & Wright (1996) argue that counselling skills should be brought to bear in the qualitative interview, partly in order to establish rapport and so maximise the quality of data, but also to respond appropriately to any resultant distress. They argue that there is no inherent conflict between research and therapeutic aims, and by employing counselling skills, both parties can benefit from the process. Participants can benefit from account giving, clarification and catharsis (Coyle & Wright, *ibid*). Others have strong methodological objections to any intrusion into care giving or therapy (eg Rew *et al*, 1993).

In the present study distressed participants were collected by a family member following interview, so they did not have to cope with their emotions alone. Where it was clear that specific advice, information or counselling were required, the researcher referred the participant to an appropriate health professional, as in the case of P12 above.

Comment

It is possible to claim that the research relationship was effective in that only one participant refused to participate in a second interview. This is supported by the fact that some participants were apparently more relaxed at the second interview, as evidenced by the spontaneous use of forenames (eg P12, P23). However, it is impossible to confidently distinguish between disclosures brought about by the quality of the research relationship and disclosures that were the result of other factors, as discussed in the foregoing sections.

9.6 The Utility Of Process Models

The exemplars presented in this chapter show that process models discussed in Chapter Three all offer useful perspectives on the data and are not mutually exclusive.

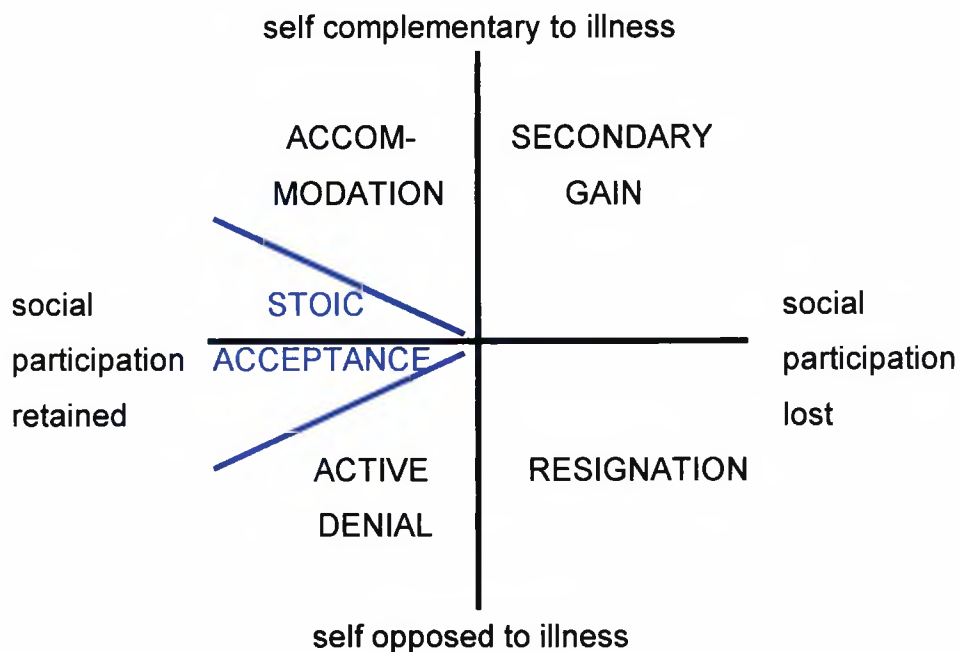
Themes from Taylor's Theory of Cognitive Adaptation are clearly visible in many of the exemplar and other cases where there was a search for meaning. Participants actively sought causal understanding, continuing with this work in-between interviews, and often felt distressed when it was fruitless.

Leventhal's Self Regulatory Model, which is discussed in Section 3.5, has the advantage of encompassing both cognitions and emotions. Illness representations form part of the cognitive system within this model and Petrie & Weinman (1997b) have studied the illness representations of heart attack victims. They found that some elements of illness representations change over time whereas others do not. Beliefs about controllability are described as a changeable element and this is consistent with the fact that several participants (including P1 above) reported a change in their sense of control as a result of the effectiveness, or otherwise, of their coping responses. Although Petrie & Weinman identified causal attributions as unchanging over time, they certainly changed for a number of participants in this study including P18 and P29 above. This is important in view of Petrie & Weinman's

finding that initial causal attributions have implications for future health behaviour. The implications of these issues are discussed in Chapter 11.

The data seemed to fit Radley's coping styles particularly well. The exception to this relates to some of those participants (reported in Section 8.4) who reported drivenness manifested as a kind of tough-mindedness and a tendency to push themselves in the face of adversity. This style seems to correspond to Greer's 'stoic acceptance' which does not fit easily within Radley's model. It can be located to the left of the horizontal axis since social participation was retained and participants felt they had to simply get on with their lives. However, this adjustment style has no home on the vertical axis since neither active denial nor accommodation were evident.

Figure 9.7 The Location Of Stoic Acceptance

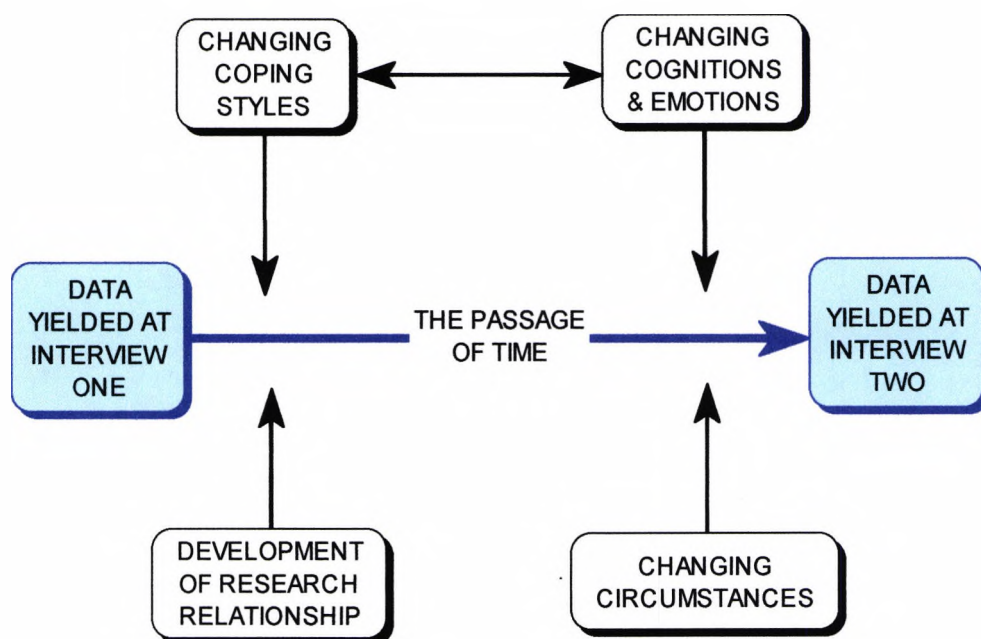


9.7 Conclusion

The exemplars provide evidence that, at least in some cases, more data were disclosed as a function of the longitudinal design. Many participants disclosed issues in Interview Two that would have remained undiscovered in a cross

sectional study. This increased disclosure at Interview Two was the result of four main groups of factors.

Figure 9.8 Factors Influencing Changes Over Time



In some cases the reasons for this seemed largely to be attributable to specific factors such as cognitive processing, circumstantial factors or the passage of time. However, in most cases it was a matter of emphasis, with some factors being the dominant influence rather than the exclusive influence for a given participant.

As Figure 9.8 shows, changes in coping style were bi-directionally associated with changes in emotions and cognition. This is consistent with all the process research referred to in Chapter Three. Changes in circumstances refers largely to the extent to which social participation was regained in the between Interview One and Interview Two. This participation necessarily involved the resumption of roles that were occupied prior to the heart attack, many of which were gender based. The exemplars show the critical importance of these roles in influencing adaptation and coping, a major theme that is taken up in the next chapter.

CHAPTER TEN

THE IMPORTANCE OF SOCIAL ROLES AND NORMS

10.1 Introduction

Chapter Two set out the cardiac literature, the overwhelming majority of which comprised quantitative studies. Those studies that included females in their samples tended to indicate that women as a group were worse off than men along a number of standard psychological and social dimensions. One explanation for this is that women might be intrinsically different to men in some way, perhaps by virtue of their psycho-biological constitution.

However, if such a fundamental sex difference did exist, then the outcomes identified in the research literature would have applied exclusively to one sex or the other, and universally within that sex. Thus previous studies have produced a literature that is problematic in that it is limited in its power to explain the varying distribution of psycho-social outcomes among men and women. It was this conclusion that led to the conception of the present qualitative study.

On the face of it the results of this study are problematic too. The data presented in Part Two show that there are few areas of experience where differences were clear cut and sex exclusive, and exceptions were common. It was therefore necessary to seek explanations that offer a better fit with the data than sex or any global concept of gender. The explanation that emerged is that the varying experiences reported by participants were the result of the social roles they occupied and of the social norms that prevailed.

Gender

In Section 1.1 the term gender was defined as all of those ways in which biological sex is defined and expressed according to the prevailing culture. Thus gender is learned and its creation and maintenance are primarily the result of social influences rather than constitutional factors. The terms masculinity and

femininity refer to the extent to which an individual's characteristics match those that are regarded by society as sex-appropriate. The psychology literature regards gender as a broad and global concept that includes attitudes, identity, sexual orientation, emotions, cognitions and so on. It can also include social roles where those roles have become gendered, ie occupied mainly by women or men.¹

Social Norms

Social norms are unwritten shared rules or standards that govern the social behaviour of individuals (Harre & Lamb 1983, cited by Berkowitz 1986). Norms are culturally defined and can vary according to sub-group membership. Some norms are gender-specific. For example, some males are brought up to believe that 'boys don't cry' and might grow into adult life believing that men are not supposed to cry or otherwise show 'weakness'. Likewise some girls might be brought up to behave in a very feminine way and grow into adulthood believing that women are not supposed to be, for example, assertive or confrontational.

So gender-based social norms are the extent to which individuals conform to gender stereotypes by displaying sex-appropriate behaviour. They are concerned with *how* individuals are supposed to act.

Some of the findings of the present study concern the coping behaviours reported by participants that were influenced by gender related norms. These are discussed in the later sections of this chapter.

Social Roles

Like norms, social roles are culturally defined. They are socially approved patterns of behaviour that are context specific. An individual can therefore be

¹ The term 'gender role' is avoided here because, although frequently used in the literature, it is not always used clearly and consistently. Further, since the major focus for this chapter is social roles, some of which are gendered, use of the term 'gender role' has the potential to cause confusion.

expected to demonstrate a particular behaviour pattern in one context (eg at work) and a different behaviour pattern in a different situation (eg when dealing with children). Roles are also particular to the position an individual holds within a group, eg parent, social worker etc. Others will therefore hold role expectations if they know what position an individual is occupying or 'part' they are playing. Within roles, individuals (actors) are expected to perform according to a role script, thus ensuring shared expectations and understandings. Roles are concerned with **what** individuals are supposed to do.

Some social roles become more or less gendered according to the prevailing culture. For example, in the UK the primary school teacher and the child rearing roles are mainly associated with females, and in both cases the role script includes a requirement of responsible behaviour on the part of the occupant. A gendered role simply means that the role is more likely to be occupied by men or women in a given culture.

Role occupancy results in both demands and rewards. Role demands can be so great as to cause role strain in which the individual finds it difficult to meet their role obligations, and this strain might partly or wholly be counterbalanced by rewards such as increased self esteem and prestige. Role conflict is said to occur when the demands or obligations of one role conflict with those of another, for example in the case of a busy working parent.

In the results chapters the terms 'role adherence' and 'role attraction' were introduced to describe the almost magnetic effect that role obligations had upon many participants as they were forced to abandon or tried to resist reoccupying roles.

The central explanatory concept arising from the present data is role occupancy. Participants occupied a number of different roles prior to their heart attack, and in many cases these were gender-related. That is to say, men were much more likely to occupy the 'worker' or 'provider' role and women were more likely to occupy the 'homemaker' or 'nurturer' role. This chapter will consider the importance of these roles as participants negotiated the process of experiencing

a heart attack. When participants were discharged from hospital they had to reconcile their role demands with the demands of convalescence and an important section in this chapter considers the relationship between role resumption and sick role adherence.

10.2 The Provider Role

The Provider Role Prior To Heart Attack

The cardiac literature identified the resumption of occupational work as an important marker of good outcome. In this sample, however, only 11 participants occupied the worker role prior to their heart attack (see Section 4.6). Of these, two participants worked part time and nine worked full time. Men were more likely than women to occupy the worker role by a ratio of six to five, perhaps partly because of their relative youth. However, many women had given up their jobs years before reaching retirement age in order to concentrate on their household roles.

Overall, working participants were younger than retired participants. Men were also more likely to have full time rather than part time jobs: all six working men compared with only three of the women. However, two of the three full time female workers were single parents, thus emphasising the family reliance on the provider role in both sexes.

It might appear that the provider role is less important than the literature suggests since it applied to only a minority of participants. However, it will be shown that this role was of considerable importance to some of them.

Strong resistance to acknowledging and acting upon symptoms clearly related to the completion of some role-based task in eight cases (see Section 5.3). In these men and women adherence was associated with role occupancy and not sex or gender in its broad sense.

The Provider Role Following Heart Attack

Since some participants found it difficult to break role it is perhaps unsurprising that they also felt compelled to resume these roles prematurely. The premature return to occupational work, which applied to four men and one women, did not appear to be related to sex. It was, however, strongly related to location of the workplace since all five home-based workers reoccupied their provider roles prematurely. Where home was the workplace, role conflict was particularly commonly experienced. Some participants, four men and a woman, stated that it would have been more stressful to resist provider role attraction than it was to resume work prematurely.

Another manifestation of work disability was evident in two participants, one of each sex. In these cases the participants returned to work after a reasonable interval but struggled to cope with the role obligations (physical demands) of the job. In these cases great distress was experienced.

The specific reasons underlying provider role attraction were varied. Some participants were driven to return to work by economic necessity, these being the two single parent females and the younger self employed men. This is consistent with the findings of Chirikos & Nickel (1984) who found that the main determinant of return to work among female coronary victims was economic necessity (see Section 2.3). And reporting on CABG patients, Zyzanski et al (1982) state that high income professionals were likely to return earlier. The only participant who could be described as a such was the senior military officer who returned to work prematurely. This man was highly driven, exhibited Type A characteristics and the data suggests that return to work was important for his self esteem.

10.3 Household Roles

The Homemaker Role Prior To Heart Attack

Participant's family roles varied. All participants were parents, most were sexual partners and many were grandparents. As regards roles involving the division of labour within the home, in most cases this tended to conform to the traditional model with the bulk of the work falling to the woman. This is consistent with the literature which states that, despite women's greater participation in the workforce, they still do most of the housework (Frankenhaeuser, 1991).

Household role style is set out in table 4.8 (Section 4.6). This was not related to marital status, with some single women continuing to occupy a traditional role in respect of other family members (male relatives and children) with whom they lived. Neither did it bear any relation to work status, with some women working full time and still accepting responsibility for all household work. Again, this is consistent with the literature which shows that women do more than their share of housework irrespective whether they work outside of the home (Frankenhaeuser, 1991).

Younger women were more likely to report a traditional gender-based approach to household work compared with older women, who were more likely to report a shared approach to household work. This suggests that, following discharge from hospital, younger women might experience greater role attraction and conflict compared with older women and compared with men.

This gender-based role demarcation among younger couples is at odds with the notion that younger people might have a more equal and enlightened approach to the division of labour at home. However, the finding is consistent with the literature in which there is a consensus that sex typing is strongest during the parenting years and diminishes in later life (Taylor, 1986). Younger couples may be characterised by greater job role demands on the part of the man, and the demands of young children on the part of the woman, thus encouraging a traditional approach to the division of labour. And the husbands of older women

are more likely to have retired, thus being in a position to contribute more to household work.

Men were more likely to report a shared approach to household work than women. This could be a function of their relative youth, but this would be at odds with the opposite finding among women. Alternatively, it may be that women were more truthful about the reality of their home situations, whereas some men succumbed to the social desirability effect by exaggerating their contribution.

The Homemaker Role Following Heart Attack

In Section 8.4 it was shown that 16 participants resumed their customary household chores prematurely following discharge from hospital. This comprised 12 women and four men but, once again, the behaviour related more to pre-coronary role occupation than sex. Of the four men who resumed household chores too early, three were accustomed to sharing responsibility for these tasks prior to the heart attack and the fourth accepted full responsibility for these due to his wife's illness. Of the women who resumed household chores prematurely, all but one was accustomed to accepting full responsibility for this work along traditional gender lines. Thus, participants seemed to be drawn to prematurely resuming those roles they had accepted responsibility for prior to heart attack.

The following examples illustrate how many of the participants viewed social roles in a very gendered way. It may be recalled that P1 talked of her fear of dependency in Section 6.3 because, as she put it:

P1 Well yeah, because I've always thought it was a woman's place to look after the home, the children and the man.

Others echoed this including P2 who, although no longer married and responsible only for herself, talked about the role of the woman in general terms.

P2 It's really virtually her place to keep the house tidy and clean. It's very frustrating, especially when, in the early couple of weeks, two or three weeks when you come home.

.....

P2 Mm, it is important because you're lifting things and doing things. You don't expect your husband or partner to come home and start cleaning kitchen units or hoovering floors.....if you are at home all day like I am, and you're sitting there and you think, "Oh look at the state of that, now should I do that?" You see, and then something seems to tell you, I've got to do that because I can't sit and look at it. It's my job to do that. If I leave it I'm going to end up with a filthy house.

Clearly P2 still felt personally compelled to fulfil this role and went on to show how homemaker role attraction was strong enough to outweigh rational concerns about her health.

P2 said to me, "Which is more important hoovering your bathroom carpet or you being well?" I could say, well, as far as I am concerned they're both equally important, in a way. Because if you leave the housework too long, it's gonna get to the stage where you are going to have an awful job to get it back up to scratch, and you want, I want to do it.

In four cases distress was explicitly linked to the woman's role in looking after the house and family. This provides evidence of role conflict, with women experiencing great pressure to keep a clean and tidy house and look after their family. One married woman talked of the difficulty in managing housework, bringing up family and doing a part time job (P19).

P19 I think sometimes women have it a little bit more difficult than men in different ways, with juggling the housework and working, albeit only working part time, and bringing up a family.

These quotations provide illustrations of how gendered roles created conflict with the requirements of the sick role.

10.4 The Salience Of Place

It is argued above that the workplace had great salience in the premature resumption of the provider role.

Place is also important since external fulfilment of the provider role also provides opportunities for social support. Outside work represents an opportunity to come into contact with stimulating and supportive colleagues. This finding is reported in the literature (eg Grossman & Chester, 1990 cited by Thomas, 1997) and was reported by participants in this study. As one female put it, the difference is that women are often unable to get away from their stressors, ie they are confined to the home whereas men usually have outside confidants at work and can leave problems behind....

P5 I think it all depends if the person whose had the heart attack was a person whose home a lot. Not mixing outside before. And I think probably, a lot of it stems from not talking to somebody....if you've got a problem. Where you never met like, em, as I did say my husband and my son was in it yes, but I was there all day and she came when they weren't there. They would go to work and talk to Tom, Dick or Harry type of thing, where I didn't and, em, I think really, yes the family knew all about it, but I was talking to the ones who already knew about it.

R So it might be different for ladies who work outside the home?

P5 Yes someone, probably was going out to work.

P5 I think, er, I think probably, I'm not saying this to be funny but women probably worry a bit different. You worry more, er, about your children, about your grandchildren, where I think with being at home all the time was the problem where John and Ronald went to work. You know they went away from it for the day. I couldn't.

Activities that were prematurely resumed emphasised the salience of the home as workplace for most females and for male and female home-based providers.

P5 I think probably if I'd been a man I would have expected to have gone home and sit in a chair a bit more, where a woman itches to get on with what was her work, you understand what I mean? Erm, she feels, I suppose you would call it irritated by the fact where a man wouldn't be where his work was would he, exactly.

P20 I think so, I think 'cos when you're a woman, I think a woman would worry a little bit more about her chores than a man. Because, you, most women run the home don't they. And I think that would concern women more than it would a man. Because a man, I think with the garden, they say do the gardening (?) could leave the garden. With the housework, it's not quite so easy to leave.

Thus the resumption of the homemaker role was related not to biological sex but to the roles previously occupied prior to heart attack. These roles were often gendered and usually but not always resulted in women working at home and men working outside the home. It was the exceptions to this, the so called negative cases, that demonstrated the importance of roles and the salience of place.

10.5 The Sick Role

In 1984 Gove identified a qualitative difference in social roles by introducing the notion of fixed and nurturant role obligations. He argued that people vary in the extent to which they occupy roles involving fixed obligations, ie roles involving tasks that are difficult to reschedule. Men tend to have more fixed roles than women because they are more likely to occupy full-time worker roles. In contrast to this many women do not go out to work, or work only part time (Gove, *ibid*).

Minor Illness

The full time housewife role, which Gove describes as nurturant, and which is relatively free of inflexible time and task constraints, makes sick role adoption relatively easy. Those people, often women, who have many nurturant role obligations, are free to reduce their usual activities when they are ill, for example to spend half a day in bed with a bad cold. In contrast to this, people with many fixed role obligations, most often men, are less likely to define a symptom as illness and will 'soldier on'.

Major Illness

According to the Gove formulation major illness is very different.

For those with fixed role obligations health and sickness have an all-or-none quality: either the person is well enough to carry out their work role or they are certificated and formally consigned to the sick role. Work is something that is generally undertaken at another place, eg a factory or an office. Those occupying fixed roles, mainly men, might find it harder to get half a day off and rest when unwell but they are likely to fully adopt the sick role when seriously ill. Once they do take the decision to go off sick, they are more likely to be looked after at home and less likely to be troubled with child care and other domestic tasks. In the present study some employed men did not return to work for 12 weeks, during which time they rested at home and were looked after by others: their customary DIY or gardening chores could wait.

Those people occupying nurturant roles, who have major responsibility for household tasks, children, spouse and relatives, may find it difficult to adopt the sick role when they are seriously ill. They tend to experience the demands of others as excessive and impairing their ability to rest and relax. They complain of having to continue doing chores, being unable to get a good rest and find it more difficult to have someone care for them when seriously sick. Gove (*ibid*) concludes that there is a major causal link between nurturant roles and poor mental health, particularly in women.

The present study provides examples of men and women whose occupational work was home-based. For these participants, the provider role can be regarded as being less fixed since they were largely in control of the duration and pace of work, starting and finishing times, and so on. It is suggested that this lack of role fixedness resulted in increased role conflict and inability to resist the attraction of the provider role. In all these cases the provider role was reoccupied prematurely because the home had another meaning ie it was both a place to relax and a place to work. These participants, like the homemakers, could never really get away from their work.

For those with nurturant role obligations health and sickness are relative terms, ie there are degrees of sickness and degrees of sick role occupancy. Nurturant role obligations such as household roles may not be incompatible with the sick role in the way that paid work is since flexibility allows pacing in relation to ones energy, the taking of frequent rests, the lowering of standards and elimination of unnecessary tasks. Unlike occupational work, household chores allow some alternation between work and the sick role. A sick person who has a traditional approach to the homemaker role, ie accepting responsibility for most of the work and looking after others, might experience contradictory pressures created by the identity of the home as workplace as well as a place for convalescence. This was evident in the present study and, conversely, those participants with a shared approach to household chores were less likely to feel drawn into premature role resumption.

The greater incidence of frustration among female participants may be linked with the tension of being in their workplace (home) and yet either unable to or forbidden from adequately fulfilling their role. Many women had high standards and it was distressing for them to see the state of their homes decline. As portrayed by the Radley & Green (1985) model, tension existed between the demands of the illness (eg to rest) and the demands of social participation (eg homemaker role). This tension is a type of role conflict and led to the experience of frustration and distress.

10.6 The Nurturer Role

Social Support Role

Dating back to the 1970s the general social support literature shows that high levels of perceived social support are good for the health (eg Cobb, 1976). However, some more recent investigations including a replication of the classic Berkman & Syme (1979) study have questioned the extent to which support relationships benefit women (Minkler, 1986). Indeed, some studies have shown that social support might be detrimental to womens health. Shumaker & Hill

(1991), for example, conclude from their review that women with high levels of support suffer increased mortality.

Thus there appears to be a lack of reciprocity within support relationships with men benefiting more than women and women being net givers of social support, particularly in the affective domain. There is some evidence that this might be particularly the case for women scoring high on the traditional attributes of femininity (Luchetta & Alberts, 1994 cited in Thomas, 1997). The findings of this study are consistent with the literature since they provide many instances of female participants giving both practical and affective support, but often receiving little.

As regards practical support, female participants were much more likely than males to provide support through informal care giving. In contrast, there were numerous examples of husbands and other family members failing to support women in their time of need. Examples of this include lack of assistance with smoking cessation, rehabilitation attendance, practical help around the house, and so on.

As regards affective support, some women complained about the expressive interactions and emotional support within their spousal relationships and there were references to husbands whom they could not talk to or who were uninterested in their health problems.

P7 Er, he is and yet it shook him because he's a northerner. You're not a northerner are you? (laughter) And he goes round sometimes. I mean he's not, he's not as hard as he makes out he is, you know, he is quite soft underneath. But 'cos he always riles them up and that. Em, makes out he's harder than what he is.

P15 "...you can't tell my husband you've got a bad cold, you can't say you're going to bed early because you feel a little bit off colour. He doesn't want to know, he just blocks it out, he's not interested."

This is also consistent with the literature that comments on studies reporting women's lower levels of happiness, of satisfaction with companionship and

expressive interactions within their marriage compared to men (Bernard 1982, cited by Thomas, 1997).

Stress Holding Role

Another facet of the nurturer role that some female participants accepted was that of 'stress holding'. This term is used here to describe the phenomenon whereby people shielded or protected others and, in so doing, increased their own felt stress. Women were often found to put others first in a variety of different ways including the withholding of information. For example P3 knew she was having a heart attack but did not tell her husband until the very last minute in order to avoid worrying him and P14 did not tell her disabled husband she had had a heart attack, merely that she had gone into hospital for tests.

There is some reference to stress holding in the literature, though it is not referred to by this name. Kessler (cited by Turkington, 1985) interviewed husbands and wives separately and found that women tended to "carry" their husband's stress for them, eg by withholding information that they would have worried about.

Affect Management Role

Yet another part of the nurturer role seems to be the maintenance of affective relationships within the family. In the present study some women were identified as 'the strong one', having at some point proved to be the focal point that held the family together during times of difficulty. An example of this is reported in Section 7.2 in which P18 recounted a family attitude captured thus: "If mum's alright, we're all alright...." Many examples of this were reported in the results chapters and a number of women drew connections between their role in managing family relationships and their heart attack.

There are also reports in the results chapters of women accepting responsibility for family members, often independent middle aged children, and worrying unduly about them. It might be recalled that P19 provided a good example of

this in Section 7.3, worrying excessively about the well-being of her three grown up children.

According to the literature, women are more distressed by home conflict than men and find arguments more stressful (Bolger et al, 1989). They also worry more about the quality of relationships and feel responsible when their marriage falters (Barnett, 1996). When relationships are conflictual women experience more health consequences. One study found that social conflict, in this case criticism and undermining, led to higher coronary proneness in women but not in men (Cornell et al, 1994, cited in Thomas 1997). In another, Keicolt-Glaser et al (1993) studied couples in a laboratory setting and found that women showed a sharp increase stress hormones during arguments with their husbands, but this did not apply in reverse. Thus, women seem to be more sensitive to disharmony and unpleasantness than men.

Vicarious Distress

In the present study this sensitivity extended the suffering of other people within and outwith the family resulting in what is termed vicarious distress. This seems to stem from that part of the nurturer role which requires many women to get involved in, and accept responsibility for, the misfortune or distress of others.

In Section 7.3 it was reported that female participants were also much more likely than men to talk about family problems such as illness, children's marital problems and especially bereavements. Women appeared to be more deeply affected than men by the suffering and misfortune of others, taking on the burdens and concerns of others as if they were their own. The reader might recall examples of women talking about illness among family members, behavioural problems in their grandchildren and spousal unemployment.

There is some research literature to support this finding. For example Thomas & Donnellan (1993) conducted a study involving the interviewing of 500 women, who were asked what their greatest source of stress was at that

particular moment in time. The most common response was vicarious stress defined as:

"...stress originating in the lives of loved ones rather than events in the women's own life." (Thomas & Donnellan, 1993, cited by Thomas, 1997:547)

However, in the present study this sensitivity and concern for others also extended to non-family members. In Section 6.5 it was reported that women expressed vicarious distress at the plight of fellow hospital patients. Their suffering evoked expressions of feminine characteristics like sympathy and even actual helping behaviour.

Comment

Stress arising from aspects of the nurturer role might be particularly harmful because the individual has limited control over its occurrence or management. Additionally, Thomas & Donnellan (1993) argue that the kind of stressors involved in vicarious distress do not respond to the usual range of coping strategies and claim to have shown that vicarious stress can contribute to disease vulnerability and immunosuppression.

The various elements of the nurturer role that were identified in the data can also be described as flexible or 'nurturant' according to the Gove formulation. This means that participants, exclusively females here, have to face them as soon as they return home, thereby creating affective as well as physical demands on the convalescing heart attack victim.

10.7 Passive Coping

Passive coping is not a social role but a coping style that is strongly related to socio-cultural norms appertaining to the feminine behaviour pattern. Passivity can be described as the converse of assertiveness and fits with descriptions of femininity dating back to Parsons's formulation in 1951.

Many but not all women demonstrated passivity in two areas. Firstly, when faced with acute cardiac symptoms, they were more likely than men to waste time seeking advice from someone else (usually a man) about what action to take. Unlike men, they did not generally take the initiative in contacting the EMS themselves, thus resulting in prolonged patient delay intervals.

In the second area women often proved to be passive when they were dissatisfied with aspects of their treatment and care in hospital. Unlike men, no women discharged themselves from hospital. Of the two women who wrote to the hospital manager complaining about their experiences, it transpired that one of the letters had been written by a (male) relative on behalf of the woman concerned. The other woman who wrote a letter of complaint occupied a professional work role. Such professional roles, which are usually occupied by men, are usually associated with decisiveness and approach coping. Rather than being inherently more decisive than women, it is probable that occupants of such roles are socialised into behaving in a decisive way and formal complaints are an appropriate way to deal with problems.

Inherent in the Sick Role is the transfer of responsibility and control to the medical profession. Patients are expected to minimise their needs and potential criticisms and behave in a passive and co-operative way. Patients are labelled as good or bad according to how they meet this role expectation. For example, they should not ask too many questions and they should not be too critical of lapses in standards. Here women generally showed more tolerance and patience, characteristics that comply with gender-based social norms whereas men acted decisively, if perhaps unwisely, by discharging themselves from hospital.

It is also note-worthy that all three of the participants who asserted their right to be interviewed at home/work were men. They took control of the situation and made sure that Interview Two was conducted on their terms.

Cultural beliefs about how men and women typically cope with stress suggest that men are generally prefer problem-focused strategies and are be more

proficient in their use, while women have a similar affinity for emotion-focused strategies (Stone & Neale, 1984). The literature in this area is sparse and some of the results conflict (Miller & Kirsch, 1987). However, six out of seven studies reviewed by Miller & Kirsch (1987) lend some support to popular ideas about gender differences in coping and two of these studies involved chronically ill patients. The review also included three studies that associate women with blunting and men with monitoring.

It might be that, as a result of cultural norms about femininity, women are more likely to adopt coping strategies that are focused on blunting out stressful stimuli, distraction, self consolation and otherwise managing their emotional reaction to stress. Conversely, men's masculine characteristics may make them more likely to adopt a more instrumental approach in actively approaching and attempting to manage the stressor itself. The extent to which either of these styles can be considered adaptive or maladaptive depends largely on the situation. It is probably the case that problem-focused coping and monitoring are adaptive in controllable situations, whereas emotion-focused coping and blunting are adaptive in uncontrollable situations.

Women in the present study certainly avoided confrontation, they avoided responsibility for decision making and expressed a wish to talk through their problems. However, men more commonly used denial as a coping strategy, perhaps because it allowed them to resume activity which distracted them from the crisis of heart attack. Emotional discharge through crying, which can be considered a coping response, was demonstrated during interviews by eight female participants and no males (see Section 6.7).

10.8 The Importance Of Social Roles And Norms

It is clear from the data presented that participants were strongly motivated to behave in a way that is consistent with their social roles. Many participants found it difficult to abandon customary role based tasks in the face of acute cardiac symptoms, experienced anxiety about role displacement quite soon after their heart attack and took considerable risks through premature role

resumption. There was also a tendency for participants to behave in a gender appropriate way outwith their social roles, eg in relation to coping with negative affect and with problems in hospital. It is believed that this behaviour was influenced by social norms. Since it is clear that social roles and social norms had a powerful influence on the behaviour and inner experience of many participants, the question arises as to why this should be the case.

Explanations for all this could be constructed by appealing to any of a number of psychological theories such as Rogers's Self Theory (Rogers, 1961). Several feminist psychology theories also promise to provide plausible explanations, for example Gender Schema Theory (Bem, 1981), or Self In Relation Theory (Miller, 1986). The need for brevity does not permit their exploration here. However, studying the present data gives a strong sense that participants motives were frequently centred on self concept.

Social roles and norm related behaviour are acquired through the processes of social learning and eventually become incorporated within the developing self concept. It is not hard to find existing psychological theories which argue that that role fulfilment becomes an important influence on self judgements and therefore in determining self esteem. This general principle has long enjoyed general acceptance in the psychology and sociology literature (eg Mead, 1934 cited by Thomas, 1997).

If this is the case, it would explain the appearance of resistance to anything that that might cause role displacement, as in the case of participants ignoring chest pain while undertaking a role-based task. It would also explain why, following heart attack, these participants felt 'drawn' or 'driven' to prematurely resume their customary roles, often at great risk to their health.

Earlier sections of this chapter contain evidence of some participants feeling strongly that women and men are obliged to fulfil certain roles. Sometimes this obligation was motivated by the need for economic provision and sometimes by the need to look after others in the home. In other cases, however, participants took considerable pride in fulfilling their home-based roles (see Section 8.4).

This attitude mainly applied to women who set great store in keeping their house clean and tidy, though many participants of both sexes took great pride in their garden. These accounts conveyed a strong sense that successful role fulfilment was a key factor in determining the self esteem of these participants and their perceived prestige within the family.

Viewing role in relation to self esteem also provides a link with the dysphoria that was widely reported in this study. When participants were finally forced to break role they experienced tension, conflict and psychological distress. The finding that role displacement and loss was associated with psychological distress is consistent with theories such as those of Rogers (*ibid*) and Bem (*ibid*). It is also consistent with the wealth of research data on other forms of losses that involve role displacement such as redundancy and bereavement, which have the potential to lead to depression.

10.9 Conclusion

In Chapter Three it was proposed that CHD could be usefully viewed as a process rather than a discrete event and a model was constructed. This chapter has focussed on the main finding of the study: the importance of social roles. These social roles, and to a lesser extent social norms, had a substantial influence on the experience of participants throughout most stages of the process.

The conclusion that social role occupation provides a better fit with the data than does sex or gender per se is not inconsistent with the findings of the Radley et al (1998) study discussed in Section 2.6. This UK cross sectional study focussed on the problems reported by men and women following heart attack and was conducted in chronological parallel with the present study. In a recent paper Radley et al (2000) state that analysis shows masculinity was a better "determinant" of positive outcomes than sex. Masculinity is a manifestation of gender, different from but at least in some cases likely to be closely associated with the occupation of certain roles.

Figure 10.1 - Social Roles, Norms And The Heart Attack Process

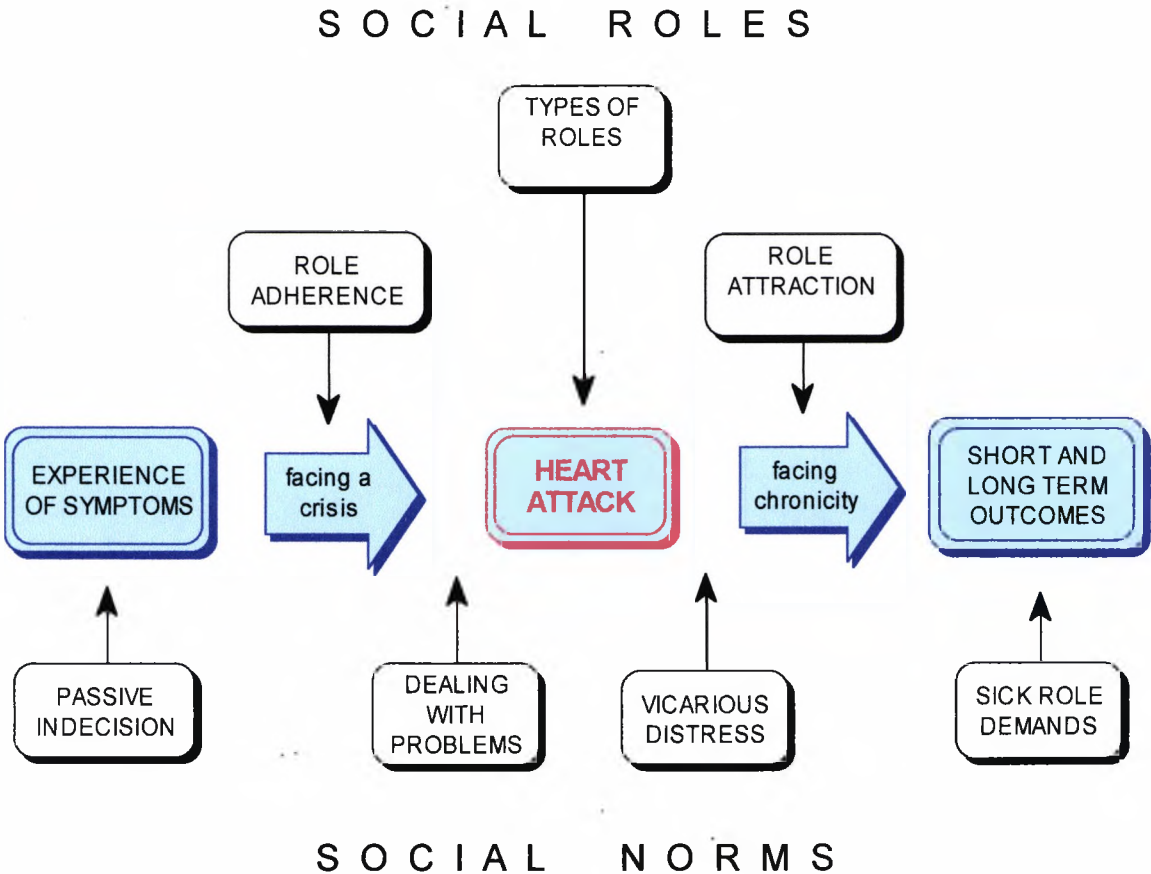
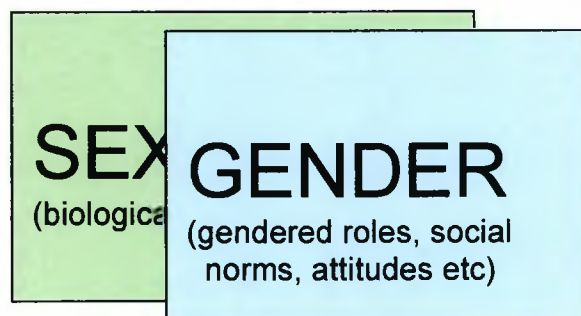


Figure 10.1, which is developed from the process model introduced in Chapter Three, depicts some of the behaviours and experiences that were related to social roles and social norms. As argued in Chapter Two, previous cardiac studies have focussed solely on outcome measures such as depression and anxiety. Although these prior studies have identified clinically significant sex differences in outcomes, they explained only a modest part of the distribution of such dependent variables.

This study has shown that the reason prior research has enjoyed limited success is that it was focused on sex rather than sub-components of gender.

Figure 10.2 - The Relationship Between Sex And Gender



The substantial overlap between sex and gender means that prior studies were able to demonstrate differences between men and women, albeit inconsistent and sometimes modest ones. However, individuals within a single-sex group will vary in the extent to which they subscribe to the components of gender including social roles and social norms. This explains why some participants were more strongly affected than others by role adherence and role attraction, and why only some participants experienced distress.

CHAPTER ELEVEN

IMPLICATIONS

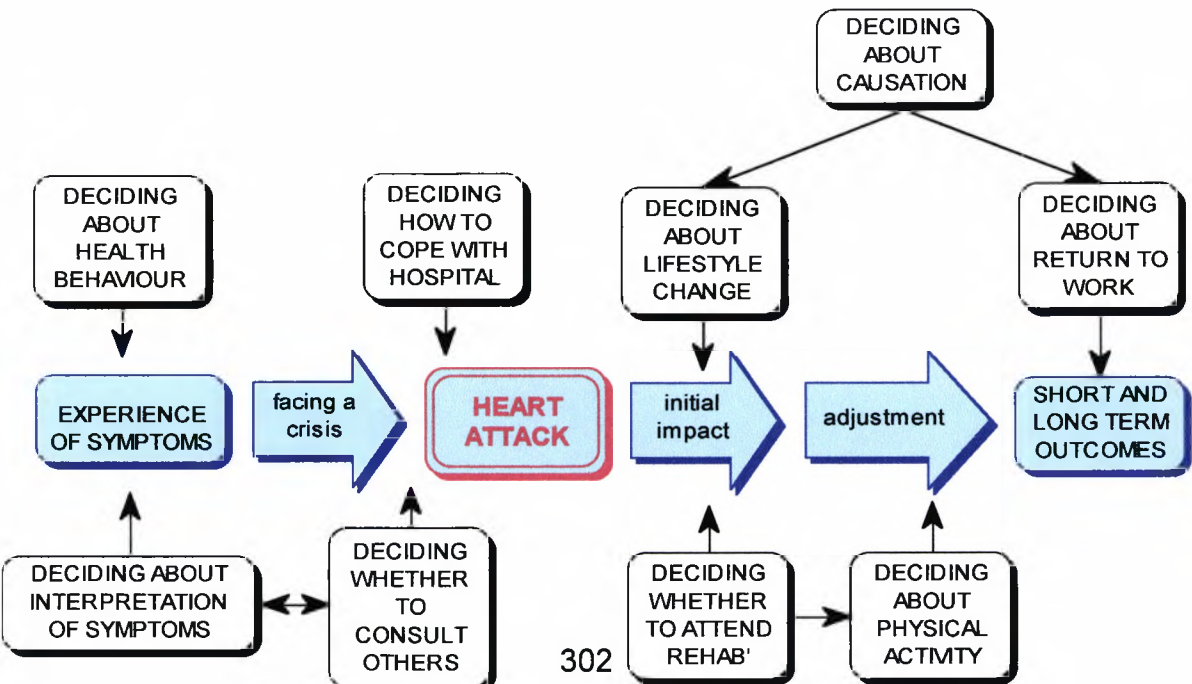
11.1 Introduction

This final chapter considers the implications of both the methods used and the results of this study and is divided into two main sections. The first section identifies some implications for health professionals working with heart attack victims and the second section identifies some implications for those who are contemplating research in this area.

11.2 Implications For Clinical Practice

The participants in this study did not decide to have a heart attack. However, they did make a series of important decisions throughout the process leading up to and following the heart attack. These decisions had the potential to influence psycho-social and physical outcomes and therefore provide opportunities for interventions by health professionals. This section is structured around these decision points which, as shown in Figure 11.1, are built around the process model that was first introduced in Chapter Three.

Figure 11.1 - Decision-Making Points



Deciding About Health Behaviour

It was noted in Section 1.3 that, in accordance with social norms about self nurturance and vulnerability etc., women generally engage in more positive health behaviour than men. In theory, therefore, they should be at lower risk of CHD and other illnesses.

However, this is not always the case. For example, some sub-groups such as young working class females, engage in very risky behaviour such as smoking (BHF, 2000) and are thus at high risk of CHD. There are many possible explanations for this including the human propensity for self deception in respect of personal susceptibility.

In the present study participants were asked to reflect back to the pre-coronary phase and comment on their own perceived susceptibility. As reported in Section 7.2, almost all participants claimed not to have viewed themselves as being at risk of heart attack and were very surprised by what had happened. Although there was no sex difference in perceptions of susceptibility in this study, there are some data that suggest that certain groups might be particularly prone to low personal risk appraisal. Two studies discussed in Section 1.4 suggest that women constitute such a group (National Council For Ageing 1997), Legato *et al* 1997).

Since perception of personal susceptibility is one of the factors that is known to influence health behaviour (eg Becker & Maiman, 1975), there is a clear message here for those involved in primary prevention and health promotion. National and local health education initiatives should ensure that their health messages and materials explicitly address all at-risk groups including women and young men. This has not been the case in the past (Price 1985, Karpf 1988).

Deciding How To Respond To Symptoms

It is regrettable that, although the NSF for CHD (DoH, 2000) includes a section on reducing 'pain to needle' times (total delay period), it discusses only EMS and hospital delay periods. There is no comment and no target in respect of reducing patient delay intervals. This is regrettable because, as the literature testifies, the patient delay interval constitutes by far the greatest portion of the treatment delay interval (eg Ho, 1991).

In this study many women acted passively in relation to their symptoms, deciding to delay through consulting others rather than seeking EMS help straight away. Clearly public education needs to include instructions about how to act in the event of unexplained or suspicious symptoms. The public need to understand the importance of rapid action, if necessary erring on the side of safety when they are unsure. In the USA the Heart Attack Alert campaign was recently launched by the National Heart, Lung and Blood Institute. This aimed to increase public awareness of CHD symptoms and reduce treatment delay. Such a campaign could usefully be considered for the UK.

Re-education about changes in the pattern of vulnerability, which now includes women and others, also needs to be extended to the health professions. In this study three participants' lives were put at risk by male doctors misdiagnosing female patients and the literature indicates that this might not be an isolated finding (McKinlay *et al* 1991, cited by Moser & Dracup 1993). In the HARP study the identity component (symptoms) of CHD illness representations among patients were different from professional ones in a third of their sample (Petrie & Weinman, 1997b). Part of this health education effort, ie of the general public and the health professions, should take account of the possibility that heart attack symptoms might be experienced differently by women since erroneous symptom expectations clearly lead to delayed help seeking and misdiagnosis.

In view of the evidence presented in Section 1.4 (eg Clarke *et al*, 1994) and the findings of this study, the full range of health professionals need to debate the question of equal access to emergency treatment. Female participants

sometimes arrived in hospital too late for thrombolysis and were sometimes admitted to a general medical ward rather than a specialist CCU or ITU.

Deciding Whether To Attend Rehabilitation Classes

The NSF for CHD stipulates that written details of rehabilitation programmes should be given to all patients while they are in hospital in order to maximise encourage initial attendance. Such written details were not available in either of the hospitals studied which relied instead on making verbal contact with patients who were in or had been in the CCU or ITU.

In the present study two women were not given the option of deciding whether to attend (P11, P14). One of these women was elderly and remained uninvited despite a reminder from the researcher. These observations are consistent with findings reported in the literature and reported in Section 8.2 and provide another example of unequal access to treatment and support.

The literature agrees that women are more likely than men to miss out on programme invitations because, they are more likely to be admitted to an ordinary ward than a CCU (Clarke *et al*, 1994). Another reason that women are left out is through what appears to be institutionalised ageism. Therefore, clinical policy makers in rehabilitation programmes need to consider whether admission criteria are inadvertently discriminating against older patients, most of whom are women.

It might be argued that, because of their greater age, women are sometimes too ill or too frail to participate in exercise programmes. This view is not supported by the literature, which shows that womens poorer physical state simply means they have more to gain through exercise (Lavie & Milanie, 1995). Besides, even if it were the case, patients who are too ill to exercise should still be invited in order that they might benefit from the other aspects of the programme.

A major finding in the present study was that female participants often decided not to attend because of the siting and timing of programmes. It should not be

difficult for programme managers to adjust the timing of classes to suit those for whom winter evenings are forbidding. Indeed, there are numerous examples of programmes in rural Wales which offer minibus collection where necessary and a home-based multi-modal rehabilitation programme has been developed in Scotland (Lewin, *et al*, 1992) and is now offered in a number of localities.

The data presented in Section 8.2 provides grounds for suggesting that programme attractiveness is another issue that must be addressed. It might be that women decide to discontinue more readily than men because of the content of the programme or the way it is conducted. Indeed, some elderly female participants indicated that they did not appreciate being asked to lie on a floor mat in a draughty gymnasium. It is possible to imagine the reaction of women entering a typical exercise-based programme in which lycra-clad men sweat profusely on power cycles and similar equipment. More imaginative programmes might include activities that are familiar to many women such as aerobics or 'movement to music'. And different arrangements entirely might need to be made for women belonging to minority ethnic groups, for example Muslim's might respond better to single sex classes. These suggestions are based only on experience and impressions gained during the research process.

The results of the HARP study showed that rehabilitation attendance was greater among people with CHD illness representations that included a strong belief about controllability (Petrie & Weinman, 1997b). If this is the case, then patients decision making might be influenced by information about the role of rehabilitation in controlling CHD.

One aspect of rehabilitation schemes that might be particularly attractive to women is the opportunity to receive social and professional support. The results chapters are littered with examples of women who had a social support deficit and this is discussed more fully in Section 10.6. widows and other single women are at particular risk of the consequences of social isolation and lack of support (eg Case *et al*, 1992). Patients who lack social support need to be encouraged to identify and exploit what social resources they have or find ways to increase their network. They need to be assisted to ask people in their lives

for support when they need it. Counselling might also be directed at helping women to set limits in respect of helping others, especially when they feel that their personal resources are being over-stretched. Health professionals need to be sensitive to the conflict that many patients will experience in relation to their role demands in relation to the requirements of the sick role and these discussions must involve other family members.

One final issue is that, in line with the literature presented in Section 1.4, female participants were seldom given the chance to decide whether or not to undergo angiography. This is another example of apparent inequity that needs to be addressed.

Deciding What Caused The Heart Attack

Almost all participants in this study attempted to reach a decision about what had caused their heart attack. In one sense it might not be important whether causal attributions are accurate or not since, according to Taylor (1983), what matters to people is finding meaning in their experience. Therefore just holding a causal attribution might in itself be beneficial.

In another sense, however, the nature of the causal attribution is very important because of its relationship with subsequent lifestyle changes. In the present study many participants attributed their heart attack to stress, family problems or heredity and their views were frequently in conflict with those of medical staff. In the HARP study Petrie & Weinman (1997b) found that those patients who decided that their heart attack was due to a lifestyle factor such as smoking were more likely to modify risky behaviours. In contrast to this, those patients who attributed their heart attack to stress, family problems or heredity were less likely to modify risky behaviours. The power of these attributions to predict behaviour change also extended to spousal attributions and spousal behaviour, thereby supporting the argument that health education should be directed at couples or families and not individual patients (Petrie & Weinman, *ibid*).

Quite clearly the starting point for any educational activity must be the knowledge and beliefs currently held by the learner. It seems obvious that teaching a patient about the dangers of smoking when they have already decided their heart attack was due to stress would be futile. Health professionals need to work with patients' beliefs and attitudes rather than their own. It might also be futile to simply raise anxiety levels by telling patients about the dangerous nature of their health behaviour. It has long been recognised that health-related fear arousing messages have limited effect unless accompanied by support and plans for action (Leventhal, 1986).

Deciding Whether To Change Lifestyle

Quite apart from causal attributions, other factors also influence patients' decisions about lifestyle change. In this study it was noted that many participants were advised to modify risky behaviours but received little or no professional support in doing so. It is not surprising, therefore, that some participants struggled to follow such health-related advice and often failed to maintain changes over time (Section 8.3).

Given modern day hospital smoke-free policies, patients are effectively forced to give up smoking for a week. This, along with the absence of environmental cues and the shock of a heart attack, provides a real opportunity for permanent cessation. The time of maximum risk for relapse is immediately after discharge (Miller & Taylor, 1995) so education must begin in Phase 1. Intervention studies have shown that impressive results can be achieved through minimal interventions. For example, Taylor *et al* (1990) instituted a nurse led brief intervention in hospital with telephone follow-up that achieved a 51% cessation rate at one year.

In this study a number of participants found that their attempts to give up smoking were thwarted by the experience of irritability and similar emotions. There is evidence that 'negative affect smokers', ie those people who smoke to control negative feelings such as frustration, depression or anger, find it harder to stop than others (Pomerleau *et al*, 1978) and might therefore need

professional help to help to give up. Rather than simply advising patients to stop smoking, health professionals need to focus on the maintaining factors and provide appropriate support such as anger management and relaxation training. The importance of this might extend beyond the hazards of smoking since those patients who attempt to give up smoking and then relapse might experience a fall in their sense of self-efficacy leading to failure in other areas of lifestyle modification.

In the present study some participants reduced their cigarette consumption and switched to a less harmful brand, but were unable to stop completely. This may appear to be a significant gain. However, the evidence is that even the lightest of smokers (one to four per day) run double the risk of death from heart attack (Willett *et al*, 1987) and there remains a danger that such people will gradually slip back to their former consumption rates. Another issue raised by participants in relation to difficulties in stopping smoking is weight gain. This realistic concern was not addressed by health professionals, for example, by offering dietary advice. In view of social constructions about the ideal body image and the importance of physique in day-to-day life, this concern might be more pressing for women.

Most rehabilitation programmes have access to a clinical psychologist, but this person is highly unlikely to be a cardiac specialist and waiting lists are often extremely long. A recent survey of 273 UK rehabilitation programmes confirms that psychological and social factors were "particularly poorly assessed" and only 9% of programmes involved a talk to patients by a psychologist, let alone individual interventions (Lewin *et al*, 1998).

The writer considers that it is unethical to raise anxiety among patients by advising them to change their lifestyles without providing the support needed to maintain those changes. Thus a variety of referral points are needed following heart attack including psycho-sexual counselling, clinical psychology, smoking cessation and dietetics. In practice, both Hospital A and Hospital B offered a 'one size fits all' programme was not sensitive or responsive to the needs of individual participants.

Deciding About Advice And Education

In this study it was difficult for participants to decide about complying with advice because it was generally lacking. The advice that was given was generally inadequate and lacked specific relevance to participants' individual lifestyles. Participants were therefore left to decide for themselves about important activities such as driving and exercise. Most of the advice giving that was reported was generic in nature and delivered to patients in group settings.

It is recommended that educational interventions should be personalised, with individual patients being offered advice and other interventions selected from a 'menu' according to individual need. In the present study any attempt at assessing individual learning needs, which is an essential pre-requisite to the menu-based programme model proposed, would have revealed ways in which advice needed to be tailored to the lifestyles of individual participants. These views are consistent with the requirements of the NSF for CHD which stipulates that an individualised care plan should be negotiated with each patient, thus raising hopes that rehabilitation packages can in future be tailored to the assessed needs of individuals. They are also consistent with the UK Guidelines¹ on cardiac rehabilitation (Thompson *et al*, 1996).

Based on the results of this study it is suggested that such an assessment might include the following:

- role occupation: for example some participants will need to focus on aspects of home management and others will need a detailed discussion of the demands and fixedness of their work roles
- teaching should preceded by an assessment of patients' individual illness representations which could be done by using a validated questionnaire such as the Illness Perception Questionnaire (Weinman *et al*, 1996) or simply by systematically exploring the elements of patients' CHD illness representations

¹ These national Guidelines were produced jointly by the National Institute for Nursing, the Joint Medical Practice & Audit Committee of the British Cardiac Society and the Royal College of Physicians.

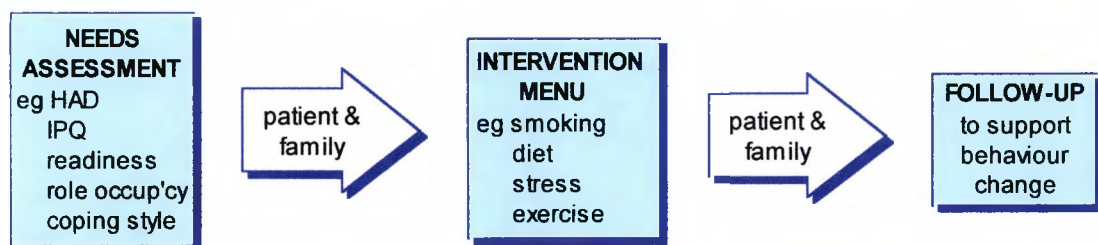
- assessment of affect by the use of a structured tool which offers a score to assist in making defensible judgements about referral and treatment

The evidence presented in Chapter Nine shows that the psycho-social sequelae of heart attack do not stop at a particular point, but changes continue to take place over time. The weeks and months following heart attack might constitute a period of recovery from a bio-medical perspective, but from a psycho-social perspective this might be a period of deterioration. Just because a participant appears to be coping well following discharge from hospital, therefore, does not mean that they will continue to cope. Changes in circumstances, emotionality and coping therefore need to be assessed at regular intervals following discharge. Where patients decline to attend rehabilitation classes, or where resource limitations permit only limited follow-up, telephone contact provides a practical and affordable alternative.

Readiness to learn is a very familiar concept in the health promotion literature and this study has confirmed that readiness to learn varies through time (eg P1, Section 9.2). People who are unduly anxious, embarrassed, in denial or otherwise distracted will not be receptive to health teaching. Therefore health professionals need to assess readiness to learn before embarking upon health teaching.

Figure 11.2 summarises the conclusions of this passage which argues for individualised interventions based on an assessment of individual needs.

Figure 11.2 - Menu-Based Model For Cardiac Rehabilitation



10.3 Implications For Further Research

The process and results of this study raise a number of issues that could usefully be the subject of further investigation. These are described under four headings.

Other Groups

This study set out to investigate the experience of a group that have been neglected by researchers: women. The results and conclusions indicate that the research design was appropriate for the task in hand. This being the case, it would seem appropriate to apply the same design to other neglected groups about which little is known. These include the disabled, young men, people from minority ethnic groups and the elderly. It is also high time that the views of husbands of female heart attack victims were heard.

Theoretical And Conceptual Issues

The nature of gender remains to be clarified but the results of this study suggest that global gender *per se* is not the major variable in post-coronary morbidity. Sub-components of gender, particularly role occupancy but also the influence of social norms, were more important in this study and their mode of effect needs to be further investigated.

There is sufficient literature to offer plausible explanations for the link between role occupancy and dysphoria, though it is beyond the scope of this study to explore this link in depth or to test the explanations. Studies might usefully focus on the following:

- the reasons that some people find it so difficult to break role and why subsequent role attraction is so strong
- whether this is a function of different types of roles or of the individuals concerned

- the relationship between role occupancy, self concept and self esteem
- the relevance of other sub-components of global gender, eg gender schema and social norms
- the relationship between different emotions experienced following heart attack since some emotions identified here have not been previously reported

Methodological Issues

Although there is a growing body of research on the utility and reliability of qualitative software, this has not yet involved the relatively new programme NVivo. In particular, a new software programme called Merge For NVivo is to be released early in 2002. This new programme will allow team working on qualitative projects. The methodological importance of this is that it will allow two different researchers to work simultaneously on the same data set, thus providing an opportunity for more rigorous inter-rater reliability checks than have so far been possible. However, in view of the time and software familiarity requirements of the second researcher, this is most likely to be of value in professional team-based research rather than individual studies such as this.

Practice Issues

Useful areas for more structured large scale studies that would yield generalisable results include the following:

- cardiac illness representations in different groups
- the decision making process in response to chest pain
- symptom patterns in female heart attack victims
- women's needs and preferences in cardiac rehabilitation programmes

Research methods that might be appropriate for investigating the above include structured interviews and focus groups. Both of these methods can generate structured quantitative information involving fairly large numbers

whilst remaining open to the unexpected. Patients attending cardiac rehabilitation programmes or self help groups would offer promising opportunities for focus groups and could be realistically be targeted in a number of centres.

However, there is a particularly urgent need to investigate the experiences of people who, for one reason or another, do not attend rehabilitation classes. This vulnerable group might have important perspectives on programme attractiveness and other possible barriers to attendance.

Comment

This study has problematised the prior literature, which has focused on sex (often referred to as gender) differences. If the findings of this study gain acceptance future studies will have to focus on specific attributes, which might or might not be connected with gender, such as social roles and social norms.

11.4 Conclusion

Although there were times when numerical differences between groups appeared quite clear, the whole qualitative approach (ie sampling strategy, sample size etc) precluded the use of inferential statistical tests. It is not possible, therefore, to make generalisable claims based upon the findings of this study. However, it is hoped that health professionals working with heart attack patients will consider these findings thought provoking. It is also hoped that researchers will be influenced by both the findings, which surely provide a basis for hypothesis formation, and the research approach.

This study has attempted to provide an insight into the psychological experience of women following heart attack. The study did not attempt to demonstrate cause and effect relationships between variables. Instead it sought to illuminate and provide explanations for apparent gender differences that were reported in the prior literature.

Quantitative studies in this field have been predicated on the assumption that, on average, women differ from men according to certain variables that influence all women to some degree. But this study shows that the different experience of women is a function not of their biological sex or any other innate aspect of womanhood, but largely due to the gendered social roles they occupy. These roles are not occupied universally by all women so it is more helpful to regard women as a heterogeneous group that differs along a number of variables including role occupation. This qualitative difference has not previously been demonstrated and would not have been adequately detected by another quantitative study.

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